



dhg

down's heart group

Newsletter Summer 2008

Issue 38

In this issue ...

Conference / Family Weekend

News

Fundraising update

Letters

... and more !



Chair's Report

Welcome to the Summer edition of our newsletter.

This issue has further details about our bi-annual conference which takes place at the Holiday Inn, Filton, Bristol in November. Our theme this year looks at moving towards Independence and we have speakers from various forums throughout the country. The venue is very easy to access either by train or road so we hope that many of you will be able to join us for what will be both an informative and enjoyable weekend for all.

Apart from the plans for the conference, our other work continues to keep us busy. We are involved with various committees that are looking at the development of the cardiac units around the country and the introduction of a structured GUCH (Grown Up Congenital Heart) service that will be equitable for all.

Our Information Packs continue to be used by many people in the NHS and Learning Disabilities sector and Penny and Sarah, our Director and Information Officer, are being asked more and more to go and talk to learning disability nurses. They have also attended several conferences recently to raise awareness of Down's Heart Group.

We want to continue our work and to develop our services, but like many charities, we are feeling the effects of the current financial climate and whilst we have never asked for a membership fee, we are at a point in time where if we are to survive we need to ask you all to consider making a voluntary contribution.

We are here to support you all: parents, children and adults, in all aspects of your life so if you need information or support don't forget to give us a ring!

I hope to see lots of you in November at the conference.

Chris Stringfellow
Chair

email: chris@dhg.org.uk
or phone: 02920 764608

Cover Story - Kyle McIlmoyle



Kyle

This is my amazing son Kyle who was born on the 21st May 2006 and diagnosed with Down's Syndrome. This was not a complete surprise as I already knew that Kyle had a complete AVSD with Tetralogy of Fallot after tests at Leeds General Infirmary.

Whilst searching the Net for congenital heart defects, I discovered an excellent site called the Down's Heart Group, which had the most information concerning Kyle's heart problems. Intuitively, I knew there was a comparison and that Kyle could have Down's Syndrome, however I was looking forward to becoming a parent, despite the circumstances.

When Kyle was born I visited him the following day. The situation was difficult as I was separated from his mother at the time. When Down's Syndrome was confirmed, it didn't matter at all as I was a 'DADDY' and after visiting Kyle in hospital for a few days, it was clear to me and the staff that he was responding to me and we were forming a bond.

Kyle has had a BT Shunt fitted to increase the blood flow to his heart as the pulmonary artery was narrowing. This, however, is only a temporary measure and Kyle will still need corrective surgery in the future.

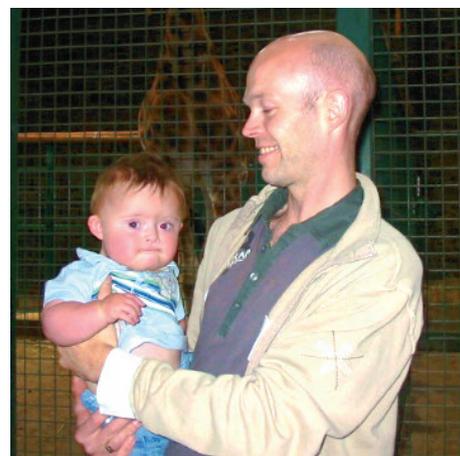
We remain unsure about the facts concerning Kyle's condition - his left ventricle is poorly formed and may be inoperable in which case Kyle would need further shunts fitted as an alternative to corrective surgery as the risks would be too serious.

Apart from surgery he has had

Bronchiolitis and episodes of cyanosis, which is relatively minor in comparison to what we were told in hospital as the doctors believed that Kyle would be very poorly with his heart defects. Fortunately we are blessed with a very happy and contented little boy with much love to give.

Kyle is receiving Occupational Therapy and Physiotherapy and he attends the local Children's Centre catering for children with special needs. At present he is not crawling and this frustrates him no end!! He is so determined and his development is progressing so we feel it won't be long before he is on his feet!

