



**dhg**  
down's heart group

**Newsletter**  
**Spring 2007**

Issue 35

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**AND**

**ways you can  
help DHG  
support  
children  
like  
Luca?**

## Chair's Report

Over the past three years Down's Heart Group has achieved a great deal as I have mentioned in previous newsletters, but sadly there is one down side to this, the increased costs.

Activities such as the production and mailing of four newsletters a year, the costs involved in printing our high quality Information Packs and the related additional management and administrative costs has seen our annual operating budget double over the past three years to around £60,000.

Down's Heart Group is only a small charity compared with high profile organisations like Down's Syndrome Association, British Heart Foundation and Children's Heart Federation. As well as more staff they also have paid fundraisers enabling them to generate a much higher level of funding than we could currently justify, but whilst we don't need to be as big as these charities, we do need to maintain the quality of our service to members and professionals wanting to tap into our unique resources, all of which costs money.

None of our staff or trustees has professional fundraising experience, nor do we use any commission based fundraising, so the onus is on all of us to find our funds. As a committee we don't actually like asking for donations, especially from our members and we have been fortunate in the past to have received fabulous assistance from our volunteers and supporters in generating the funds needed to continue and develop our work. The recent increases in our costs though, mean that NOW is the time when we have to ask for your help in raising a minimum of £60k to ensure DHG survives.

We believe DHG makes a significant difference providing information, support and the facility for families to have contact with each other as well as in the areas of personal advocacy, political lobbying, NHS enquiries, reports and care standards.

**Our work is vital  
~ so is your support!**

**Cliff Lake**

## Front Cover - Luca Frost

Luca demonstrates his gorgeous smile on this issue's front cover.



Luca's Mum, Paula writes: I thought I would just send a few pictures of my baby boy who is 18 months old.

The time since his birth has been the hardest I and my family have ever faced. Luca has been a very poorly child due to having Tetralogy of Fallot, but throughout he has remained the most happy and content child you could ever meet.

When his initial diagnosis of Down's Syndrome was made we were distraught - then finding out he a severe life threatening illness blew all of our worries into proportion - the Down's Syndrome was nothing compared to this!

As you can see from the pictures he has remained smiling, even when he was full of tubes in hospital - and he never gets a minute's peace from his big sister, Tierney, who said "I never realised I could love someone this much".



Luca has now had his surgery and although he came home with a pacemaker he is doing brilliantly.



His surgery was a big milestone in our lives and we had to stay in Liverpool with him for about 2 months. We are getting into a normal routine now though and in the next couple of weeks he is starting nursery as I am going back to work as a theatre nurse - the nursery staff will probably lose half their body weight chasing after him!

**Paula Frost  
Burnley**

## Paul Giardina's Story

My name is Carla Giardina and I am a 20 year old university student in Australia. At the moment I should be finishing off an assignment which is due tomorrow but I came across DHG's website and decided to share my story with this Group. My connection with this community is my brother Paul.

Paul, like most people with Down's Syndrome was an extremely loving individual. He was forever smiling and laughing and didn't seem to have a care in the world.

Growing up with a brother that had Down's Syndrome taught me so much. It seems so unfair that such beautiful people have to go through so much in their life. Paul had two open heart surgeries. I only have vague memories of the first but very much remember the second.

My first memories of my baby brother were in hospital. He spent the first three months of his life there entangled in a web of tubes and monitors. I remember wanting to hug him but I was unable to so I had to settle for a kiss on the forehead.

Those three months definitely took a toll on my parents. The doctors didn't think little Pauly would make it but thank God he did!

The next few years of my life consist of my fondest memories. At primary school (mainstream education) everyone knew and loved my brother! I was so proud to go after class to pick him up from his classroom and walk with him to Mum's car.

Thinking back it is amazing how accepting the other children were of my brother. Everyone looked out for him and made sure that he had someone to spend lunch times with. But eventually the gap between Paul and the other students became too wide and he moved on to a special school.

Merriang Special Developmental School in Melbourne is an extraordinary little school consisting on some of the most loving students and dedicated staff I have ever met. Paul and his friends were definitely the trouble makers of the class. They were always



Carla and Paul Giardina

mucking around and on excursions always sat at the back of the bus (bless their little souls!)

