



**dhg**  
down's heart group

# Newsletter Autumn 2006

Issue 33

## **Celebrating 15 Years of Down's Heart Group**

Conference and Fun Weekend - 4th & 5th November



## Note from our Chairman

Welcome to the autumn edition of the DHG newsletter which I hope you enjoy.

When I first began thinking about this piece for the newsletter we were experiencing Britain's hottest ever recorded July day, beating such holiday destinations as Malta, Athens, Bermuda and Rome. You may love or hate the British weather but my point is "record breaking".

We have set ourselves some very ambitious targets for fundraising this year. If we can reach them it will be a record breaking achievement for the Group. This year's fundraising started slow but is gradually gaining pace, the turning point being the London Marathon. A department at BAE Systems in Preston has chosen to support us at their event on 19th August this year thanks to Alan Quinn, one of our members who works there. One of the prizes for the day is a signed Ashes cricket bat, obtained by our patron David Graveney. Thank you David, for your support.

The new website now has an on-line giving facility and we have just joined the Payroll Giving scheme. We do really need your help and support as every little counts. At our conference this year on 4th and 5th November, at the end of DHG Awareness Week, we have organised a balloon launch. Balloons are on sale for £1. Lets see if we can get a balloon to float further than Spain this time!

And having mentioned the 2006 conference event you are all invited to be there - details are inside this issue and on the website. Barnsdale Hall is a fabulous place to stay with lots to do for everyone. The conference will see the unveiling of our 2006/07 business plan and in the next issue I will be focusing on the details of some of the projects we have planned, so help us to continue our vital work.

Thank you and I look forward to seeing you in November.

**Cliff Lake**

## CONFERENCE & FUN WEEKEND 2006 "COMMUNICATION"

4th & 5th November 2006

**Barnsdale Hall Hotel**  
**Near Oakham, Rutland, LE18 8AB**

Check out the venue at [www.barnsdalehotel.com](http://www.barnsdalehotel.com)

Barnsdale Hall is set in extensive grounds on the banks of Rutland Water and the facilities make it a superb venue for this event  
- a special place for DHG's 15th Anniversary.

### Conference - Saturday

Speakers include a cardiologist and speech therapist. There will be workshops on accessories to communication, liaison between parents and hospital and the latest research from Bangor University. The programme has yet to be finalised but is sure to contain something for everyone.

There will be a creche run by appropriately qualified staff, where the children will be split into age groups so that safety and age relevant activities can be ensured. As places are limited priority will be given to people staying for the whole weekend.

The AGM will take place before the conference begins.

### Fun Weekend

Following the conference and until 4pm on Sunday, all the facilities of the hotel are open to us - pool, spa, fitness rooms, bowls, sauna, steam room, tennis, squash, snooker, petanque, crazy golf and more!

On Saturday there will be an evening meal and entertainment for the children, giving parents time to relax and chat and on Sunday join us for an indoor picnic on Sunday lunchtime and watch the DHG Balloon Launch which will bring our Awareness Week to a close.

Rooms are available from singles to family rooms for six at an excellent rate and the whole venue is wheelchair accessible.

**Contact National Office for more details - 0845 166 8061**

We look forward to seeing you there!

## Cover Story

Tom Pearce took our wonderful cover shot of his daughter Ali who has just celebrated her 21st birthday. The photo recently won an award in a national competition and is currently on display at the Victoria and Albert museum.



## Tim Davies - greatly missed

I want to tell you about a very special man, my big brother Tim. Words cannot describe the sorrow we feel now that he has died, but I want to tell you about his life.

Tim was many things to many people. To strangers he was a short, slightly dumpy man who had Down's. To shopkeepers and bar staff he was a polite and chatty person who didn't always have enough money to pay for what he wanted. To his friends he was kind, caring and good fun. He was always ready with a good one-liner and his visual comedy reigned supreme. To us he was more than this. He was an inspiration. He taught us unconditional love, patience and a consideration for others which makes us the people we are today.

Tim was born in 1970, the first of four children. At the age of two he was diagnosed with a VSD but it was left untreated. More recently his health had started to deteriorate. He coped admirably with very painful arthritis. His heart condition meant that he had to take it easy or he would turn blue.

