

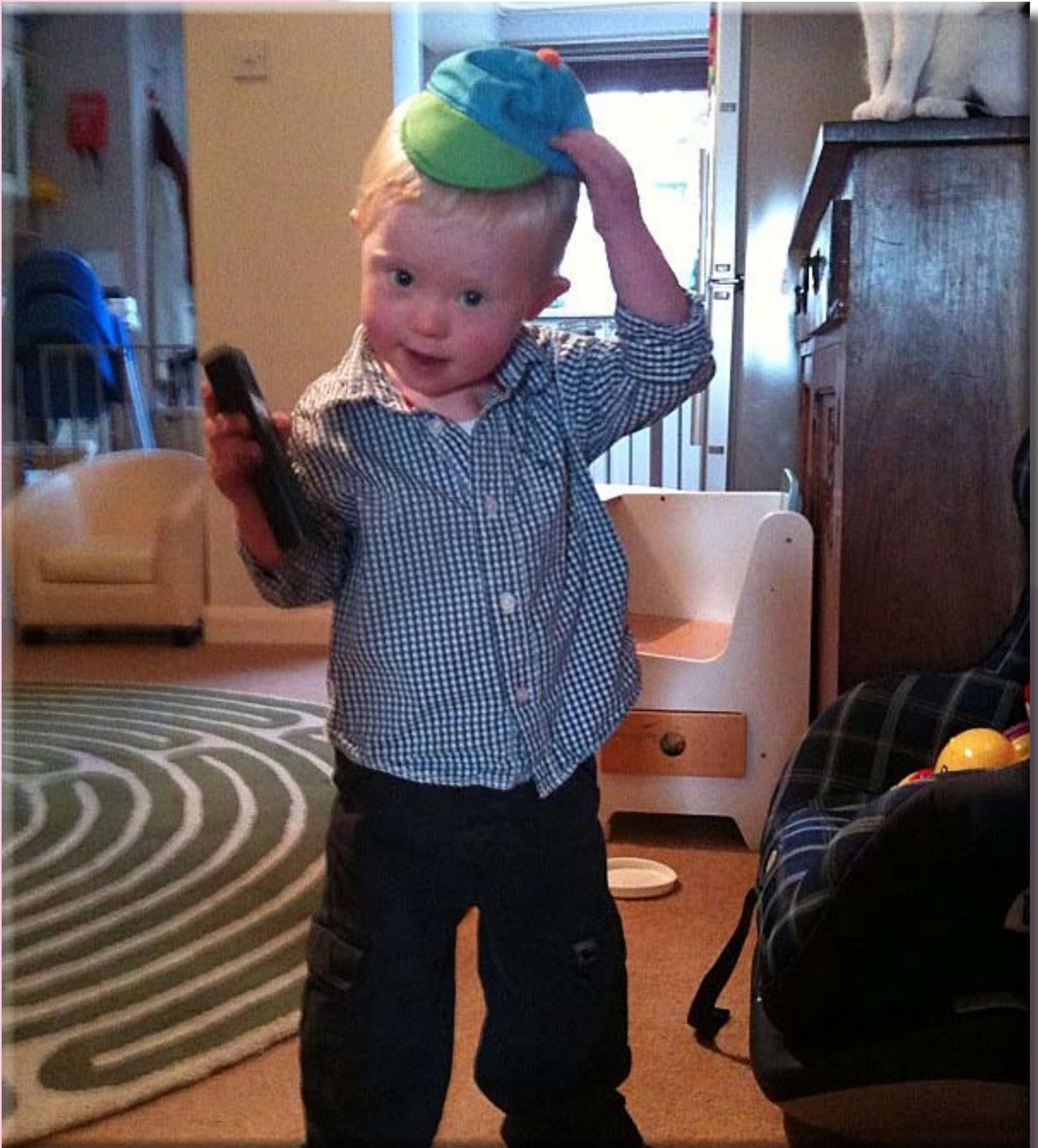


dhg

down's heart group

Newsletter Spring 2010

Issue 40



Chair's Report

Welcome to Issue 40 and some Committee changes. At our AGM last October, Lindsay Allen, Gareth Hammond and Helen Stringfellow all stepped down from office and Linda Stokes has resigned since. We would like to thank them all for their support of DHG and offers to continue to help out on a less formal basis.

We were pleased to welcome two new committee members

- Richard Mowberry who brings experience both from his role as a health care professional and as the dad of twins Claire and Nicola.
- Maralyn Adey, who has since sadly had to decline her nomination.