Having Kyle has opened my mind in so many ways with respect to Down's Syndrome. There is a definite growing awareness of the condition and social acceptance which is pleasing. They truly are very special children, as anyone who has the privilege of knowing a person with Down's could tell you. The genetic difference is minimal, but sets them apart, from the so called 'norm'.



Kyle with his Dad

Thank you DHG for raising my awareness on the subject and for being a caring charity that relates to the plight of youngsters with Down's Syndrome regarding their heart problems.

Please keep up the good work!!!

Many Thanks
Stephen McIlmoyle



From Cradle to Independence

8th and 9th November 2008, Holiday Inn, Filton, Bristol

Saturday Programme

AM - Speakers

Dr Rob Tulloh and Dr Graham Stuart, Consultant Cardiologists, Bristol Children's Hospital
Covering a wide variety of topics which may affect our members including exercise and exertion for heart children, self regulation and enforced rest and new developments in the cardiac arena.

Jill Davies, Research Programme Manager for Foundation for People with Learning Disabilities
Reporting on the "What Kind of a Future?" project which has been looking at supporting young people with Down's Syndrome to lead a full life after leaving school.

PM - Workshops

Laura Rossiter, Department of Work and Pensions
Advice on claiming benefits including Disability Living Allowance, Attendance Allowance, Incapacity Benefit

Amy Worton, Lecturer at Derwen College, Oswestry
Information about college life, nurturing independence, opportunities for those with medical issues.

APL Solicitors - TBC
Advice about wills including setting up discretionary trusts for people with learning disabilities to protect their benefits.

Music Therapy - TBC
An opportunity to unwind whilst learning how music therapy can help our youngsters.

Evening

Family meal and disco with bar

Sunday Programme

Events - TBC

Organised activity and lunch
This will be at a different venue where we may not be able to provide lunch ourselves but it will be child friendly and not expensive.

Other Information

Child care

There will be a creche and activity workshop provided on Saturday during the conference with priority being given to those staying for the whole weekend. Parents / Carers will be responsible for supervision during lunchtime and at all other times throughout the weekend.

Accommodation

We have reserved a number of rooms at a favourable rate, including family (inter linked) and wheelchair accessible rooms, but early booking is advised.

Flexibility

It is possible to book different parts of the weekend if you only wish to attend on Saturday or live locally and do not require overnight accommodation. Please speak to National Office.

As we are still finalising arrangements with the hotel and for Sunday, it is not possible to give an exact pricing at this time, but we anticipate that it will be in the region of £150 for a family of four for the weekend. A £25 deposit per room secures your place, which will be refundable if the cost is significantly higher.

Joanne Harris

It was with great sadness that we heard of the recent death of Joanne Harris aged 25 of Shrewsbury.

Jo became a celebrity after television cameras followed her fight to raise the issue of transplant rights for people with disabilities.

The campaign got a real boost when family friend Craig Phillips donated his prize money from winning the first series of 'Big Brother'. The publicity prompted the Government to pledge that disabled people would not face discrimination in any form of health care including organ transplants.



Sadly after getting a cold in March this year, Jo contracted an infection leading to complications. She was admitted to the Royal Shrewsbury Hospital and then transferred to Birmingham where her parents, Marion and Michael, praised staff at both units for their care.

Jo learned to ride a bicycle by the age of six and attended mainstream schools and college. She joined the Brownies, won medals for dancing and trained to be a hairdresser.

Jo will surely remain an inspiration to many other young people with Down's Syndrome and their families.



10th World Down Syndrome Congress August 19th - 22nd 2009 in Dublin, Ireland

The proximity of the location of the next World Congress presents a great opportunity for families and professionals in the UK to get involved. DHG is planning to attend with information and a display, so we hope to see many of you there. If the last two Congresses are anything to go by, this will be a really worthwhile event for everyone!

The theme for the Congress is "**Lifelong Living and Learning**", which was chosen to stress the fact that people with Down's Syndrome and their families develop right throughout their lives and are constantly encountering new experiences and personal demands, in circumstances that can be both challenging and fulfilling for each individual, family and community.