It was during his attendance of Merriang Special Developmental School that Paul went in for his second heart operation. By this stage I was old enough and mature enough to understand what was going on (I think I was about 14 or 15). Seeing Paul lie in a hospital bed in ITU absolutely shattered me. Here lay before me one of the most vivacious characters I knew and all of a sudden he looked so small and helpless.

The worst feeling was when Paul came to and kept asking us what had happened. He was not a high functioning chap so it absolutely broke my heart to see him so confused and in pain. But a few weeks later Paul was back to his old self - dancing and jumping about while watching the Wiggles! It was a proud day when he went back to school.

Paul attended Merriang Special Developmental School until he was sixteen years old.

Paul passed way on the 26th of December 2004 in Thailand when the tsunami hit.

My brother was very special to a lot of people and I miss him dearly. I've always known that I have loved my brother but until that special someone is taken away from you one does not realize just how deep that love runs.

Individuals with Down's Syndrome are all very special people. If I could give one gift to the world it would be that everyone could know at least one person with Down's Syndrome. To be lucky enough to be connected to a person with Downs I think makes you a better person. They open your eyes and teach you so much about life and about appreciating and taking pleasure in the simple things. They truly teach you how to live.

**Carla Giardina**

## Best Man is Usher!

21 year old Richard Stringfellow from Cardiff was clearly the "Best Man" as he carried out his duties as an usher at his sister Louise's wedding last year. As you can see he looks very smart in his suit and he took his duties very seriously, especially when it came to chasing after the bridesmaids!

Derwen College, Oswestry, is Richard's term time home. He is one of several Down's Heart Group members who attend Derwen and all are doing very well.

At home he enjoys watching DVDs and trying out all the new skills he has picked up from college.

Richard is the inspiration for two of this year's London Marathon runners Gareth Hammond and Steve Taylor. They had already raised £1,600 before running a yard of the Marathon course as they had a very successful fundraising evening with a raffle and an auction.



## Brittany Holden

Brittany was born with AVSD which was successfully repaired at 11 weeks with no related problems since. She has been offered a place at Derwen residential college to commence September 2007 - which she's very excited about.

She enjoys her hobbies of Rangers, horse riding, swimming, youth club, Saturday leisure club. She also enjoys watching and listening to Grease, Annie, Oliver, and anything to do with Steps or McFly. She's a great flirt with a smashing personality and has given us untold joy in her 17 years. We thought you would like to see a photo of Brittany all dressed up for her first school Prom in June last year.

## Lapland Adventure

Thanks to the generosity of Dunstable and District Round Table and the support of Children's Heart Federation, Nottinghamshire members the Mowberry family were able to visit Lapland just before Christmas. Twins Nicola and Claire (both of whom have Down's Syndrome) were very excited, as were big sister Lauren and parents Shirley and Richard, who told us:

"We had a fantastic day in Lapland. It was incredibly cold (minus 25) where the front of our hair froze when not covered by a hat.

We especially enjoyed the reindeer ride and the sledging and of course the visit to the man himself. His 'house' was in the middle of the wood. To get there we took a ride on a skidoo (a sledge pulled by a sort of motorbike).



Claire meets Santa

We then waited by a huge bonfire until one of the elves came and fetched us and we walked the last 20 yards or so to Santa's 'house'. The house was absolutely as you would expect it to be and he gave all the children a present and had a chat with us before we left."



The Mowberry family



Nicola meets Santa

## Message From The Director

Hello everyone and welcome to our latest newsletter.



Penny Green - Director of DHG

I guess you may be wondering why I've got a section in this issue, so I'll right get on with it and tell you that I'm here to ask for your help.

PLEASE don't stop reading now because you think I'm asking for your money, if you read on you'll see there are many ways in which you can help that don't involve you putting your hand in your pocket (although if you want to that's fine!) We really do need YOUR assistance to help DHG survive.