Your help needed

This leaves us with vacancies on the Committee and we would like to encourage all members to consider getting more actively involved with the running of the Group. This is your opportunity to help the future development of DHG and we would welcome the involvement of some parents of younger children as well as anyone else interested in furthering our work.

This year promises to be another busy one for DHG including an awareness campaign by our Director, Penny Green in memory of her son Daniel, who sadly died. Without him, Penny would not have got involved with the Group, so to celebrate her 50th birthday this year and Daniel's 21st, Penny will be visiting members throughout the year and joining in with a variety of activities in order to raise awareness and hopefully some funds too.

Read more of Penny's plans later in the newsletter, but if you would like her to visit your area please get in touch.

To coincide with the end of Penny's campaign, we have arranged our conference and family weekend to take place in Reading on 13th & 14th November. On the Saturday evening we have arranged a dinner dance and we hope that past and present friends and members of Down's Heart Group will join us.

Chris Stringfellow
Chairperson

Giggle-Bug

Giggle Mail is a new concept in raising awareness and funds via the internet.

Down's Heart Group has teamed up with Giggle-Bug for a pilot project spanning three months. Signed up contacts receive a joke each week, which they then forward to as many people as possible, who in turn forward to their friends and colleagues. Thus the Giggle Mail reaches all parts of the English speaking world.

The Giggle Mail has information about Down's Heart Group and links to our website, as well as a carefully selected joke. There is the option to sign up for direct Giggle Mails and also the option to donate a joke.

People can use Twitter, Facebook and MySpace to follow Giggle Bug. There is already a solid fan base on Facebook and Giggle-Bug reported 10,000 "hits" in the first week, far more than anticipated.



This means that awareness of Down's Heart Group is spreading at fantastic speed with minimum use of our resources as there has been no financial outlay for DHG.

On the fundraising side there is the opportunity to donate money to DHG or for companies to become sponsors and have their logo travel the net alongside Down's Heart Group's.

Perhaps you could get work or college involved? Or perhaps Facebook friends? Your company may wish to become a sponsor, if so please encourage them to get in touch.

To get registered for Giggle Mail please go to

www.Giggle-Bug.co.uk

Whatever happens with this venture we will at least raise a few smiles!

Goat Cup

Richard Stringfellow won the Goat Cup for swimming.

He was really excited to be presented with this huge piece of silverware and medals too, at an awards ceremony last autumn.

Well done, Richard!



This summer The Big Fun Run is being staged in 22 different locations across the UK. All runs are 5km and take place within scenic parks that are both safe and pleasant running, walking, buggy pushing environments.

More information, sponsor forms and access to the Virgin Giving site for anyone who would like to take part, is available from National Office on

0844 288 4800
or email info@dhg.org.uk

The venues are listed on

www.bigfunrun.com

- there is bound to be one nearby!

Cover Story - Leo Collins

The front cover shows Leo Collins four weeks after open heart surgery. Here his mum, Joanna, tells the story:

Leo was born with a large Atrial Septal Defect. We had an agonizing three year wait before surgery. The reason for waiting was to ensure he was strong enough (the bigger the better) and there was a slim possibility that the hole may close a little by itself resulting in him only requiring keyhole surgery. But every visit the hole seemed to be getting larger and Leo was suffering from more and more chest infections.

When Leo was 18 months old he also became diabetic, I thought what else is God going to do to this poor gorgeous child of mine? It was all getting too much and I didn't know where to turn. However, just being with Leo and helping him helped me in more ways than I could imagine - the love and bond we have is the best feeling in the whole world - he is my world.

Leo was approaching his 3rd birthday and we had still not heard anything regarding his surgery. Then in July we had a meeting with Dr Archer, Leo's heart doctor, and he advised us they would probably carry out the surgery before Christmas. Argh! Is all I could hear in my head and heart! Every time I thought about it I would burst into tears - I was so sure it would all go wrong and the day he had his surgery would be our last together.

Review date came again on August 18th, with the normal blood tests, echo's, ECG's etc. and then a surprise, surgery would be on the 20th August - in just 2 days time!!! I was numb and did not know what to think, do or say.

Leo was admitted on the 19th. He had his pre-med the following morning at 8.15am which made him seem very, very drunk and had no strength in him at all. At 8.30am we all walked down to the anaesthetic room and this is where I said goodbye, lots and lots of kisses and I managed to hold the tears until I turned away. That was the worst moment in my life and I never wish to experience it again; the feeling of guilt, worry, and fear all rolled into one.