He then started to have episodes that resembled seizures, but epilepsy

was ruled out. Our investigations led us to a cardiologist and a brand new diagnosis – Tetralogy of Fallot. The shock was awful but then we were told his condition was operable, giving us hope for Tim's future.

We agonised over the decision regarding surgery. Tim led the way with his great hope and unwavering belief. He was very excited at the prospect of being able to do so many things with his mended heart. He wanted to go on a plane to Spain and his sister's place in Crete. His passion was swimming and he revealed a desire to learn to snorkel.

Tim underwent surgery in December and while the surgery was a success his recovery did not go to plan. For 35 years his heart had worked so very hard to compensate for its weakness, now it needed to start working in the normal way it was simply unable to adapt. He died four days later when all hope was lost and multi-organ failure led us to the decision to withdraw treatment.

When we were faced with filling in Tim's death certificate we strongly felt we couldn't leave "Occupation" blank.

Tim saw himself as a weatherman and one Christmas tucked himself behind the curtains waiting for it to start snowing. He suddenly yelled "It's snowing!" so we all rushed to look. It wasn't but he was laughing so much at tricking us.

Tim loved cuddly toy dogs and would apologise to all the ones he left behind in the shop and promise to buy them next time. He was addicted to television, especially Dr Who and the Daleks, and had a passion for animals. His cats always received the best bits of meat from Tim's plate.

We decided eventually that Tim's occupation should be Voluntary Worker as he worked for Oxfam a couple of days a week. But Tim was no saint. He was rude to people he didn't like. He lacked grace when receiving presents that disappointed him and he always clapped and cheered when something got broken in a restaurant! We miss him so much.

**Rachel Davies**

*DHG are very grateful to have received a donation of £350 in memory of Tim.*

## Leaving School

When twins Clare and Nicola left primary school all their friends and teachers signed their school shirts for good luck for the future.

Both girls enjoy horse riding and winding up their older sister, Lauren.

Although being twins usually means sharing so much, Nicola and Clare had very different types of heart problems when they were born. Clare had a particularly bad time, needing to spend some time on the ECMO machine at Glenfield hospital after surgery. She really did give her parents and hospital staff many scares and it was touch and go for what seemed like months.

The girls now look such a picture of vitality and mischief!



Double Trouble! The Mowberry Twins

## Samuel Robert Barton

I was so excited when I found out I was pregnant - we had been happily married for a year and everything seemed perfect although my pregnancy was not great. I had a lot of sickness and an ever growing ovarian cyst, but I didn't complain too much as my baby was healthy, growing well and jumping around.

The birth was a bit traumatic as the baby was in distress so I ended up having an emergency Caesarean, but I was not too upset as they removed the cyst as well. As I was recovering I felt overjoyed that my baby had arrived safely and everything was behind me.

I was gazing down at my perfect baby boy when a midwife came to me and asked me if I had noticed anything 'different' about my baby. She then said the words I will never forget - "we suspect your baby has Down's Syndrome". The room span and my perfect little world

came crashing down.

My husband and I had already fallen head over heels in love with our



Baby Samuel

special little boy when the next blow was delivered. We were informed that babies with Down's Syndrome

often have heart defects so our baby would have to have his heart scanned. I remember thinking that Sam would be fine as his heart was looked at in a pregnancy scan. Also life had given us a child with Down's Syndrome so surely he wouldn't have heart problems as well! - The heart echo showed a large AVSD which is in need of definite repair.

Samuel is nearly 3 months old now and we are very proud of him. He is a lovely baby who has melted many hearts. He will need an operation this year and we are just watching and waiting. Samuel is very strong little boy and his personality is already beginning to show.

We know he will get through this and have a fulfilling,

active life.

*Emily Barton*

## Back in Touch

I was absolutely delighted to read "Megan's Story" in the Spring newsletter. For almost five years I have wondered what happened to the little girl who I first saw battling pneumonia at Alder Hey Hospital at the same time my son Ben was recovering from AVSD surgery (a battle of his own). I remember Ben left ICU on the same day as Megan had her heart surgery and I hoped all would go well for her. My son made a full recovery, and now aged 5 attends the same mainstream school as his older sister (also called Megan!)

