



# dhg

down's heart group

# Newsletter Extra Winter 2006/7

Issue 34

DHG's conference has been and gone and according to feedback from participants if you weren't there you missed a treat! Barnsdale Hall Hotel was fantastic, the staff were very helpful and the food was great.

The conference ran like a well oiled machine, each speaker engaging the audience with information and new ideas. Then after a hard day listening and learning, or for the children, playing, painting and singing, followed an evening of relaxation and fun with everyone joining together for an evening meal. After which Chris Davies provided a wonderful disco that had the dance floor full all evening.

On Sunday, following a hearty breakfast, families had a vast choice of things to do with many deciding to enter the Crazy Golf competition, which was won jointly by the Pearce and Russell families. After the morning's activities Brenda Marshall's picnic lunch was a welcome sight!

The weekend's finale was the balloon launch which took place in rather windy conditions. Firstly our Founder, Linda Walsh, released 75 white balloons representing some of the youngsters who are no longer with us. There was not a sound as the balloons raced towards heaven, but many a tearful eye and lumpy throat in the crowd.

Contrastingly there was much enthusiasm as the 1300 red "competition" balloons were released, followed by laughter as the wind caused a local press photographer to become completely engulfed in one of the nets, as though he'd been caught in the nearby lake!

Thanks to everyone who helped blow up and tie balloons, hang on to the nets before the launch and generally to make the weekend a success.

**It really was appreciated.**

## Communication – A Two Way Flow (the DHG Conference)



## Note from our Chairman

I would like to wish everyone a very Happy New Year and welcome you to the first newsletter of 2007.

The 2006 Conference and Fun Weekend was a great success enjoyed by all, I'm looking forward to meeting you all again in 2008. Yes, we've decided to do it again!

I would also like to welcome Peter John, Maggie Linde and Helen Stringfellow, our three new committee members and trustees who were elected at the AGM.

In the last issue I focused on breaking records and in particular fundraising, I cannot stress enough how important it is for us to maintain the good effort started in 2006.

We have recently received funding from the British Heart Foundation which will allow us to produce and distribute copies of the "I'm Gonna Go for It" DVD together with the accompanying booklet. Copies of our video "Heart Problems in Children with Down's Syndrome" are now exhausted, so we need to raise another £10,000 to complete the re-edit and produce new stock on DVD.

Operational expenses for Down's Heart Group amount to £60,000 each year, which we have to acquire from our own fundraising efforts as most grant funding bodies will only support specific projects rather than running costs. Currently we struggle to achieve this amount, but if each of our members were able to donate the equivalent of £5 per month we would be on target.

This could be done through payroll giving, where tax relief would mean the actual cost to the donor was only £4; by holding a fundraising event, where proceeds of £60 would produce the same revenue without members donating their own hard earned cash; by any other legal means you can think of. (See our next issue for more ideas on how YOU can support our work.)

I will leave you with that thought.

**Cliff Lake**



**Dr Frances Bu'Lock** who is Head of Congenital and Paediatric Service at Glenfield Hospital, Leicester, was the first speaker to address this year's conference with "Down's Heart Disease; Current Challenges, Problems Undiagnosed and Rediagnosed and New Treatments."

Dr Bu'Lock has been in post for seven and a half years, her main interests are fetal and adult congenital heart disease. She is seeing an increasing number of adolescents and young adults with Down's Syndrome who have never had an echocardiogram or had one a long time ago. Some have previously undiagnosed defects whilst others have diagnoses or prognoses rather different from that originally given.



*Dr Frances Bu'Lock*

Communication both with patients and their carers and planning or changing treatment direction, pose some of the biggest challenges of Dr Bu'Lock's day to day practice.

Dr Bu'Lock's work with older patients gives her a greater insight and helps with her counselling for fetal diagnosis. She explained different "pointers" for picking up Down's Syndrome or heart problems on a fetal scan, although

some heart defects cannot be picked up until the baby is born.

She went on to discuss use of the ECMO machine, which was first used in the UK at Glenfield. This is used to do the job of the heart or lungs for prolonged periods, sometimes weeks, although there is generally a poor survival rate for cardiac patients relying on ECMO, it being more successful for respiratory conditions. Although there are no statistics for how many patients with Down's Syndrome have used ECMO, she recommended that it is only used in experienced centres.