Four hours later we were told Leo was in recovery down in ICU. Leo's father, Peter, and I had been for a McDonald's breakfast to keep us occupied, it did for a while and somehow the four hours went by quite fast. At 12.45 we were taken to PICU to see Leo and nothing could have prepared me; he had tubes coming from his neck, his groin, his chest, his arm - in total we counted 21 tubes going into him, all doing a different task. He also had a ventilator to help him breathe.



Leo in ICU

Leo looked terrible, but what did I expect - he'd just had heart surgery! There were some moments where Leo got very distressed and I couldn't handle it and ran away in tears. His dad stayed with him, but I wished I could have been stronger for him.

Day by day tubes were removed, in fact, the very next morning pulled out his ventilator! He had a very dry mouth and gulped down many offers of water.

Day two am -

his pacing wires and his chest drain were removed. Day two pm - his neck line and catheter were removed. Day three Leo was moved to PHDU and was eating and drinking (when he felt like it) and he even did a little painting. He wasn't able to sit up by himself yet but he was trying. Day four he went onto the children's ward where we had a bed next to him. Leo was eating, smiling and nearly sitting up (supported). They removed the line in his arm and now he was completely line free. Amazingly, day five we all went home!

The chest wound had a couple of infections but that was expected with his diabetes, but with antibiotics he was fine. Leo has been a complete barrel of strength throughout, but I hope he never has to have anything like that again.

I offer my thoughts, love and hope to all who have to go through heart surgery. If anybody wishes to speak to me or see pictures I took of each day's recovery please do not hesitate to contact me, we are all in this together.

Joanna Collins

Annual General Meeting

Our AGM for 2009 took place in Leicester on 24th October with a good turn out. It was great to see faces old and new.

Chris Stringfellow, who remains as Chair, welcomed Maralyn Adey and Richard Mowberry onto the committee and thanked Lindsay Allen, Gareth Hammond, Maggie Linde and Helen Stringfellow all of whom had stepped down during the year or at the AGM. They have been valued Trustees and thanks go to them all.

The next AGM will be on Saturday 13th November at Wokefield Park in Reading, during the Family Weekend.

Flu Vaccinations

Annual flu vaccinations for seasonal flu and annual vaccinations against pneumonia are available for people with Down's Syndrome and heart conditions.

Take up varies greatly across the UK and not everyone is routinely offered the vaccines or indeed decides to go ahead with them if offered. Some of our members don't particularly need these vaccines, but many have issues with their heart, chest or general immune system which means vaccination against both are advised. Both flu and pneumonia are potentially fatal illnesses.

If you feel that your youngster would benefit from receiving these vaccinations you should discuss with your GP or cardiologist.

Carers can also receive flu jabs so it is well worth considering if you are the main caregiver in your household.

Babies that have had bouts of bronchiolitis or RSV can receive vaccinations to prevent reoccurrence of these conditions. These jabs are generally given on a monthly basis through winter months. Again, these are not always offered so remember to ask at the cardiac clinic well before the cold weather arrives.

Thurlaston Carnival

The small village of Thurlaston in Leicestershire has been holding a carnival for more years than the original Carnival Queen would like to acknowledge. The committee works extremely hard throughout the year for the big day, but instead of making life easier by holding on to the funds ready for the following year, they give most if it away to local charities.

For the past few year's Down's Heart Group have received between £50 and £100 each year.

Thank you to all involved.



A **Parent Partnership Service (PPS)** is a **free, impartial** and completely **confidential** service that offers advice, support and information to parents and carers of children and young people with special educational needs. It aims to help parents and carers make the right choices for their children.

PPS can also put you in touch with other local and national organisations. PPS have a role in making sure that parents' views are heard and understood and that these views inform local policy and practice. PPS are based with a voluntary organisation, with a local authority (LA) or Children's Trust.

All Parent Partnership Services, wherever they are based, are at 'arm's length' from the LA and the services they provide and impartial and confidential.

They can give you information and advice about:

- How to get your child's special educational needs assessed.
- Statements.
- Who you can talk to in a school or LA about your concerns.
- The Special Educational Needs Code of Practice.
- Your rights and responsibilities
- Meetings and reviews about your child.
- How progress is monitored and reviewed.
- What you can do if you are not happy with a decision about your child's special educational needs.