Down Syndrome Ireland plans a dynamic and exciting programme that will cater for all professionals including health, educational, and research practitioners, together with a parallel participative programme for parents and siblings and children and adults with Down's Syndrome which will include the first "**Synod of People with Down's Syndrome**".

The full programme and registration will be available on the congress website from August 2008 www.wdsc2009.com

"I'm Gonna Go for it"

Going to hospital for an operation on your heart

This DVD which was part funded by DHG, follows the journey of Andrew, a young man with Down's Syndrome as he is actively involved in the decision to have corrective cardiac surgery.

The narrative is in simple, easy to follow language and the accompanying booklet is written in plain English with simple pictures in order that people with a learning disability can be helped to understand the process of having an operation.

"I'm Gonna Go For It" has received great reviews from many professionals working in the field of learning disability and is being used by some lecturers for training students.

Copies of the DVD and accompanying booklet are available from Down's Heart Group. Simply forward a donation (minimum £2.50) to cover postage and packing to:

Down's Heart Group
PO Box 4260
Dunstable
LU6 2ZT



News from DHG Director Penny Green

As I started to write this, it struck me that I only seem to get a piece in the newsletter when we're asking for your help, one of the less pleasant aspects of being Director I guess, so once again it falls to me to explain what we need. I hope that you will read on, understand why we need your support and feel able to help us in some way.

Many of you will appreciate that DHG has always been against charging a membership fee for fear of excluding families at the time they possibly need us the most - just after their child's birth when finances are often at their tightest. Sadly though, like many charities in today's economic climate, we are facing increased running costs and greater competition to secure funding. The need to build greater diversity into our funding streams has forced us to look again at this issue and our Executive Committee has agreed that rather than introducing a compulsory membership fee, we will invite our members to make a voluntary contribution towards their membership.

We are currently putting a great deal of time and effort into looking for funding from Trusts and other sources, but the majority of these will only fund projects and not day to day running costs such as phone bills, salaries, stationery etc. which are of course vital to keep the Group functioning. The following may partly explain why we need your help:

- To edit, print, post and put on the website, four newsletters a year, costs approximately £7,500
- It costs approximately £800 a year to provide telephone and internet access to our staff
- Helping a new family including sending out an Information Pack costs on average £10 per initial contact
- We provide personalised support and information via our helpline with 24/7 cover in emergency
- We are involved on many groups and committees representing the needs and views of our membership
- Having no office, our overheads are very low and with a tight budget most things are done in-house
- Our workload is too great to function without paid staff (but salaries have not increased for three and a half years and salary costs have dropped since the resignation of our Admin Assistant in December 2007)

We are asking all members to consider making a contribution towards membership. Our **suggested donation** is £15 - £25 annually, or £1.50 - £2.50 monthly. And we are asking everyone that is eligible to do so, to give us authority to claim the Gift Aid on this and any other donation given so that we can make your donations go even further.

It would be more efficient for us administratively if you could donate by standing order or with a debit or credit card (which can be done via our website), but if you prefer to send a cheque that's fine and of course you can donate via your employers Give as You Earn scheme or with a Charities Aid Foundation cheque or card.

All member families should have a letter enclosed with this newsletter, but if you don't get one or you are not a member but would like to help, please contact National Office and they can let you have all the necessary details.

THANK YOU FOR WHATEVER SUPPORT YOU CAN GIVE - we really do appreciate it!



Utility Warehouse

Switch some or all of your utilities (gas, electricity, phone, internet or mobile) to the Utility Warehouse Discount Club, save yourself money and support DHG at the same time!

Call 0800 131 3000 and quote our appeal number B84554



Everyclick

DHG now has 169 people raising funds by using Everyclick as their search engine. So far they have raised over £700 for us for free.

Click on the Everyclick logo on our website to sign up to this easy way of raising funds

Changes at DownsEd

Many of you will know of the valuable research and work done by our colleagues at The Down Syndrome Educational Trust. They contacted us recently regarding some important changes within their organisation.