Our second speaker was **Deirdre Reilly**, a final year PhD student at the University of Wales, Bangor. Her presentation was called "Raising and Losing a Child – Experiences of Parents of Children with Down's Syndrome."



*Deirdre Reilly*

The European Social Fund and Mencap Cymru are jointly funding "The Wales Study of Bereavement in Families of Individuals with a Learning Disability" because little has been done to investigate the needs of those left behind when an individual with a learning disability dies. The project aims to investigate what these support needs are and inform service providers on how to supply them.

Deirdre explained that the aims of the research project are to;

- Talk to bereaved parents and other family members about their experiences
- Examine the support services families receive
- Look at how families cope before and after their loss
- Examine how support may be improved

29 family members who had lost a relative with Down's Syndrome and a heart problem were interviewed along

with 26 other people who had lost family members with other disabilities. The age range of those who had died was stillborn to 43 years and the time elapsed since their deaths was between 10 months and 29 years.

Themes to emerge from the interviews include ways of coping, relationships with medical professionals and the benefits of parenting a child with a learning disability. So far some general conclusions have been made:

For families

- Do things your own way
- Don't be afraid to accept support
- Preparation if possible can be helpful

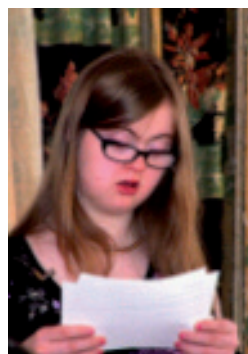
For services

- Parents should be invited back to hospital
- Clear honest conversations without jargon
- Involving parents in decisions
- Supporting fathers
- Not talking about the child in their presence as if they weren't there

Many people said that they became redundant as a parent and carer, suddenly having a lot of time on their hands. It was different to losing other family members and the loss did not end the support needs of the carer.

Various studies have discussed the importance of post-bereavement support networks that put families in touch with others who have been through similar experiences to provide advice and support.

The study revealed that Down's Heart Group does this very well.



*Kylie Jarvis*

21 year old **Kylie Jarvis** was the final speaker of the morning. She has achieved seven passes at GCSE, Duke of Edinburgh Bronze Award and English Speaking Board Level 3 with Distinction. Kylie appeared in the

“Now We're Talking” video and is a consultant with Clear, a company that ensures information is accessible to people with learning difficulties.

Her talk “**Communication and Me**” held the audience spellbound as she talked about the ups and downs of her life so far. Her own fight against bullies has led to her involvement with pressure groups against hate crimes.

Kylie speaks at various functions about learning disabilities, what it is like to have learning difficulties and how others could help make improvements to the lives of those with such problems. She believes in speaking out about discrimination and rights issues and feels the world should be a fairer place to be. She is a fantastic advocate for people with learning disabilities.

Kylie lives in a care village, which she loves as she is quite independent. She is very close to her family and her mum, Ros, helps her with her public speaking business.

### Workshops

In the afternoon there were three concurrent workshops which were run twice to give everyone the chance to attend two different ones. They all focused heavily on audience participation, with speakers and delegates being able to share their vast wealth of experience with each other.

In her workshop “**Communication Through the Ages**”, **Julia Williamson** covered all aspects of communication and most participants came away with new tips. Julia is a speech therapist with many years experience working with children in the UK and overseas, she also runs sessions once a month for the Leicestershire Down's Group.



*Julia Williamson*



*Mandy St Marshall*

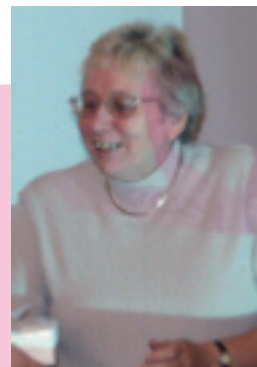
*Jane Cox*

Cardiac Liaison Nurses, **Mandy St Marshall and Jane Cox** from Glenfield Hospital set the room up like a bistro to help get their point across.

“**Communication – Are We Getting it Right**” was the title of their workshop in which they worked closely with participants to find out how Cardiac Liaison Teams could improve their service.