And lots more.

Each PPS develops its own local aims based on national guidelines:

- PPS are free, impartial local services
- PPS work directly with parents and carers of children and young people with SEN
- PPS provide confidential information advice and support
- PPS work in partnership with parents/carers, schools, the local authority and other agencies
- PPS support parents to inform and influence local policy and practice
- PPS enable parents and carers to make informed choices and decisions with confidence

National Partnership Network

8 Wakley Street

London

EC1V 7QE

Tel: 0207 843 6058

Email: nppn@ncb.org.uk

www.parentpartnership.org.uk

Daniel Green Memorial Celebration

DHG Director Penny Green writes about her awareness campaign. You can keep up to date with events by visiting her blog - <http://dhgorguk.blogspot.com>



Daniel Green

Back in August 1989 on my 29th birthday, I received a slightly unexpected present. My second baby was born a month early complete with an extra chromosome 21, as well as heart and bowel defects. Despite the best efforts of the wonderful team at Great Ormond Street, in particular Dr Phil Rees and Prof Martin Elliott, Daniel was only to be with us 14½ short weeks before getting his angel wings, never having made it home from hospital.

As you can appreciate, losing a child is never easy, but when you share a birthday every year that day serves to re-enforce your loss. To be perfectly honest I went from being a big kid who loved her birthday to someone who would have preferred to crawl into a hole for the day and ignore it.

However, other things conspired to make that impossible: our eldest niece was eighteen the day after Daniel's birth, my sister-in-law gave birth to a baby girl two days after I had Daniel and four years later, my daughter, Sarah, was born seven weeks early, arriving the day before my birthday.

So, instead of ignoring my birthday, I have learned over the years to celebrate Daniel's life. This year, I turn 50, and Daniel would have been 21, I decided that this occasion warrants an extra special celebration of Daniel's short life and the incredible gift he has been to our family; and so the "Daniel Green Memorial Celebration" was born!

My intention is primarily to raise awareness and secondly some funds for Down's Heart Group by spending time with some of the children and young people in the UK who have Down's Syndrome and heart problems. I want to see what their lives are like and how our wonderful children can lead full, rich and happy lives. So I am now looking for young people who are willing to share some time at school, at play, at work or at anything else they enjoy.

I've already had a great response and it looks as if I will be spending time in various schools and playgroups, at hydrotherapy, working in a cafe staffed by individuals with special needs, enjoying the botanic gardens and feeding the ducks, oh and being put on horseback by a Special Olympics medal winner! And on top of that I am hoping to get to meet a load of my online friends and their special kids - it's going to be great fun!

Then, to finish it all off, Down's Heart Group are holding their bi-annual conference on November 13th and 14th at Wokefield Park, Reading.

The Saturday night gala dinner and disco will be the finale to the campaign, which is very appropriate as it is the anniversary of Daniel getting his angel wings.

I am hoping that many friends, both old and new, that I have met along this wonderful twenty one year journey will be able to join us at the Dinner and make a very special end to this celebration of my son's life.

Events so far

Penny attended the House of Lords in March during Down's Syndrome Awareness Week to celebrate the Down's Syndrome Association's 40th Anniversary and was present at the launch of the new Down Syndrome International website.

On World Down's Syndrome Day, Sunday 21st March Penny joined a sponsored awareness walk across the old Severn Bridge.

Penny has also promised that she will dye her hair bright pink if she gets £1000 sponsorship. Thanks to her lovely Facebook contacts she is already half way there.

Contact DHG to pledge your support or to invite Penny along to an activity.



Daniel and big brother Andrew

Down's Heart Awareness Week

6th - 14th November 2010

Finale event
Conference and Family Weekend
13th / 14th November
Wokefield Park, Reading

**Down's Heart Group
is 20 years old!**

What will you do to mark the occasion, raise awareness or raise much needed funds?

Please contact us with your ideas and events. We can provide sponsor forms, posters, advice etc.

0844 288 4800
info@dhg.org.uk

London Marathon 2010

This year's London Marathon is on Sunday 25th April. Down's Heart Group have six runners:

Emma Fuller
Ellena Talbot
Barrie Watson
Marco Van De Water
Tom (Tosh) Evans
Simon Hanson

Please support them by going to:
www.dhg.org.uk

and following the Events link to the Marathon and the donation facility for each runner. Or call National Office on

0844 288 4800

Marco, Emma, Tom and Barrie also have a page on Virgin Money Giving,

uk.virginmoneygiving.com

Good luck to all six runners with their training and for the marathon itself. We look forward to printing their achievements in the next newsletter.