The Down Syndrome Educational Trust has adopted the new name of Down Syndrome Education International to better reflect the wide reach of their work. Via it's website, the charity now reaches thousands of people in over 170 countries and their new Open Access publishing initiative will bring all of their books, teaching materials and films online by the end of 2009.

new name reflects their commitment to deliver improvements in the quality of life for young people with Down's Syndrome everywhere.



They have also recently formed Down Syndrome Education USA (DownsEd USA), which is a US non-profit public benefit corporation based in California. Working closely with DownsEd International, DownsEd USA will provide a platform for progressing developmental research and education programs in North America.

You can read more about the changes and keep in touch with all the developments by visiting their website

www.downsed.org

Games Marathon



Craig (on right) at the games marathon

Earlier this year, DHG member Craig Beardmore, 27, took part in a 24 hour games marathon organised by Eldwick Youth Fellowship. The event began at noon on 9th February and continued until noon the following day. During that time they played many different indoor games from Bingo to Boppit and as well as everyone having a great time, they raised £400 for DHG.

Many thanks to Craig and his friends for all their hard work!

Paris Marathon

DHG member Angus Fraser completed the Paris Marathon on 6th April in a time of 3 hours and thirteen minutes – a personal best.



Angus with son Santi in front of Arc de Triomphe after the race

Unfortunately, his wife Andrea wasn't able to take part due to illness, but she was there to cheer Angus on.

Angus raised a fantastic £1622.00 for Down's Heart Group.

Well done Angus!

London Marathon

Just one week after Paris it was the London Marathon and we headed off to support our team hoping that there wouldn't be a repeat of 2007 when one of our runners ended up in hospital.

Despite the weather not being too friendly, a little rain was a lot better for our runners than the heat of last year.



Anthony and Jason after the race

All six DHG runners finished safe and well achieving brilliant times.

John Tyszkiewicz	3	57	25
Sue Gardner	4	03	13
Anthony Jones	4	36	14
Jason Curtis	4	54	36
Philip Longster	5	04	02
Eifiona Williams	5	13	30

The total received so far is £7538.44

Thank you everyone!



Philip Longster and daughter Hope



Mike's Marathon Undertaking

DHG was recently contacted by Mike Blamires telling us about his plans for 2009. Mike writes:

I would like to let you know that in just under a years time I am going to be running the Marathon des Sables. My reasons for this as you may imagine, are personal, however, it would be unforgivable not to use this opportunity to support good causes!

I have chosen 3 charities based on certain criteria, one of which was a charity which is close and personal to me - Down's Heart Group.

My Uncle David who had Down's Syndrome passed away earlier this year at the ripe old age of 56, having undergone pioneering valve replacement surgery a number of years ago. After speaking to my Mum and Grandparents we agreed that your charity would be most suitable as my Uncle received wonderful support and it would be great to think I could help others receive the same.

averaging almost a marathon a day

To give you a small idea of what I will be getting myself into with the Marathon des Sables, it is a 150+ mile self sufficient ultra-marathon across the Sahara Desert. This means for seven days I will be averaging almost a marathon a day with up to 12 kilos on my back in heat which can rise to 50°C or more, all across sand, dunes and scrub land under the relentless desert sun.

I am hoping that this craziness will enable me to raise lots of money and awareness for DHG

I have started a blog which is charting my progress and will soon have a website dedicated to the run.

www.ultramarathonmike.co.uk

Asics London 10K

Juliet Thomas will be running the London 10K on Saturday 5th July, just as this newsletter goes to print.

She says "My daughter, Emily, who is now 2, has Downs Syndrome and a heart defect. I started running last year in an attempt to get fitter and am so pleased to be able to run the London 10K to raise money for the Downs Heart Group, which helps so many families to deal with the real challenges which arise when their child faces heart surgery.



It is great to run for a charity which is close to my heart - I will be running for Emily and all the other children like her."

London Marathon 2009

The online entry ballot for the 2009 London Marathon has already closed, but DHG has five guaranteed places.

They are currently all allocated, but we have a waiting list in case people drop out.

To add your name to the list, contact National Office.