In return, delegates found out just how extensive the Liaison Team's work is and ways of contacting appropriate staff and getting questions answered. Mandy and Jane are putting their findings together and promise to show us the working document they want to put into practice.

Down's Heart Group Vice Chair, **Chris Stringfellow's workshop** focused on “**Independent Living Fund and Other Adult Benefits**”. Chris works as a Health Visitor in the Cardiff region and is Mum to 21 year old Richard, so she has a wealth of first hand knowledge on what our young adults require and how to go about getting adequate services.



*Chris Stringfellow*

Some parents attending who also have young adults were able to add even more information and both her workshops were quite lively. Due to space restrictions it is impossible to give all the information put forward, so we hope to include a more in depth feature in a future issue.



# dhg

down's heart group

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## Maryport Fundraiser

On 25<sup>th</sup> November a group of friends and I held a Christmas Fayre to raise funds for DHG. I chose Down's Heart Group as my younger sister Charlotte has Down's Syndrome and was born with two holes in her heart, so I wanted to help people like her.

We hired the local Working Men's Club and had a number of stalls including "Name the Teddy", tombola and "How Many Sweets in the Jar?" Andy, who runs the Club, was kind enough to donate a bottle of whiskey for a raffle prize and £25 to cover the cost of the room hire which was very kind.

It wasn't the best of weather and the turnout wasn't great, but we managed to raise £230. As we still had things left at the end of the day my Mum suggested we did a car boot sale on the following Sunday. So at 6am we packed the car and headed for Cockermouth. The weather was awful again but the venue was indoors so lots of people braved the rain to get there. A number of people didn't buy anything, but gave a small donation which all adds up. At the end of the day we had made an extra £92.62, giving a total of £322.62. We hope this helps in your work.

I would like to say THANK YOU to all my friends that helped with the stalls including Becca, Sam, Kerry, Brendan, Zoë, Charlotte, Sophie, Louise, Ashleigh, Courtney and my sister Charlotte. Finally, thanks to my Mum, also a special "thanks" to my Auntie Tina for going to the trouble of making banners and price stickers for us and my Grandma for making up a hamper for the raffle.

Carrie Dougherty  
Age 14

## British London 10k Run 1st July 2007

Run for Down's Heart Group! Reserve a place **now** for the 2007 British 10K London Run taking place in Central London on Sunday 1st July at 9.35am. Contact National Office - 0845 166 8061



## London Marathon 22nd April 2007

DHG runners in this years London Marathon can be sponsored by contacting National Office on 0845 166 8061 or by clicking the Sponsorship button on the website - www.dhg.org.uk

## Well Done!

**Emily and Jamie Berry ran the Junior Great North Run and raised £64.50 for DHG.**

## £4200 for DHG

Back in August 2006, DHG's Penny Green and Cliff Lake were invited along to an Open Day at BAE Systems in Salmsbury and were amazed by the amount of effort that "2 Building" put in to make the day so enjoyable and raising funds for the Group.

## Motorbike Madness



On Saturday July 14<sup>th</sup>, DHG supporter Wayne Brown is arranging a London to Leeds motorbike ride to raise awareness and funds.

Starting from London in the morning a swarm of motorbikes will travel northbound to Leeds, stopping off at cardiac centres along the way. We need as many bikers as possible to join in for at least part of the journey and lots of well-wishers along the route and at the cardiac units.

For further details about the route, taking part or cheering the bikers on please contact National Office and keep a check on the website for up to date information.

Since then a further £910 was raised at a BAE Reunion Evening organised by DHG member Alan Quinn and £100 was donated by T J Pritchard, who won first prize in the Lancaster Club's raffle. This brings the total raised by BAE to £4,200 and we would like to thank everyone concerned for such a wonderful effort.

## Comment on Transplant Issue

In our last newsletter the interview with Hannah Carty's parents implied that patients with Down's Syndrome might not be given the chance of a transplant at certain units.

We have been asked to clarify the fact that UK transplant centres are willing to consider all patients referred to them, however, the problem sometimes occurs when referring centres are reluctant to put forward a patient with Down's Syndrome wrongly assuming that the transplant centre may turn them away.