### How it all began

Firstly I'd like to take you through a little history of Down's Heart Group. For some it will be old news because you were part of it, for others it will be the first time you have heard how we come to be where we are today. As you are reading I'd like to ask all of you to think back to your contact with the Group, particularly the first time you found us and how it felt to know that you were not alone in what you were going through!



Linda Walsh - Founder of DHG

DHG started back in the mid 1980's when our Founder Linda Walsh was told that her daughter Katie's heart condition was inoperable. Not the sort of person to just accept that news, Linda went looking for a second opinion and was told by another consultant that surgery was possible – now she faced a dilemma, which consultant should she go with? She decided asking other parents about their experiences might help with the decision, so she wrote a letter to the Down's Syndrome Association which was published in their newsletter and soon she was being contacted by many other parents, not only offering advice but also asking her for information.

### DHG was born



Members of the original steering committee with the first DHG banner

It soon became obvious to Linda and a number of these families that there was a need for a specialised support group dealing with the heart problems associated with Down's Syndrome and so Down's Heart Group was born. Then the work really began; contacting hospitals, publicising the Group, raising awareness, finding volunteers to manage things and of course raising funds to cover printing costs, phone bills etc.

It was not an easy task but belief in the role DHG had to play gave people the drive to keep things going and by 1992 the Group was ready to become a registered charity.

Things have continued to grow from there and DHG now has worldwide recognition for its work and has contributed in many inquiries and reviews to ensure that the needs of individuals with heart problems and learning difficulties are represented, striving to ensure

that they have access to appropriate services to meet their needs.

We know that things are still far from perfect but we have seen great changes and improvements over the past 20 years and these in turn have led to a need for our work to increase and diversify beyond just offering support and information to new parents.

### Responding to change

Many of our original members are now in their 20's and 30's and this has raised new issues surrounding the care and treatment of adults with congenital heart defects which DHG is now responding to as well as a huge increase in contacts with families who have a pre-natal diagnosis and are looking for realistic information in order to make informed choices.



All this may make DHG look like a large well funded charity with plentiful resources at its disposal but that is not the case. Yes we now have three employees, but we are all part time with our total hours amounting to only 49 per week. We all work really hard to keep our running expenses as low as possible, so please don't imagine we work in some swanky office because it couldn't be further from the truth as those few who have visited will know - National Office is actually based in my home.

Yet with the increased demand from families and an ever growing membership we now need about £60,000 a year to keep DHG running.



Those of you who know me will realise that whilst I now get paid for working for DHG, I would gladly do the job for free if I could afford to because it is so much more than a job to me! I really believe in what we do and just knowing that we may have helped one family is reason enough to keep going, even after 17 years. Not to mention how privileged I am to have met so many wonderful youngsters and watched so many of them grow over the years into remarkable young adults.

### Now we need your help!

Sadly we can't do it without money and that's why we really do need YOUR HELP NOW. Funds are critically low and although money is due from events such as The London Marathon we are currently surviving on our reserves. We will start eating into the Marathon funds as soon as we have them and then wait desperately for the next event. That is why I am asking for your help.

### Please think back to when you first contacted us

- Did it help?
- Were we able to answer some of your questions?
- Did we provide you with relevant and easily understood information?
- Were we helpful and supportive?
- Were we at the end of a telephone if you needed us?

### And now

- Do you find the newsletter interesting and helpful?
- Have you rung the helpline for information?
- Have we advised you about getting a second opinion or how to deal with issues you have with your child's hospital?
- Even if you haven't contacted us recently is it helpful to know we are there if you need us?
- Have you been to one of our conferences and found it useful?

### And have you ever been asked for a membership fee?

No, because we want our support and information to be available to

- anyone who needs it,
- whenever they need it
- without consideration of whether they can afford it or not

because at the end of the day that is what DHG is all about. Families helping other families, sharing information and experiences to improve the lives of our children and young people and continually working towards a better future for people with Down's Syndrome and heart defects.

Take a moment to think about how things might have been different for you if Down's Heart Group didn't exist and if you feel that we have helped your family in any way, please now think about how you may be able to help us continue our work.