Adidas 5K Women's Challenge



Up for a bit less of a challenge? Then why not sign up for this event which takes place in Hyde Park in London, Sefton Park in Liverpool and the City Centre in Birmingham on Sunday 7th September.

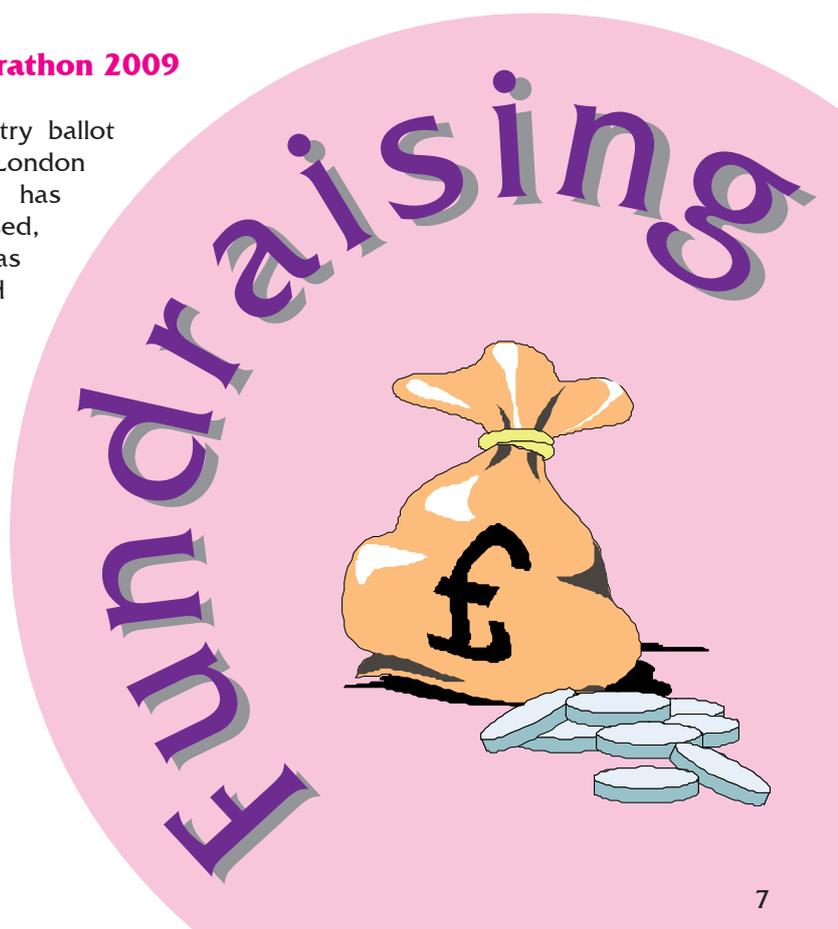
It's open to all levels with a fun atmosphere and you get a goody bag - all for a £15 entry fee, £5 of which goes to your nominated charity.

Get friends and family to sponsor you and see how much you can raise. Better still get them to join you and have your own DHG team.

You can register online at

www.womenschallenge.co.uk

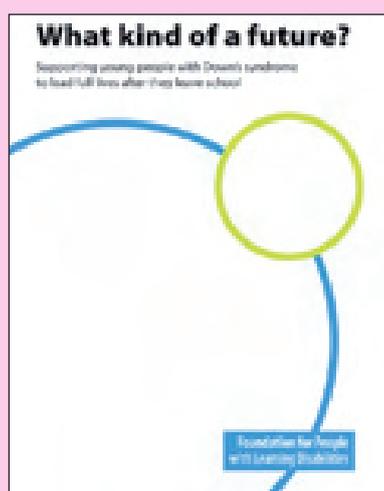
or contact National Office for an entry form and to request sponsor forms.



What kind of a future?

supporting young people with Down's Syndrome to lead full lives after they leave school

As part of an ongoing project, the Foundation for People with Learning Disabilities has published an easy-to-read booklet for young people with Down's syndrome, their families and carers that gives guidance on finding employment and building social networks to help them lead more active and fulfilling lives after they leave full time education.