Cervical Cancer Vaccine - HPV

Girls aged 13-17 are being given the HPV vaccination to help protect against cervical cancer. Several families have been in touch



seeking reassurance regarding the vaccine's safety. Research is ongoing, but an advisor to Children's Heart Federation says the vaccine is not "live" and can find no contra- indications for its use in females with congenital heart conditions.

There are two different types of the HPV vaccine - Gardasil and Cervarix. The vaccine used in the UK national vaccination programme is Cervarix. The vaccine has undergone rigorous safety testing as part of the licensing process required in the UK and other European countries. It offers protection against two specific types of HPV, types 16 and 18, which cause 70% of cervical cancer. The vaccine also protects against genital warts.

There has been one fatality in the UK after receiving the vaccine, but independent official medicines control laboratories in the UK and

Belgium can find no direct link with Cervarix. There is no evidence to suggest that anyone with a congenital heart problem or

Down's Syndrome is at any more risk from side effects of the HPV vaccine than the general population.

The vaccine is given to girls as three separate injections into their arm, over a period of six months. The second one to two months after the first and the third injection will be given about six months after the first.

There may be some swelling, redness and pain around the area where the injection was given. Other mild side-effects can include headache, fever, sickness, dizziness, diarrhoea and muscle pain. Fainting is also reported but this can be the case with any vaccine.

It is well documented that nuns and other ladies that lead a celibate lifestyle do not contract cervical cancer, so if you are absolutely sure your daughter will never be sexually active, she will not require the HPV vaccine.

"CHANGES AND CHOICES" **Conference and Family Fun Weekend** **13th and 14th November 2010** **Wokefield Park, Reading, Berkshire**

Wokefield Park is a stunning hotel, situated in acres of parkland. Facilities include pool and gym, disabled rooms, free computer games suite.

Twenty years after Down's Heart Group's inaugural Annual General Meeting this conference looks at how surgery and services have changed and how current choices will improve quality of life for now and the future

This weekend marks the end of Down's Heart Awareness Week and will be the grand finale to the Daniel Green Memorial Celebration.

£50 deposit per family required

Bursaries available, please call

0844 288 4800

or email

info@dhg.org.uk

to discuss your requirements

Hear about the latest research in surgery, diagnosis and treatment

Meet other families and share experiences

Attend workshops tailored to your needs

Relax and unwind, chat and play, eat great food and dance the night away

Join us for the whole weekend or just part of it - all welcome!

Conference

Saturday 10 am -4pm
Discounts for members
Creche available

Gala Dinner and Disco

Pink and purple theme
7pm - late

Sunday Funday

Family focused fun

Bed and Breakfast

Family Room £85
Single £75

My Amazing Year

In September 2008, Emily Smith from Thurlaston, Leicestershire qualified for a place in the East Midlands Equestrian Team for the Special Olympics to be held in Leicester in 2009. Last July, Emily won three medals there - this is her story.



Emily with her medals

"Last year was fantastic for me because I did the Special Olympics.

First we had to take my pony, Snazzy Tazzy, to a competition to see if we could qualify. It was really scary because we didn't know anything about what would happen and we didn't know any of the other people.

I have been competing since I was little but I had never done dressage or working trials before. My sister, Grace and my mum helped me to learn the tests. I tried really hard and won my section, but nobody knew who would be picked for the team until weeks



The Dressage Test

later. I was so excited when I found out I was on the team!

We went to lots of training days with the rest of the team who are now my friends. I had lots of riding lessons and lots of practice. Me and Taz lost weight and got fitter.

We had to raise money to help to pay for all the stuff we needed like show jackets and boots. The ponies all had matching rugs and bandages, as well as feed buckets and brushes.

Grace organised a fun ride around the fields and also a disco. The Elephant and Castle pub let us do a raffle. They had a grand opening night for the new restaurant and I was asked to open it with Richard Everard from the brewery, I felt very proud.

I also opened Thurlaston Carnival. I wore my Special Olympic tracksuit and walked in the procession through the village and then I cut the ribbon and got a big bunch of flowers.

I was on television three times and in the newspapers as well. I was famous! Everyone in the village kept shouting "Good Luck" when they saw me and asked lots of questions.

At the Special Olympics I shared a flat with some of the team and Wendy who looked after us. She needed a long rest when she got home!