As we also live in East Lancashire I made enquiries with the local DSA branch to see if they had heard of a child called Megan Hodgkinson. When they hadn't I feared the worst and was therefore so pleased to read that Megan was happy and healthy and doing so well.

*Charlotte Priestley*

### We need your ideas!

### Foundation for People with Learning Disabilities

The Foundation for People with Learning Disabilities is planning on doing some research to improve the lives of people with Down's syndrome and we want your ideas on what we should be doing.

We would really like to hear from people with Down's Syndrome and their parents and carers about what you think the gaps in research area. From our work we know that some young people find life difficult when they leave school or college. We also know that some people develop health needs as they get older.

### What do you think we should be doing?

If you have any ideas please do not hesitate to contact me, Jill Davies, at

[jdavies@fpld.org.uk](mailto:jdavies@fpld.org.uk) or on 020 7803 1141.

For more information about the Foundation for People with Learning Disabilities log on to [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk).



Issue 32 featured Hannah Carty, the three year old who has recently undergone successful heart transplant surgery. She continues to amaze everyone around her. Parents Elaine and Steve took time from their hectic schedule to answer a few questions for our readers:

**Q:** Firstly are you able to put into words how you feel to see Hannah so well?

**A:** It is hard to express how we feel to see Hannah doing so well. It was touch and go for such a long time that now we try and put the bad times out of our heads and think only of the positives, and there are a lot of positives now. Hannah is getting stronger each day and just this week Hannah took 10 steps unaided.

**Q:** When did you first realise Hannah was ill with leukaemia? What were the signs and are those signs relevant for each child or do they have different symptoms? Did the doctors look for anything specific because Hannah has Down's Syndrome?

**A:** When we found out that Hannah had Leukaemia we felt that our insides had been torn out. She did not show any symptoms at all and her Leukaemia was found by chance on a random blood test.

Just before her first birthday Hannah was unwell with respiratory problems and ended up on a ventilator. As a result of this we were sent to see a respiratory specialist at Newcastle's RVI. He noticed a rash on Hannah's

arm and requested a blood test to see if this rash was a post viral rash. The result showed a low white cell count and the test had to be repeated several times over a period of a few months. Eventually blast cells were seen that led them to diagnose the Leukaemia.

Hannah's Leukaemia was what is known as a "pre cursor", that is it was not fully developed. The leukaemia cells were occupying 14% of the total cell count, where to be classed as leukaemia this percentage has to be 28%. The treatment, however, is exactly the same.

**Q:** Is cardiomyopathy a regular side effect of chemotherapy or was Hannah just very unlucky?

**A:** Cardiomyopathy is a potential risk of chemotherapy, and this was explained to us when Hannah was diagnosed with Leukaemia. However, it is rare, and if it does happen it is usually several years after the treatment is finished and not a few months as was the case with Hannah.

**Q:** How did you react when you discovered the only option was a transplant? Had you heard of youngsters with Down's Syndrome being told they didn't meet the criteria?

**A:** To discover the only option for Hannah was a transplant was devastating news, and all the way through the ordeal when she was on the list waiting for a donor we prayed that her heart would improve and she would not need it.

When the cardiomyopathy was initially diagnosed Hannah's consultant had told us that in the past and still to this day in some hospitals children with Down's Syndrome would not be considered for transplantation, but this would not be the case at the Freeman Hospital where each child is assessed as an individual and Downs Syndrome by itself would not be seen as a reason for exclusion.

**Q:** Did any of the team have reservations about Hannah's suitability for transplant, as regards her immune system and rejection of the organ?

**A:** There were no special concerns regarding Hannah's transplant. Fear of rejection is there for all transplants and Hannah was treated like any other child.

**Q:** What are your thoughts on the Berlin Heart, can you describe it to us as most of us have never heard of it!

**A:** After waiting four months for a heart a donor became available on the 25th November. During the night when things were being planned and co-ordinated, Hannah took ill and the operation was cancelled.

By the end of that day Hannah was on a life support machine and in a medical induced coma. The life support machine is called ECMO, and she would be on this until a donor became available. However, there is a time limit - the longest anyone has survived on ECMO is 6 weeks.