Alison Giraud-Saunders, Co-Director of the Foundation for People with Learning Disabilities, says "Many young people have great support at school and feel really included in the classroom, but once they leave school or college they lose their support and often find themselves unemployed, depressed, neglected and lonely."

'What Kind of a Future?' provides practical solutions to common problems and includes the positive stories of ten young people with Down's Syndrome.

Copies are available FREE

telephone 020 7803 1101

or

download from

www.learningdisabilities.org.uk

Jill Davies from FPLD will be giving a presentation and updating us on further progress of the project at the DHG Conference in November.

Important Endocarditis Update

Following recent changes in the recommendations regarding the use of antibiotics, we have received many calls from concerned parents.

Put simply, recent studies suggest that the risk of endocarditis from medical and dental procedures is minimal and patients are at greater risk from infection that is resistant to antibiotics due to their overuse.

Cardiologists and Dentists will continue to advise patients according to their individual condition, but below are some general guidelines from The National Institute for Health and Clinical Excellence (NICE).

In the past, people at risk of infective endocarditis have been offered antibiotics when they have certain medical or dental procedures. NICE is recommending a change in practice, so now antibiotics should only be offered if the procedure is at a site where there is a suspected infection.

Who is at risk of infective endocarditis?

Only some heart conditions put you at risk of developing infective endocarditis. These include:

- some types of disease affecting the heart valves
- having a replacement heart valve
- some types of congenital heart problems that affect the structure of the heart, even if they have been repaired (but not isolated atrial septal defect, repaired ventricular septal defect or repaired patent ductus arteriosus)
- hypertrophic cardiomyopathy
- having had infective endocarditis before

Should antibiotics be offered?

Antibiotics to prevent infective endocarditis should not be offered for any of these:

- a dental procedure
- a procedure on the bladder or urine system
- a procedure on the gullet, stomach or intestines
- a procedure on the airways, including ear, nose and throat procedures and bronchoscopy

They will be offered for a medical procedure at a site where there is a suspected infection in the gullet, stomach or intestines, or in the reproductive or urine system. **Everyone** with a suspected infection is given antibiotics if they have these types of procedure, the only difference for people at risk of endocarditis is that antibiotics will be chosen that kill the bacteria that can cause it as well as other types of bacteria.

What do I need to know about reducing the risk?

You should ask your healthcare professional about:

- the benefits and risks of antibiotics and why antibiotic prophylaxis is no longer routinely recommended
- the importance of looking after teeth and gums, including brushing, flossing and using mouthwash
- symptoms to look out for that may indicate infective endocarditis and when to seek expert advice
- the risks of procedures involving piercing the skin, including body piercing or tattooing

Study of attention in children with Down's Syndrome

Dr Kate Breckenridge of The Visual Development Unit based at University College London and the University of Oxford, recently wrote to us as follows:

We are looking for children with Down's Syndrome aged between 5 and 15 years to take part in a study of attention.

We know that the ability to pay attention actually involves quite a number of related processes and the aim of this study is to investigate which of these processes are more difficult for children with Down's Syndrome. We are conducting a large study to see how children with Down's Syndrome do on a range of attention tasks recently developed at the VDU.

The tests all take the form of games involving pictures and sounds which are fun for children to do, but also place some demand on their attention. Some basic vision testing and an assessment of vocabulary and visual-spatial skills will also be done.

To take part you would need to visit one of our Units in London or Oxford to complete the session, which normally takes around 2-3 hours, and we would refund all travel expenses. We may be able to see some children at home (time and funds permitting), so please do get in touch even if you feel that you're unable to come to us.

We always provide a full written report of your child's results, which you are free to use as you wish. Many parents find that this information can be used to help in access appropriate educational support for their child.

