



dhg

down's heart group

Newsletter Extra
May 2006

Issue 32

HANNAH'S NEW HEART

transplant for girl with Down's Syndrome

Our daughter Hannah celebrated her third birthday in November 05. In February this year she became only the second child in the UK with Down's Syndrome to have a heart transplant.

At birth, Hannah did not have any heart problems, in all aspects Hannah was well, she ate and slept like a baby should. However, just before her second birthday Hannah was diagnosed with Leukaemia, a condition that we did not know until then is more common in children with Down's.

We were admitted to the Royal Victoria Infirmary, Newcastle, where Hannah was treated with love and care, as were all of the children on the ward. However, the intensive chemotherapy required to treat the cancer left her with a heart condition known as "cardiomyopathy" which is where the heart's function is impaired. In Hannah's case the left side of her heart was enlarged and not beating as powerfully as it should.

We were told that her condition could go one of three ways, her heart could improve, it may stay the same but with daily medication life should continue as normal, or it could deteriorate and then a heart transplant is the only option. The condition was diagnosed in May and in early July Hannah suffered heart failure. We were admitted to the Freeman Hospital in Newcastle. We were told that before being placed on the Heart Transplant List each child is assessed.

The assessment looks at each child as an individual and the fact that she had Down's Syndrome would not affect

the assessment. Staff told us that 10 year ago the fact that Hannah was born with Down's Syndrome would have immediately excluded her from going onto the transplant list, and other hospitals in the UK still to this day would not put her on the list. You can imagine our shock and disgust at hearing this, can you imagine the outcry if a child was excluded because of race or gender, yet here we are in the twenty first century in the UK and children are being excluded from life saving operations because of their disability.

Luckily for Hannah and us the Freeman Hospital in Newcastle are leading the way in removing the barriers and changing the attitudes on cardiac transplants. We were in the hospital for 8 months, awaiting a suitable donor, and all through that time Hannah was treated superbly. In no way was she ever treated differently from any child. We are not able to praise the staff at the hospital enough for the way they treated and cared for Hannah.

Hannah has been supported throughout her life by her special needs team. This team covers all aspects including teaching, playing, physiotherapy, health etc. She has recently been assessed for main stream school and the support required for her to attend is being made

available. The local school is very keen for Hannah to be a pupil there, as they believe strongly in integration being the way forward for all children.

To date all of the professionals we have encountered in relation to Hannah and her life, have all had a positive attitude, we have not encountered any discrimination or obstacles to overcome because of her disability, although this might not always be the case. It is a shame to think that if we did not live in the North East of England that the outcome may have been different, and Hannah would not be with us now.

Stephen Carty



Escape For The Weekend!!!

The Children's Heart Federation will be running two activity breaks for young people with heart conditions later in the year.



Therapy and Games Weekend

This will be held at a hotel in Disley, Cheshire in August. Day one of this event will concentrate on discussion. Workshops will be held on scar therapy (scars can be a big issue for teenagers) and the 'transition period'.

A workshop will also be held for parents, encouraging their child's independence and letting them take responsibility for their illness. Day two will concentrate on activities.

Activity Break

This will be held at the Calvert Trust Centre at Keswick, from Monday 23rd October to Friday 27th October. The Centre is specifically designed to help children, young people and adults with disabilities and limiting conditions take part in all types of activities, which can include horse riding, canoeing, rock climbing, archery and orienteering.



Participants of both events will have the chance to enjoy new and exciting experiences, as well as connecting with other teenagers with similar problems, experiences and anxieties.

There will be staff from CHF and some Grown Up Congenital Heart members attending as well as the centre staff, allowing for all the participants' needs to be met.

Contact DHG office on
0845 166 8061 for more
details.



Since DHG registered with Everyclick we have raised £157.07. This is through people using Everyclick as their homepage and search engine and requesting DHG as their chosen charity.



If you don't subscribe already, please consider it - it doesn't cost you or DHG a penny!