### So how can you help?

Well you could decide to make regular donations either monthly or annually, perhaps on a special day such as your child's birthday. You can do this in several ways:

- Set up a standing order with your bank
- Send it to us by cheque
- Pay it online on our website
- We can send you a Covenant form to fill in for your bank to pay us
- We can send you a form authorising us to take regular payment from your debit or credit card.
- Encourage your employer to setup Payroll Giving and make a monthly payment through them
- If you have a Charities Aid Foundation account send us a cheque from there.



Whatever the amount, if you are a UK tax payer, please consider Gift Aiding your payment so that we can reclaim the tax on it too (except Payroll Giving where this is arranged automatically).

### Don't worry if you can't afford to make a cash donation!

There are lots of other ways to support our work, some of which are really easy and can be fun too!



If you use the internet, use Everyclick as your search engine and every time you search for something you make money for DHG. Simply go to [www.Everyclick.com](http://www.Everyclick.com)

and register as a user then select us as the charity you wish to support and set Everyclick as your homepage so you don't forget to use it.

Don't forget to ask all your friends, relatives and work colleagues to use Everyclick too – perhaps add a note at the end of your emails to tell everyone what you are doing. (NOTE I use Everyclick to search for everything, even those pages I visit regularly, it doesn't take much longer and every visit adds another click to our total.)



Get everyone you know to collect used postage stamps for us – schools, youth clubs, Scouts and Guides, your office. Most of the envelope needs to be torn or cut off to keep the weight down, but be careful not to tear the stamp. Stamps from overseas and British commemoratives (the fancy ones that get issued every few months) are worth the most to us. When you have collected a few pop

them in an envelope and post them off to our National Office – depending on the contents if you send a heavy packet it may cost you more to send than we will make, so keep it small.

Need to have a clear out? Why not hold a car boot or garage sale and donate the proceeds to DHG.



Only got a few items to sell? Try selling them on Ebay instead. DHG is registered with their charity programme so you can select us to receive anything from 10% or £2 (whichever is the greater) to 100% of the proceeds. Just select the donate to charity option and choose DHG as the charity you want to support. If this all sounds too confusing or troublesome, give National Office a call and they will talk you through it or they may even be able to sell the item direct if you are prepared to deal with the packaging and despatch. (I can recommend this as good fun, watching the bidding as the auction nears its end can be very exciting and you may be surprised at what you can raise).



What about organising a sponsored event? It doesn't matter what it is (well as long as it doesn't bring DHG into disrepute), if you can think something up and get people to sponsor you, then we can supply the sponsor forms and we'll try to help in any way we can with publicity and advice. In the past we've had sky dives, bungee jumps, hair cuts, walks – why not see what you can come up with!

Do you have contact with a celebrity who might be prepared to help us, perhaps by putting their name to our work as a patron or by hosting an event or providing prizes for an auction.



How about helping us fill places in the London Marathon, the British 10k and the Hydro Active Womens' Challenge? There are varying degrees of difficulty and sponsorship requirement (just ask National Office if you're not sure) and if you're not up for the challenge yourself how about checking to see if you know someone who is – you'd be surprised how many people are looking for a Marathon place but are worried about raising the minimum sponsorship some charities ask for. Or perhaps you could just sponsor one of those brave souls taking part for DHG – details on the website events page.

Why not suggest to your company, local Round Table, Rotary club, school, church etc. that DHG is a charity worthy of their support. We've been fortunate to receive a lot of donations this way, not least that from BAE last year which all started from one member putting our name forward.

Got a celebration coming up where people will want to give you presents but you don't need anything? Why not ask them to make a donation to DHG instead – in the past we've had donations instead of birthday, wedding and anniversary presents.



Remember at Christmas that you can buy cards in support of DHG from which all the proceeds go to the Group (not just 30 or 40 pence like some in the shops) and provided you purchase at least one pack of cards you can also order as many books of stamps from us as you like. They are exactly the same as you get from the Post Office it's just that we make a small commission on the sales, so it doesn't

cost you any more but it helps us. What about getting everyone at work to agree not to send Christmas cards to each other this year but to make a donation to DHG instead.