We had our meals at Walkers Stadium and had to catch a bus every morning to Abbey Park, where the riding events were held.

Grace was Taz's groom. She had to stay in a smelly caravan on the park! I had an ensuite bedroom. Grace worked really hard and we had never seen Taz look so smart, he usually looks like a hippo!

Dressage was my first event and I was so nervous I was shaking. Mum looked really pale and Grace was getting stressed. Even Dad felt sick!

When I got to the arena I could see so many friends and family that had come to cheer me on - it felt really good and I wanted to make them all proud of me. Mum shouted out my test and Grace ran by my side just in



Working Trials

case Taz saw some nice grass to eat. I got bronze!

My next event was Horse Care Knowledge. I had to answer questions and name parts of the horse and equipment. It was hard to remember the answers but I got another bronze!

My last event was Working Trials. This was the hardest for me because I think that I'm going to fall off when I have to reach out for things. I was really scared and Taz was being a bit naughty because he was fed up of waiting.

We went into the arena and managed to do all the obstacles. I was so relieved that when I got out of the arena I burst into tears! I won silver! I couldn't believe it!

Special Olympics was the best week of my life. When I got home there were banners and posters in the village saying "Congratulations".

I won the Journal Award for sporting achievement and me and Grace received the Young Achievers award from Thurlaston Parish Council.

Emily Smith, aged 19



Team Smith!

My Visit to Down Syndrome Association of Nigeria by DHG Director, Penny Green



The Welcoming Committee

Last October I spent 10 days in Lagos, Nigeria as the guest of Down Syndrome Association Nigeria during their Awareness Week. The President and founder, Rose Mordi had originally approached me to speak at a seminar as she was aware that I was an advocate for Down's Syndrome and had 20 years experience that could be drawn on.

DSAN were not in a position to fully fund my trip, nor could Down's Heart Group as its charity registration only allows work in the UK, so with the fantastic support of Down's Heart Group members, friends on Facebook and Stepping Stones Nigeria, I managed to raise the money for travel, visa and vaccinations.

I pinched a few hours sleep on my late night flight from Heathrow and eventually, melting in the heat, I made my way into the arrivals area at Lagos airport wondering how I would find the DSAN representatives that were going to meet me. I need not have worried as it was hard to miss the sea of DSAN printed t-shirts and green baseball caps, that despite being only 5am, had turned out in force to welcome me.



The walk through Lagos



So many walkers!

After a journey in the Association minibus, thankfully with air conditioning, I arrived at the resource centre and finally met Rose. There were some hurried introductions before I was whisked away to the guest house where I had just enough time to open my suitcase, change and don a DSAN polo-shirt before we headed off to the start of the Awareness Walk through the streets of Lagos.

It was so hot, although I was the only one who seemed bothered by it! Everyone had a great time and there was lots of interest in the walkers from motorists and passers-by. Afterwards we all gathered together for photos and to talk to the press. Everyone was laughing at how hot and red in the face I was.



There were lots of photo opportunities!



Children From the School perform a dance routine

My next official engagement was a presentation at the Awareness Seminar which took place at the local hearing impaired school.

The hall gradually filled up but the children from the Down Syndrome Centre were all sat in the middle rows. So before we got started, Chuks, our MC for the day asked all the adults to take one of the children to sit with them. There was a lovely moment when one man led a young lady with Down's Syndrome to sit with him and then turned round to find there were two sat beside him - he hadn't realised that they were twins and there was lots of laughter about him getting two for the price of one!



The main presentation

Then it was time for my presentation about some of the medical issues our young people can face and the importance of identifying and treating these in order to ensure they can be as healthy as possible. I highlighted what some people with Down's Syndrome can achieve with good health care and given suitable opportunities, using Sujeet Desai, Dylan Kuehl and Karen Gaffney as examples.

We were then treated to a dance performance by some of the pupils from the Down Syndrome School.

All together it was a very successful event and there was lots of media coverage.

At the Awareness Seminar, the lady sat next to me was Elsie Akerele. Her presentation was a poem she had written about her son to explain to other parents the joy of having someone with Down's Syndrome in your life. Part way through she mentioned his name and I realised her son was David, a quiet, pleasant, very talented musician I had already met at the DSAN school.

My Angel has Down Syndrome

Yes! His birth unusual; his growth, unique;
His make, different.
At first a challenge and later a task,
And finally an assignment,
And then a mission.