Hannah's time on ECMO was not good, she suffered a pulmonary haemorrhage, her lungs filled with blood and blood was running down the ventilator tube.



The Freeman Hospital are pioneering the use of artificial hearts that operate outside of the body, called Berlin Hearts because they are made in

Berlin. In the hospital there was already a child fitted with a Berlin Heart who was doing well, sitting up, eating and playing.

We were desperate for Hannah to have a Berlin heart so she could have a better quality of life. We wanted to see her awake as well as providing a longer bridge to transplant, because the longest anyone had survived with a Berlin Heart is 18 months.



**Q: Were you given any statistics on the outcome of surgery?**

A: As the procedure was fairly new there were no statistics as such. The most frightening statistic they presented to us was that there was a 50% of chance of getting her from this stage through to transplant, but it was the only option available because time was running out for Hannah on the ECMO machine.

**Q: Were you given unbiased and thorough information throughout each stage of Hannah's illness?**

A: All the way through Hannah's treatment at the RVI and the Freeman Hospital we and Hannah were treated excellently. We were presented with the facts all the way through her treatment and told all of the potential dangers and risks involved, and we can not praise the staff enough.

**Q: Were you told of any support groups like DHG, the Cardiomyopathy Association or Heart Transplant Families Together?**

A: We were aware of groups like DHG and the Heart Transplant Families Together, however we are very lucky in the fact that we had great support from family and friends, and without them this ordeal would have been worse, if that was possible.

**Q: How did Hannah cope with the whole ordeal?**

A: Hannah is a unique person, she has a great outlook on life and loves living, she coped well throughout the whole ordeal, as she is so young I think this helped her get through it, and hopefully will be able to forget it as she gets older.

**Q: How did you cope?**

A: It was hell for us; the whole thing was an emotional rollercoaster. We have felt every emotion possible.

When Hannah was fitted with the Berlin Heart the operation did not go well, after fitting the Berlin Heart they were unable to get her off the heart and lung bypass machine and they told us that they believed it would be kinder to let her go. We could not accept that and asked if they could keep her on the bypass machine over night and try again in the morning.

The surgeons agreed to do this but told us that there was no chance of her surviving and that she would be dead within 2 minutes of switching off the by-pass machine. We planned her funeral, where Hannah's body would be laid to rest, each aspect down to the last detail.

When we found out they had switched the machine off and she was holding her own it was an incredible feeling. We had gone from the lowest feeling ever possible, losing your child and we do believe that we have experienced that emotion, to sheer joy.

That day just got better and better as she got more stable. Our joy was mirrored by the staff who worked on Hannah.

**Q: Did you find it particularly scary to have Hannah back at home after the security of the hospital and have you had any scares since?**

A: It was great to have her back home at long last. We did have the odd scare since coming home, but nothing major to date. Every temperature she gets or when she is off her food we worry is it something serious but in time we will relax more and realise that all children get bugs, sickness and diarrhoea - it is just part of growing up.

**Q: What follow up will Hannah require and is there a point when the hospital will say they don't need to see her quite so often?**

A: Hannah is presently attending clinic once every two weeks, and hopefully in the next few weeks, this will become monthly and then once every two months, but after spending eight months solid in hospital, attending clinic is not a problem.



## Recipes Required

DHG Chairman Cliff Lake is putting together a cook book to raise funds for the Group. He is hoping to get a few celebrities to give their favourite simple recipes and is also looking for contributions from our readers.

Ideally the recipes should be ones that with a little help our youngsters could cook themselves.



Cliff intends to try each recipe before it goes in the new book, so if you have the recipe for tuna and banana surprise be sure to send it to him!

More traditional dishes would also be welcome, so please either email them to Cliff at [chair@dhg.org.uk](mailto:chair@dhg.org.uk) or mail them to National Office.

The cook book will be professionally published and all proceeds will go to Down's Heart Group. As soon as it is ready, it will be available through the website or National Office.

## From a Happy Couple

We were married on 22nd April. The day was warm and sunny, so we were very lucky. The wedding was followed by a honeymoon in the Maldives.