Go to www.everyclick.com to get involved

Marathon 2006 - All Safely Over The Line

Well done "Team Down's Heart Group"

A HUGE THANK YOU to our fantastic runners for all their effort and to everyone who has sponsored them.

Paul Smith	4hr 06min 56sec
Jack Pow	4hr 20min 12sec
Mark Barnfield	4hr 25min 12sec
Rebecca Gooch	4hr 39min 11sec
Anthony Tidder	4hr 53min 47sec

Their times were great but have they beaten last year's sponsorship total? More to come in the next newsletter or for the latest news go to

www.dhg.org.uk



Paul was the first one home for DHG

Runners Urgently Needed For Two Important Fundraising Events

British London 10K on Sunday 2nd July in Central London

Hydro Active Women's 5K Challenge on Sunday 3rd September in - London, Birmingham and Liverpool

all events are fun, any standard catered for, top athletes to window shoppers

all events have a carnival atmosphere, with parachutists dropping in at the start of the London 10K, loads of balloons and fancy dress - a great day out!

all events offer warm up and cool down routines and huge goody bags!

get fit and raise money for Down's Heart Group
call 0845 166 8061 for run details

Message From Our Chairman

Welcome to issue 32 of the DHG newsletter, I hope you enjoy reading it as much as I have.

As part of last year's business plan we appointed Sarah Smith to the new post of 'Information Officer'. Her main objective was to ensure the timely publication of four newsletters a year. She published her first newsletter in Spring 2005 and this is now her fifth, all having been delivered within the time constraints set. I offer my congratulations on Sarah's success in her principal objective. Last Spring I asked for your views on what you might like to see in future editions and how you would like to see our journal improve. I thank you all for your valuable feedback; the result of which you are now looking at! Fantastic; don't you think?

With Sarah settled and Penny Green elevated to the position of Director, supported by Lynda Hale, the team had an ambitious business plan to accomplish. Sarah started the ball rolling with the newsletters and you may just have noticed our new logo and identity. The committee agreed on a design brief, we wanted to retain the hole in the heart and the basic "pink" theme, and the result is just what we had hoped for. Sarah and Penny take the credit for managing this project but as usual had great input from the committee.

With the new logo and identity ready we were able to apply this to everything we do:

Newsletter - A complete makeover of the newsletter has been achieved; full colour 2 x 12 pagers and 2 x 4 pagers a year

New Logo & Identity - I think this fresh new image is terrific!

Website - A new look site was launched in November 2005. The web site has a lot of new functionality but will continue to evolve and develop.

We hope to be selling Christmas cards online this year together with other items of DHG merchandise, sponsorship and donations can be

collected directly through the site just as soon as the credit card page is complete.

Updated Video - Although our video 'Heart problems in children with Down's Syndrome' is now 8 years old, its content is still very relevant. A new introduction has been added, featuring my sons William and Josh, the dog, the cat and me. We've updated the graphics to reflect the new image and it is now available on DVD. Shortly we plan to have multiple choice language tracks to select from.

New DVD - In collaboration with British Heart Foundation, United Bristol Hospital Trust and Photosymbols we have produced a new DVD; "I'm Gonna Go for it". Andrew is a young adult with Down's Syndrome and a heart defect which needed corrective surgery. The film follows Andrew through every step of his journey; from before going to hospital, through his consultation, going for the operation and through to his full recovery. Andrew says he feels much better now his heart is fixed.

Awareness Week - This year Down's Heart Awareness Week is from Sunday 5th November through to Saturday 11th November. Our first year's event was a balloon launch and fireworks display at a golf club in Weybridge, organised by Elaine Archer. We raised a staggering £5k from that event alone, as well as the money raised by other events such as coffee mornings or social get togethers.