Perhaps you or someone you know has fundraising experience and would be willing to donate some of their time and expertise to helping us.

Could you run a quiz night or fashion show or host one of the many 'party nights' available, be it naughty nighties, ceramics or scrap booking you may well be able to negotiate with the organiser to receive a donation to DHG instead of the hostess gift.

So there are just a few ideas of how you can raise some much needed funds for DHG. Don't forget, if you are undertaking any kind of fundraising event, please tell National Office so they can let you know of any help and support we can provide. Most importantly remember to let your local press and radio know – it's not only about money but also raising awareness, so take advantage of the opportunity to tell people about DHG and why you are helping us.

**Penny Green**

P.S. Don't forget to check out details of the motorbike ride on July 14th which appear on page 9. That event alone gives you four more possible ways to support DHG including "Sponsor Penny a Penny".





### Fundraising....

can be fun as these participants at the BAE Open Day demonstrate

- Elvis outfit optional!



### Suzanne's Skydive

Suzanne Adams has very kindly raised some money for Down's Heart Group by jumping out of a plane!

On Saturday 21st April 2007 in near perfect conditions, Suzanne took part in a tandem skydive over the Nottinghamshire countryside. Below is a website link to take you to the video of Suzanne actually leaving the plane and her freefall descent. The video then shows her very safe and professional looking landing. She can even manage to speak to the cameraman!

<http://www.realxstream.com?XStreamID=42847>

Well done and Thankyou to Suzanne.

## THE **asics** BRITISH 10K LONDON RUN

"The 10k that really does run London" takes place on Sunday 1st July, starting at 9.35am from Hard Rock Café on Hyde Park Corner. Participants must be aged 15 years or over to be eligible for this fantastically popular Run that takes in many of London's sights. The course covers 10k or 6 miles of Central London, including Pall Mall, The Embankment, Westminster Bridge, Big Ben and finishing on Whitehall.

All runners and walkers receive an ASICS goody bag and a finisher's medal – and still have all afternoon free to revisit Central London at a pleasanter pace!

Down's Heart Group has places available for the British 10K London Run – all the charity asks is that you raise sponsorship money and that you are able to get yourself to and from the venue. Apparently 10k is a really good distance to run, as you don't have to be super fit to attempt it. Why not cajole some of your friends into entering and make a great day (or weekend!!) of it?

Contact Penny at National Office for a place – 0845 166 8061 or check out [www.thebritish10klondon.co.uk](http://www.thebritish10klondon.co.uk) for more information and free training schedules.

## Down's Heart Awareness Week Sunday 28th October - Sunday 4th November 2007

### What will you do?

### Hydroactive Women's Challenge

This year's challenge takes place on Sunday 16th September. Venues are the same as previous years – Hyde Park, London, Sefton Park, Liverpool and Birmingham City Centre. The run is 5k or 3 miles. Many women walk rather than run and it suits almost every fitness level, there are gentle slopes rather than big hills and the ground underfoot is even. Tempted?

Lots of women choose to run as part of a group, so why not ask your mothers, daughters, sisters, cousins, grannies, nieces, friends, and colleagues to do it with you? We would love to have you on board the team in 2007! Previous participants for DHG have all enjoyed the atmosphere of the day and the goody bags are amazing!

You may also have noticed that the three venues are all very, very close to shops! So after the event what will be needed is retail therapy instead of physiotherapy. If you are interested in taking part please talk to Penny or Lynda at National Office.



tel. 0845 166 8061  
or email [penny@dhg.org.uk](mailto:penny@dhg.org.uk)  
Go on - you know you want to!



## Motorbike Madness Saturday 14th July 2007

was the idea of motorbike mad Wayne Brown, who has a younger brother and sister both with Down's Syndrome. Wayne's brother had successful heart surgery at Leeds General Infirmary.

"Motorbike Madness" is an organised ride from Peterborough to Leeds via children's cardiac units at Leicester and Birmingham. The object is to raise awareness and funds and hopefully to have a great day out!



For a chat about the event contact wayne on [redacted] or email [redacted]

### Families

The bikers would love to see as many families at each hospital stop as possible.