We enclose a cheque of £250 for Down's Heart Group. We explained on our table menus that we were donating instead of giving table favours.

We wanted to donate in memory of my sister, Heather, who sadly died some years ago, but who is still very much in our thoughts.

*With Best Wishes,*

*Obi & Cath Obiorah (nee Newbery)*

## Wedding Fun

Mandy and Andrew Sinstadt found a novel way to stop the yawns during the speeches at two weddings recently, by asking guests to guess how long they would last. They charged £1 per go and the person with the closest guess took half the money raised whilst the other half was donated to DHG.

The two weddings raised £130.

**THANK YOU  
TO EVERYONE WHO HAS  
MADE A DONATION, IT  
REALLY IS APPRECIATED!**

## Birthday Girl

When Georgina Parkes celebrated her birthday recently, instead of receiving presents, she asked for donations to be made to Down's Heart Group, in memory of Natasha Grange, who she says was like a sister to her.

Thank you to all those who contributed towards the £540 Down's Heart Group received from Georgina's party.

## BAE Fundraising

On 19th August 2006 BAE Systems are holding an Open Day, when around 10,000 employees, subcontractors and their families will be able to tour their Samlesbury site.

Although BAE's already have a charity of the year, each building is fundraising for a chosen charity on the day and 2 Building are supporting Down's Heart Group, after we were nominated by one of our members.

They are planning a wide range of events from having managers in fancy dress, to raffles, tombolas, paper aeroplane competitions and face painting, and the main site will have the TA, Police, Fire Brigade, TVR Owners Club, Model Aircraft Association and much more.

They have already held a raffle for Farnborough Air Show tickets, won by Graham Dixon who has now offered his services for a free charity fund raising concert in aid of DHG. Graham's band is called Trouble at Mill, and are well known locally. The raffle raised £376 for Down's Heart Group.

For information on Trouble at Mill visit [www.troubleatmill.com](http://www.troubleatmill.com)



Newly weds Cath & Obi - photo by Jo Newman

## Junior Great North Run

Emily and Jamie Berry are taking part in the Junior Great North Run for the third time on 30th September 2006. They originally wanted to run because their Dad was taking part but now they do it because they like to raise money for charity.

The Junior Run is approximately two miles around the quayside in Newcastle. Emily, like a lot of our members tends to overheat when she is running, especially if the weather is warm; she uses a cooling spray like Magicool and it seems to make a lot of difference.



Emily and Jamie after last year's run

Hi

My name is Emily, I am 12 years old and this is my brother Jamie who is 11. I have nearly finished my first year at secondary school in Kendal and Jamie is starting at the same school in September.

Again this year we are going to run the Junior Great North Run on Saturday 30th September in Newcastle. In the past we have raised money for Alder Hey Children's hospital because that is where I had my heart surgery but this year we have decided to run for the Down's Heart Group.

If you feel you would like to sponsor us please contact Penny at DHG.

Thank you  
Emily and Jamie Berry

## Nicola's Swim

Nicola Chambers raised £143.90 by swimming 56 lengths as part of her Citizenship course in year nine at the Long Eaton School, Nottingham.

Nicola chose Down's Heart Group because of her brother, Robert aged 10, who underwent surgery for a full repair for Tetralogy of Fallot in 1997 at Johannesburg, South Africa, whilst the family were living in Botswana.

Robert made a full recovery from the operation and continued to grow from strength to strength until 2003. It was then discovered that Robert had a problem with his top two vertebrae in his neck. They had collapsed, causing compression on his spinal cord. This caused his walking, hand coordination and speech to deteriorate to such a point he couldn't walk more than a few steps without falling over.

Robert was referred to the Royal Children's Hospital in Manchester, where he had an operation to have the bones repaired and stabilized. After the surgery he had to wear a halo for four months, which he coped with very well.

Since the halo has been removed Robert has learned to walk again and has come on a long way, especially as the hospital didn't know how much mobility he would regain.

## Sarah's Half Marathon!!

The Dog and Hedgehog Pub Run in Dadlington, Leicestershire has developed over the years into a serious half marathon for local runners and this year's race on May 7th was a huge step from her previous 5k races for Sarah Judd. However, she was really pleased with her time and felt that she ran well, despite the heavy rain which apparently helped to keep the runners cool.