We very much hope that you might be able to help us with this project. If you would like your child to take part in this study or would like more information, please contact:

Dr Kate Breckenridge

Tel: 020 7679 7574

Email: k.breckenridge@ucl.ac.uk



Clear Thoughts is a Department of Health funded project for individuals, their families and carers and front line social care staff. It provides information about mental health in learning disability in a clear and accessible style.

lots of topics relating to mental health for people who have a learning disability

The website has information on lots of issues relating to mental health, including positive mental health, the differences between mental ill-health and learning disability and on specific issues such as bi-polar disorder, dementia and depression. Each section has links to files and other helpful websites.

www.clearthoughts.info

Mixit

Meet Mixit, a band made up of youngsters of mixed abilities, many of whom have learning difficulties, who describe themselves as "the world's first inclusive pop group".

They're hoping to go on tour around the UK soon, so watch out for them appearing at a venue near you.

For more information see:

www.mixitmusic.com



Look Up is an organisation providing information on eye care and vision for people with learning disabilities

useful resources including a video about having an eye test

They have some useful resources including 'You and Eye', a film made by actors with learning disabilities which demonstrates why having an eye test is important as well as problems to look out for and what having a cataract operation is like.

Recently added to their website is an online version of the video with a downloadable supporting booklet and a pack containing pre and post optometry eye test forms, together with an eye surgery support plan.

www.lookupinfo.org



Livinia

I had my daughter, Livinia Jayne Mary, on 10th August 2001. Later I found out that she had Down's Syndrome. I felt very special at the time as I know I had her for a reason.

Down's Syndrome never worried me

The Down's Syndrome never worried me - it was the fact she had a poorly heart that got to me the most. We found out that Lil (that's her nickname) had an AVSD so she went into hospital for surgery at 16 weeks old.

it was the fact she had a poorly heart that got to me the most

Worryingly, before surgery, Lil was diagnosed with thrombocytopenia, a condition which means it takes a lot longer for blood platelets etc to work.



Lil

Anyway, she had her operation and was doing fine until we found that she had mitral valve regurgitation. So she then had two further operations to repair her mitral valve, which unfortunately didn't work so she had to have a valve replacement.

Lil is now doing well, although she also suffers with severe asthma.

always there making you smile and laugh!

She is a sweetie and is always there making you smile and laugh!

Donna Randall
Chalfont St Peter

Reader's Reply

In Issue 36, Cliff Lake, who was Chair of DHG at the time, wrote in his 'Chair's Report' about the achievements of his son William. This letter was written in response.

We have just read your report in the DHG Newsletter and are pleased that your son William, is doing so well. Our daughter



Beth, Gwen and Ruth Evans

Gwen, sounds very much like him! She was born 1st December 1998 so is just over a year younger than William.

Your

Gwen had a VSD repair at Bristol Children's Hospital in August 1999 and sailed through it. - you may have read our story in the DHG Newsletter some years ago. We were so grateful for the help and advice that DHG gave our family at the time.

grateful for the help and advice that DHG gave

The nearest we get to supporting DHG now is donating our used stamps, buying Christmas cards and sending the occasional donation. I suppose every little helps!

We find it difficult to attend any meetings that take place because we are always so far away and my husband and I both work and have three daughters to organise!

I suppose every little helps!



Gwen and her sisters

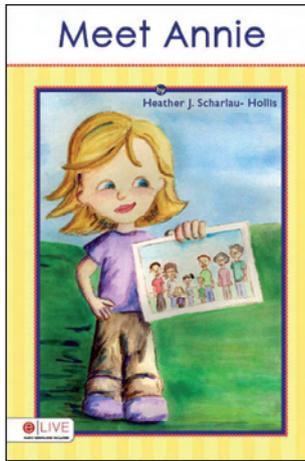
Anyway, we will continue to support this worthy cause when we can. In fact our 11 year old daughter is planning a school fundraising event in the near future (as long as she can share it with the RSPCA)!

Best Wishes to you and your family. If Gwen had her way she would want to be Chairman, too!

Julie & Richard Evans
Fishguard

Meet Annie

My name is Heather and I want to let everyone know about a book called 'Meet Annie'. First, let me tell you a little bit about myself and my daughter Annie.