Please consider giving up a couple of hours to support these riders, many of whom will not have even heard of Down's Heart Group before.

Can you offer to help supply drinks at one of the stops?

Can you bring along all the families you know who have a member with Down's Syndrome to help Penny with her "Sponsor Penny a Penny" photo marathon?

Can you encourage all the motorcyclists you know to take part? The larger the event, the more impact it will have.

Can you ask your local press to get involved?

### Donations

If you would like to sponsor any of the riders or the event as a whole please contact National Office or look on the website. Perhaps you could sponsor a biker per mile or per hospital stop.

Please remember if you pay tax to tick the Giftaid box, which means the charity can reclaim even more money.

By sponsoring Penny a Penny every little penny helps towards keeping the Down's Heart Group functioning.

### Sponsors

Space is available on support vehicles, the website, bikes, leathers and helmets, as well as at the hospital stops for any advertising.



### Riders

Motorbikers are welcome to join the ride at any point and travel as far as they wish.

The website gives precise timings and accurate maps.

Registration forms can be obtained from Wayne or DHG National Office.

Sponsor forms are available from National Office.

Can you attract sponsorship from your local dealer, garage, manufacturer and wear their logos on your leathers, helmet or bike?

Can you wear a DHG logo or heart to help raise awareness?

Can you encourage your biking friends to tag along?

### The Route

10am - leave Shell garage, Guyhirn, Wisbech (A47)

11.20 - arrive Glenfield Hospital

12.35 - arrive Birmingham Children's Hospital

15.40 - arrive Leeds General Infirmary

There are several catch up and comfort breaks through the day and a longer lunch break after visiting Birmingham.

Maps and timings are on [www.motorbike4charity.co.uk](http://www.motorbike4charity.co.uk)

### Celebrities

Do you know anyone famous who would like to attend? They don't have to be bikers, although we'd love to meet Rossi!

"Motorbike Madness" could become an annual event. Let's get the wheels rolling now!

### Sponsor Penny A Penny



Penny Green, DHG Director is hoping to ride pillion the whole route and at each hospital stop have her photo taken with as many people with Down's Syndrome as possible.

Penny would like people to sponsor her a penny for each person she is photographed with.  
email [penny@dhg.org.uk](mailto:penny@dhg.org.uk) or phone 0845 166 8061



## Quality Of Life Survey

### Do you believe that doctors and the NHS should do more to improve the quality of life of people with a disability?

If you do, one problem is that the medical profession, managers, civil servants and politicians cannot always be expected to know what you mean when you use the phrase 'quality of life'.

To help overcome this problem, Down's Heart Group members are invited to give their viewpoints on their quality of life to a study taking place in England and Wales.

The QALYity Project is an alliance of prestigious patient groups, medical professionals, academics, and journalists. It is conducting the study in order to develop an index that can measure how effective each individual medical treatment or form of care or support is at improving the quality of life of people with a long-term medical condition or a disability. This will be as determined by the individuals themselves, not by clinicians.

<http://www.surveymonkey.com/s.asp?u=723883484804>

The results of the survey, and the tools that emerge from it, will be made publicly available, will be submitted for peer review, and will also be presented to the National Institute of Health and Clinical Excellence (NICE), the government-funded body that decides which treatments and care should be paid for by the NHS.

To get a copy of the questionnaire, either use the web address below or phone Sarah (DHG Information Officer) on 01455 888344 for a paper copy.

For more about the QALYity Project see

<http://www.patient-view.com/qalyity.htm>

## Access To Useful Information

The Disabled Living Foundation (DLF) is a national charity, which for over 35 years has compiled and maintained a database of products for older and disabled people. Up until recently this database has only been available on subscription to healthcare professionals, but now DLF has launched a campaign to make it freely available for public use over the internet.



One section of the database is now available free-of-charge - 'Bathing made easy'.

[www.bathingmadeeasy.com](http://www.bathingmadeeasy.com)

## Sleep Tight All Night!

A "Sleep Tight All Night" cover is a safety bed sheet with integral waistcoat for ages 6 months to 7 years. It will enable your child to sleep in varied positions and still be warm, safe and well covered, without the feeling of being tied down or restricted.