Sarah during the race  
photo by Paul Chilton, Primephotography

Sarah would like to thank all the people who gave advice and supported her; all her sponsors from HJ Hall, where she works, and her family and friends who were there to cheer her on.

Down's Heart Group would like to thank Sarah for raising £263.00



Down's Heart Group has recently registered with the Payroll Giving Scheme, and we want to encourage people to give to DHG using this method.

If your employer operates the scheme you just tell them how much you want to donate and they take it from your salary before tax. So if you pledge £5 it costs you £3.90 if you are a standard rate tax payer, £3.00 if you pay higher rate tax. If you pledge £10 you pay £7.70 at standard rate and £6.00 at higher rate. For other amounts check the easy to use Giving calculator at [www.workplacegiving-uk.com/employee-information](http://www.workplacegiving-uk.com/employee-information)

Payroll Giving is different to Gift Aid as it is taken straight from your pre tax pay so there is no need for DHG to physically claim the tax back from HM Revenue & Customs, which saves in administration. If you are a higher rate taxpayer Payroll Giving is the ONLY way that we can automatically receive all the tax on your donation.

There is no upper or lower limit to how much you can give per month and you can alter the amount you give or stop giving whenever you wish.

If your employer isn't already registered why not suggest it to them; the scheme is free to introduce, easy to administer and any business with less than 500 employees signing up to Payroll Giving before 31st December 2006 is eligible to receive a one-off grant of between £300 and £500. More details can be found at [www.workplacegiving-uk.com](http://www.workplacegiving-uk.com)

**For new donors the first £10 of their monthly payments will be matched for six months up to March 2007, increasing their donation even further.**

Please consider supporting our work by making a small monthly donation to DHG - you may hardly miss it as it comes from your salary before you get it, but it will help provide us with a regular income so we can plan for the future with confidence.

## Awareness Week 2006 29th October to 5th November

Our Awareness Week is almost here, which is your opportunity to help us raise awareness with the media both locally and nationally and of course much needed funds.

Any event, big or small, be it a coffee morning or a dinner dance will help us maintain and develop our support services, so please do get involved and let us know what you are planning.

National Office can provide you with material such as literature, posters and sponsor forms (which must be obtained from DHG to ensure compliance with Charity Commission requirements.)

**Don't forget to take lots of photos and send them in to us!**

## Balloon Launch

On 5th November, to mark the end of Awareness Week, DHG are planning another Balloon Launch which will take place during the Conference weekend at Barnsdale Hall.

There will be prizes for the three people whose balloons travel furthest - last time this was Northern Spain, but we will also be raising awareness with all those members of the public who find and return the tickets.



The balloons, which cost £1 each, are now on sale from National Office and via the website. You can buy as many as you like so why not get friends and family involved too.

**Please help us make this a spectacular event which raises lots of money too!**

## DHG Calendar



Self by Ali Pearce

We will be selling our own calendar for 2007 shortly, featuring the work of member Ali Pearce, who has recently won a national photography competition.

Although the calendars are primarily aimed at the corporate market due to their cost, there will be a discounted price for members.

Calendars will be available to order from National Office or the website. Please get in touch for more information.

## Legacies

Your Will protects the people and causes you care about.

DHG has recently benefited from a modest but vital donation left to us in a will. Any money we receive goes directly to help children and young people with Down's Syndrome and congenital heart disease through better information and improved delivery of our support services.

If you'd like to leave a legacy to Down's Heart Group it's very simple, all you need is a valid Will. Your solicitor will help you complete a Codicil which sits with your existing Will and records your current wishes.

If you haven't yet made a Will there's no better time than now!

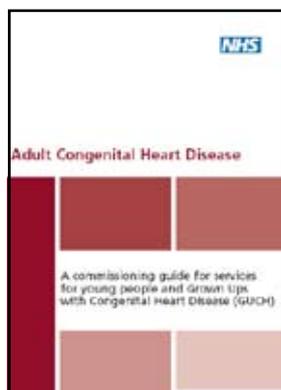
If you'd like to find out more about leaving a legacy to Down's Heart Group please contact our Chairman, Cliff Lake

Tel: [REDACTED]

email: [cliff@dhg.org.uk](mailto:cliff@dhg.org.uk)

## New Standards

The Department of Health has recently launched "Adult Congenital Heart Disease", a new set of standards and recommendations which has been produced after consultation with leading cardiologists and support groups, including DHG.