My Angel has Down Syndrome
I needed the grace, he needed the love.
His siblings were aware of the work on ground.
Their input is beyond what money could buy.
They needed to extend their unconditional acceptance
To the new arrival in the home of ours.

My Angel has Down Syndrome
I learnt to make him my angel, my friend,
My companion and my
closest acquaintance.
And I got the shock I never bargained for.
The way my Angel responded to training,
He yielded to love,
He embraced my friendship,
He was encouraged to learn some skills,
He dances like bees and drums
better than the drummer boy,
He sings like birds and his
laugh infectious.

My Angel has Down Syndrome
And soon, my Angel was
noticed by all and sundry
He began to be loved by
the neighbours and authorities
His gifts and skills have made room for him
He stands before kings and acts before princes.
To the priests, he is just the friend they want.
My Angel is humorous and so compassionate.
Is that a gift or also a skill?
You should know where I'm coming from!
We became friends and the best for sure.

My Angel has Down Syndrome
Wherever he goes, I'm always invited.

If he sees the kings, I'm seen by kings.
If he is beamed in the media, I am always accomplished.
We compliment each other in our great assignment.

My Angel has Down Syndrome
His credentials include story telling,
Children supervision and interceding for people.
David my Angel, the weak has been strong,
The fool has become wise, the poor has become rich.
And today this scripture is here fulfilled:
"That all things work together for
good to them that love God
And are called accordingly to His purpose."



Elsie Akerele and David

My Resolve
I'll love the more to gain twice as much.
My mission in life is right on course.
My Angel is the catalyst of who I am,
And a great aid to where I am.
With David, I have learnt
my lessons aright,
And placed my priorities right as well.
When I'm left with the weak,
The Lord supplies the strength I need.
When I stay with the fool,
The Lord remains my wisdom.
When my portion is with the despised,
Christ remains my lifter.

My Angel has brought me from
obscurity to limelight,
A royalty I never bargained for.
I share fame and glory with him;
I enjoy privileges with him.
He is now one of the greatest treasures
I have found in life.
He's given my life a meaning -
The greatest things God has done for me.
Who is Your Angel?
Locate him and the Lord will turn your pains to gains.
My Angel has Down Syndrome
A BLESSING IN DISGUISE!

Swine Flu

There is still confusion around the UK regarding Swine Flu and the pros and cons of vaccination for our youngsters. The latest recommendations are that all children 6 months to 5 years and anybody with a heart condition repaired or not, regardless of age should be given the vaccine.

There are two drugs used in the vaccination programme; Pandemrix is mainly used for children, unless they have anaphylactic reaction to eggs, or Celvapan. Children requiring Celvapan will need two doses given at least three weeks apart. Most children will get Pandemrix in just one dose unless they have an immune deficiency, when two half doses are given at least three weeks apart. Older children and adults should be able to have just one dose of vaccination.



Reaction to the vaccine can range from a sore arm and shoulder to flu like symptoms such as raised temperature, headache, muscle aches and sleepiness.

The risks from Swine Flu are just as varied but unfortunately several people in the UK with Down's Syndrome and heart problems have died after contracting Swine Flu.

Feedback from families who have gone ahead with vaccines suggests anxiety over the side effects is outweighed by the sense of relief that their youngsters wouldn't be catching Swine Flu.

For further swine flu information go to www.direct.gov.uk/swineflu

Special Children's Zoo Day

Children with special needs and their families are invited to the annual fun day at London Zoo on Saturday 12th June when a special reduced rate applies.

Children under 3 years; no charge
Children 3 – 18 years; £8 (usually £16)
Adults; £12 (usually £19.80)
Carer (essential only); Free (maximum one per family)

This applies to tickets pre-booked and pre-paid before 4th June 2010.

Fun Day Highlights include:

- Enter London's only living rainforest where you can come face to face with a variety of amazing rainforest species including monkeys, sloth, armadillo and tamandua, bats, rats and nocturnal wonders that make the dark their home.
- Animal Adventure (Children's Zoo) including: Aardvarks, Red Pandas, Coatis, Meerkats, Llamas + Root Zone, Splash Zone, Secret Garden and more...
- Gorilla Kingdom, Meet The Monkey's, Butterfly Paradise, Penguins, Reptile House
- Animals in Action (live animal display)
- British Sign Language interpretation for all talks and displays
- Face painting, live band.
- Discounts at all retail outlets & main cafeteria!!