"Sleep Tight All Night" ties to the slats of the bed base underneath the mattress. Then you just pop your child into the integral waistcoat. Their lower body can move around just as normal, but the upper waistcoat prevents them falling out of the bed.

It can be used at home and on holiday. Very useful for parents in need of SLEEP!

Web [www.stankidz.co.uk](http://www.stankidz.co.uk)

### Are You Supporting A Young Person Who Is Leading A Fulfilling Life? If So We Need You!

The Foundation for People with Learning Disabilities is working on a project to support young people with Down's Syndrome to lead exciting and fulfilling lives after they leave school.

We have spoken to people with Down's Syndrome and their families to find out what really matters in their lives and the transition to adulthood seems to be a key area for more work. That is why we are running this project.

#### Foundation for People with Learning Disabilities

During the first part of the project we want to speak to those young people (aged between 19 – 25 years) and their families who are having fun and doing innovative things with their life.

For example, do you know someone using direct payments that employ people to take them out to pubs or on holiday?

Do you know someone who is involved in his or her local community activities or is a self-advocate?

Do you know someone who works or does voluntary work or lives away from home?

If you would like to get involved or want more information please do not hesitate to contact Penny Green at [penny@dhg.org.uk](mailto:penny@dhg.org.uk) or on 0845 1668061.

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

## Young Person Of The Year Awards

My name is Rebecca Rollinson and I am 15 years old. I have recently come runner up in the Young Person of the Year Awards in my local area. I received the award because I care for my older sister who is 17 and has Down's Syndrome. She was also born with a heart defect. I also do a lot of charity work for Sophie's school and with with the Young Carers Project in Hertfordshire and Connexions.

As part of the Award I received £250, £125 for me and £125 for the charity of my choice. I have chosen Down's Heart Group as it is more personal to me because of my sister and also that when Sophie was born there was no real support or information about her condition and I feel that all parents deserve that support when in that situation.

I know that £125 isn't much for a charity such as yourselves, but I hope it will make a difference to someone and hope that your fantastic worthwhile cause continues.

**Rebecca Rollinson**



## Blenheim Team Triathlon

Three employees of Pathway Care, an Independent Fostering Agency in Cardiff are taking part in a Team Sprint Triathlon at Blenheim Palace on 2 June 2007.



Siân Harrison the Administrator is doing a 750 metre swim in a lake in the Palace Grounds, Colin Beardsley a Principle Officer is cycling 20 km around the grounds and John Hill, also a Principle Officer is running 5km.

They have chosen DHG "because of the incredible support and guidance provided to one of our foster carers who has been caring for a very sick little girl".

The team are now looking for sponsorship, so if you would like to support them please contact:

National Office on 0845 166 8061  
or donate via the website [www.dhg.org.uk](http://www.dhg.org.uk)

For information on the Team Sprint Triathlon see [www.theblenheimtriathlon.com](http://www.theblenheimtriathlon.com)

**Good Luck to the Pathway Care Team!**

## The 2007 London Marathon

Congratulations to all our runners! The heat this year really took it's toll and made a really hard race even tougher. Our only lady this year was Nicola Bond, who finished in a time of 3 hours and 55 minutes. The five male runners battled it out both on the tarmac and on the fundraising front, rugby players (Kev, Gareth and Steve) hoping to beat the firemen (Darrell and Mark)! We don't mind who's the best and just want to say a huge thankyou for everybody's effort, both on the day and trying so hard to raise a fabulous amount of money.

Times:



Mark with daughter Ellie and  
Brother-in-law Darrell

Mark Myers	3:48:30
Nicola Bond	3:55:47
Darrell Holman	4:08:51
Kevin Clarke	4:40:29
Gareth Hammond	4:57:21
Steven Taylor	5:05:58



Gareth and Steve



# dhg

down's heart group

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contact or answerphone  
always available

(24 hours in emergency)

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Dr. Graham Stewart  
Dr. Rob Tulloh

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David Graveney

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



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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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## Down's Syndrome

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



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