**Please support us this year.
Contact National Office on
0845 1668061**

London Marathon - DHG are 'gold bond' holders for the London marathon, which guarantees us five places each year. It costs us about £1,500.00 each year to enter runners but the return is usually over £8,000.00. The problem is filling the places with great fundraisers as well as good athletes. So if you know anyone who would like to enter the

marathon please let us know.

London 10k Run - we now hold a 6 place platinum bond (sponsored by eworks consulting) for the London 10K run. Ask National Office for entry and sponsorship forms.

It is amazing how much work gets done at DHG with only 3 part-time staff and a few volunteers. Not only have we accomplished everything listed above but all the 'business as usual' activities have been carried out as well; providing virtually constant phone cover, providing information and much needed support when required.

DHG were part of the external panel contributing to the recent Department of Health work on Services for Adults with Congenital Heart Disease - The GUCH Guide, and is currently involved in the revisited paediatric guide. We spend time supporting cardiac teams and clinicians on specific cases and of course we find some time to have a little fun.

Last year, with the help of CHF we were able to send a family on a short summer break to Cotswold Country Wildlife Park and one lucky child visited Santa in Lapland just before Christmas. We would love to do more but budgets restrict what is possible; that's why we need your support.

Nominate and sponsor us where you can, ask people to support us through 'Give As You Earn'; just £2.00 per month can provide a complete information pack complete with DVD's for a family who need it. You can sponsor a competitor in the London Marathon or the London 10K run, any other events you may be holding can be placed on our website and people can donate directly to it on-line. Please help us in order that we can continue to help others that need our support.

Next issue I will be highlighting our plans for the forthcoming year together with some exciting events for our older members.

Cliff Lake



dhg

down's heart group

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(24 hours in emergency)

A Big Day At The Big House!

Dad and I went to the House of Commons with DHG, to take pictures of the launch of Congenital Heart awareness. The House of Commons is big!!!

There were lots of people there and it was very busy. We saw lots of statues of famous people. We met Cliff, Chris and Penny and went into the Strangers Dining Room. I was very nervous and got very tired but I enjoyed it very much and made lots of new friends.

Ali xx

Ali's Dad, Tom Pearce writes:

I must admit, I do not know who was more nervous, Ali or me. This was her biggest assignment yet. Ali tends to shy away from crowded places, the noise hurts her ears. I knew this would be a noisy day, so I was fearing the worst.

I had been pre-warned by Penny that other professional photographers would be there, and I guess like most parents I had that horrible feeling of 'Have I set Ali up for a fall?' 'Will she be over awed by everything?' etc, etc.

I do it every time, and it ended the same as always. Ali produced the goods, and took everything in her stride. By the end of the day she even had the hearts of the other photographers, and ended the day with a camera fight, where all of them were trying to take funny faces of each other. The other photographers were great, and I have to thank them for showing Ali the way.

The launch itself was a job well done. It gave people with problems the high profile they deserve. Which has to be good! Thanks DHG for giving Ali the chance to boost her confidence, and giving her a sense of worth.

The Children's Heart Federation Launch at the House of Commons has paved the way for further debate regarding services for our youngsters which we hope will bring about much needed changes. DHG will keep you informed of any developments.



Ali with Cliff Lake, Chris Stringfellow and Penny Green of DHG

Ali Pearce, a DHG member, kindly agreed to be our official photographer for the recent Children's Heart Federation Launch at the House Of Commons. Some of Ali's photos from the event are on the DHG website.

You can read about Ali's life so far and see more of her work on her website

<http://myweb.tiscali.co.uk/vitalmoon>

Ali has just been invited to be an Ambassador for Mencap. She has recently donated one of her works to be auctioned off for "hearing dogs" and hopefully will be working with DHG on a calendar, which is guaranteed to be stunning.

Ali would like to encourage all our members to tell us of their achievements, big or small, so please contact Sarah on 01455 888344 with your news.

We would like to say Thankyou to Ali and also Congratulations on your photography and all your other achievements.

Good luck for the future!

*Shoot out!
Ali with other photographers*