Annie was born in September 2005. I had no idea of the complications she had until after the birth. Even then, it took about two weeks until I knew of the severity of her heart condition. Annie has had ten surgeries, two of which have been on her heart. She will have another heart surgery soon and hopefully

that will be all, for a while anyway! After her second heart surgery I was very depressed. Any of you that experienced that feeling of helplessness know exactly what I mean. Well, when people want to get away from it all, they do all kinds of things, some drink, hide away, the list goes on and on ... I decided to write a book!

anyone that has experienced that feeling of helplessness

This book was meant as therapy for myself, but with my husband's persistence, I sent it out to publishers. I didn't believe in my wildest dreams that my manuscript would be picked out of the tens of thousands that they receive! I signed my contract in March of 07, the process took a LONG year and it is now available all over the internet, worldwide!

I decided to write a book!



Annie

My book is called 'Meet Annie' and is based on my daughter. I am hoping that this will be a first in a series. My goal is to see it in hospitals and clinics. I have sold out at book signings. 'Meet Annie' has also been featured in newspapers and a radio station!

You may get a copy from www.tatepublishing.com or any other bookstore on the net!

Heather Scharlau - Hollis
Wisconsin, USA

letters

CWM's Fundraising Day

My 6 month old son Jamie has Down's Syndrome and the heart condition AVSD. He has spent most of his life in hospital, which is why my company CWM decided to do a fundraising day for Down's Heart Group. The events included dressing down for the day, selling bacon butties and cakes throughout the

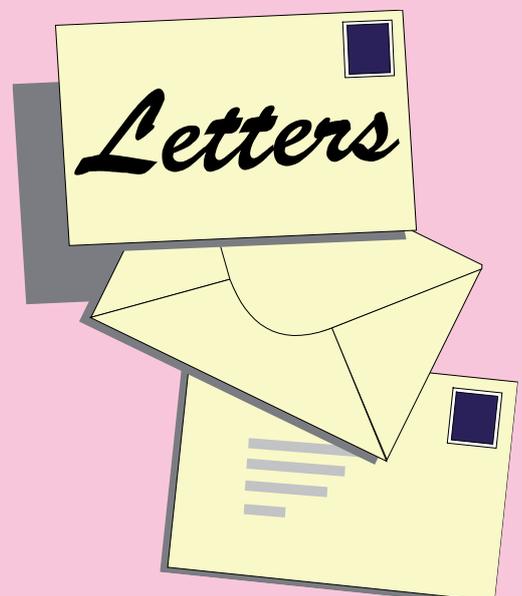


day, a naming the bunny contest and auctioning off cuddly toys.

I enclose the £561.91 that we raised and a photo of my son. I was so pleased when they told me the amount of

money as I knew that it was going to such a good cause.

Rebecca Johnson
Winsford





dhg

down's heart group

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Dunstable
LU6 2ZT

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email: info@dhg.org.uk
website: www.dhg.org.uk

contact or answerphone
always available

(24 hours in emergency)

Charity 1011413

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Dr. Phil Rees

Dr. Graham Stuart

Dr. Rob Tulloh

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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 230 0372

www.downs-syndrome.org.uk

Down's Syndrome

SCOTLAND helping people realise their potential

Down's Syndrome Scotland
158 - 160 Balgreen Road
Edinburgh, Lothian
EH11 3AU
0131 313 4225

www.dsscotland.org.uk



Down Syndrome Education International
The Sarah Duffen Centre
Belmont Street
Southsea, Hants, PO5 1NA
0239 285 5330

www.downsed.org



Down Syndrome Ireland,
Citylink Business Park,
Old Naas Road,
Dublin 12
00 3531 426 6500

www.downsyndrome.ie

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



Children's Heart Federation
Level One
2-4 Great Eastern Street
London, EC2A 3NW
0808 808 5000

www.childrens-heart-fed.org.uk



British Heart Foundation
14 Fitzhardinge Street
London
W1H 6DH
0845 070 8070

www.bhf.org.uk



Grown Up Congenital Heart Patients Assoc.
Room 5, Saracens Business Centre
25 St. Margarets Green
Ipswich, IP4 2BN
0800 854 759

www.guch.org.uk

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