Copies can be ordered by telephoning 08701 555 455 quoting ref. 273640 or downloaded from

[www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)

## New Welsh Standards

The Welsh Assembly has also recently launched it's own "All Wales Standards for Paediatric and Congenital Cardiac Services", which highlights the way forward and best working practices for anyone involved in healthcare for youngsters with heart problems..



It is available in English and Welsh by telephoning Contact a Family Wales on emailing [wales@cafamily.org.uk](mailto:wales@cafamily.org.uk).

***These important documents should pave the way to improved services for all our children and young adults.***

## CHILDREN'S HEART FEDERATION CONFERENCE 2006 "SUPPORTING THE GROWING HEART CHILD" Saturday 23rd September 2006 - Peterborough

### Morning Programme

Parent Involvement  
Parent's Perspective  
Patient's Experience - living as an adult with congenital heart disease  
Panel Questions and Discussion

### Afternoon Workshops

Claiming DLA  
Your heart and you  
Physical activity  
Support through transition  
Attendance is free

Creche available

Contact Sharon Herzog on 020 7820 8517 for more details and to book

## The Pops Family

Member Margo Leeson kindly sent in an article about Marie Dunleavy and the books she has written to help her son, Daniel, learn to read. Daniel has Down's Syndrome but the books have proved so successful that now children with other Learning Difficulties are using and enjoying them.

The books feature the Pops family (Pops standing for "Plenty of Potential"); each book slowly builds on the vocabulary most used by children, focusing on certain groups of words and using repetition as an aid to learning. Marie has also developed a range of learning games following the same themes and principles, in fact she has turned her quest from helping Daniel into a thriving business.



[www.pops-resources.com](http://www.pops-resources.com)

## Bedfordshire Down's Syndrome Support Group

Set up by parents for parents and others involved with a person who has Down's Syndrome, our group builds friendships for all - parents, grandparents, siblings, friends and professionals.

We do this by providing:

- \*Seasonal parties
- \*Coffee mornings
- \*Newsletters
- \*Group speech therapy
- \*Summer outings
- \*Friendship and support
- \*Practical advice
- \*Workshops and seminars

We work towards raising standards, helping to ensure children who have Down's Syndrome have the opportunities they deserve. We are affiliated to the Down's Syndrome Association and we are a registered charity.

So, if you live in Bedfordshire, why not give us a call or visit our website!  
Karen Forrester [redacted] Teresa Hurley [redacted]

[www.bedsdownssyndrome.co.uk](http://www.bedsdownssyndrome.co.uk)



# dhg

down's heart group

Charity 1011413

PO Box 4260  
Dunstable  
LU6 2ZT

tel : 0845 166 8061  
email: info@dhg.org.uk  
website: www.dhg.org.uk

contact or answerphone (24 hours in emergency)  
always available

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Sister Mary Goodwin  
Dr. Rob Martin  
Dr. Claus Newman  
Dr. Phil Rees  
Dr. Graham Stewart  
Dr. Rob Tulloh

**PATRONS**  
Sarah Boston  
David Graveney

For further information about Down's Syndrome you might like to contact:



Down's Syndrome Association  
Langdon Down Centre  
2A Langdon Park  
Teddington  
TW11 9PS  
0845 230037

**the down syndrome  
educational trust**

<http://www.downsed.org/>

The Down's Syndrome  
Educational Trust  
The Sarah Duffen Centre  
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PO5 1NA  
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**Down's Syndrome**

**SCOTLAND** / helping people realise their potential

Down Syndrome Scotland  
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For general information on heart related issues you might like to contact:



Children's Heart Federation  
52 Kennington Oval  
London  
SE11 5SW  
0808 808 5000



British Heart Foundation  
14 Fitzhardinge Street  
London  
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Grown Up Congenital Heart  
Patients Association  
75 Tuddenham Avenue  
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