For more details and a booking form, please contact Steve on

0207 449 6551

Or email steve.marriott@zsl.org

The Zoo opens at 10.00 and closes at 17.30.

www.zsl.org



On Saturday 5th June, Thornbridge Hall in Derbyshire hosts the FSI Challenge, where small charities can come together for a day that mixes fundraising and family fun.

The Challenge is a fun run/walk with 4 and 10 km courses, suitable for all ages, that take you through some of the most scenic parts of the Peak District. Afterwards you can relax in the grounds of Thornbridge Hall.

Please get in touch with National Office if you would like to take part and raise funds for Down's Heart Group. It promises to be a great family day out in beautiful countryside.

Contact Sarah or Penny on 0844 288 4800
email info@dhg.org.uk
or write to
PO Box 4260
Dunstable LU6 2ZT

Down's Heart Group is once again



taking part in the FSI Great Big Small Charity Car Draw.

This is your chance to win a brand new Mini First Hatchback 1.6 3 door. Tickets cost just £2, of which £1.90 goes to DHG.

Tickets can be bought online from 7th April until 6th September.

www.thefsi.org/downsheartgroup

Next Top Models



Hannah

Next Generation Children's Competition was an online modelling contest which ran for six weeks before Christmas. A voting system ensured the most popular one hundred were put through to the finals at Woburn Abbey on 21st December. Nine children with Down's Syndrome were entered and two made it through to the finals. Both have had corrective cardiac surgery.

Seven year old Hannah from the West Midlands was only eight weeks old when she had open heart surgery, having been briefly home for a week for her Christening.

Five year old Harvey from Derbyshire was diagnosed with a congenital heart defect aged four and underwent open heart surgery in July 2008.



Harvey

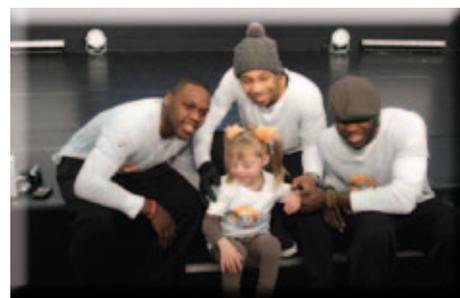
The final was a "Winter Party" and included a fitting for a party outfit to be worn that day, a photograph taken by a professional photographer, a dance workshop with Flawless and a party tea. A panel of judges comprised of Next's Childrenswear Director, Next's Art Director, an Editor from Express Newspapers and the Director of Urban Angels Children's Modelling Agency spent the day mingling with their model guests monitoring progress and compatibility. Gradually they were able to choose just twelve children for new Next advertising campaign. The magical winter party ended with several inches of snow which had fallen whilst everyone was having fun in the huge marquee.



The winning poses

Harvey Simpson from Heanor was one of the winners. He can now be spotted on Next posters all over the country. He also won a shopping spree in Next, worth £200 and a contract with Urban Angels Modelling Agency.

Harvey has become quite a celebrity, appearing in local newspapers and has been to London for a casting session with CBeebies.



Flawless with Hannah

Girls' Brigade Officer Sarah

Morag Doak sent in this fantastic photo of her daughter Sarah and her friend Nayomi, taken when they were commissioned as Officers in 1st Ellon Girls' Brigade.

Morag said "It was a very emotional and proud moment. It also happened to be almost thirty years to the day that I was commissioned as an officer so that added to the emotion! Quite an achievement for a young lady who wasn't going to live long enough to see her 5th birthday!"



Sarah and Morag Doak with Nayomi

Can You Help DHG?

Down's Heat Group provides a much needed support service to hundreds of families in the UK and many more worldwide. We are proud of what we do but want to continue to improve, develop and expand without losing that personal touch we are able to provide.

Currently the DHG team consists of two part time workers and a small committee of dedicated volunteers, who give as much time as they are able, due to work and family commitments.

We would warmly welcome any offers of help. Do you have a few hours to spare every now and again? Have you considered joining the committee? Or doing something behind the scenes if meetings aren't your thing? Do you worry that you live too far away to be able to contribute?

Please get in touch if you would like to discuss get involved in some way. We look forward to hearing from you.

write to info@dhg.org.uk
or call 0800 288 4800



dhg

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0845 230 0372

www.downs-syndrome.org.uk



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0131 313 4225

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0239 285 5330

www.downsed.org



Down Syndrome Ireland,
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Old Naas Road,
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For general information on heart related issues you might like to contact



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