



dhg

down's heart group

NEWSLETTER

Spring 2006



Children's Heart Week
12th - 19th February

your stories

spotlight on siblings

and much more ...

Welcome to another newsletter! I used to enjoy receiving one through the post but now I'm editing it it's quite a different story!

I have been Information Officer for over a year now. Overcoming my lack of desk top publishing skills has probably been my biggest and most time consuming hurdle to date, although I'm sure as time goes by I'll find plenty more "challenges".

I have been involved with DHG since Emily was two and Grace just a bump - over 13 years. I have been on the committee for most of them, only stepping down to take this post. Prior to this role I was an Advocacy Co-ordinator for Age Concern.

Emily had successful AVSD surgery at 16 months and apart from niggling ailments and minor operations has been quite well. She is getting ready to sit her exams and we are busy looking at college and sixth form courses.

2006 is a conference year and we are hoping to run an event similar to our 10th anniversary in Leeds when we had a conference on the Saturday and then a fun day on the Sunday. Look out for details!

I hope you enjoy this edition and are inspired by some of the items. Please keep sending in news, stories and photos.

Sarah Smith
Information Officer

INTRODUCING BEN

The handsome young man on the front cover is three year old Benjamin Fairhurst. He had AVSD heart surgery and bowel surgery before he was one and as you can see he is doing really well. Ben has started preschool where he has everyone wrapped around his little finger!

University of Glamorgan

SCHOOL OF CARE SCIENCES



Telling Stories, Understanding Real Life Genetics

Do you or a member of your family have a genetic condition?

Are you a healthcare professional caring for people with genetic disorders?

Could you tell your story and be part of a website that will teach nurses about genetics and genetic conditions?



Telling Stories is an education project by the Genomics Policy Unit at the University of Glamorgan, Genetic Interest Group, University of Plymouth and the Wales Gene Park. This project is funded by a PeopleAward from The Wellcome Trust

If you're interested in sharing your story and would like further information about this project, please contact Ms Kalbir Kaur-Mann (Project Officer) on the following:

Call: 01443 483141/ 01443 483185
E-mail: kkaurman@glam.ac.uk
Visit: www.glam.ac.uk/socs/research/gpu
or www.geneticseducation.nhs.uk



you live, you learn

www.glam.ac.uk

Hearing real stories about people's experiences can make a difference in helping people to understand genetics. This project will gather real life stories from families and professionals to show the impact those genetic conditions can have. This will help health care professionals to gain a better understanding of genetics in practice.

Tell your story either by posting, emailing, or by having an interview with one of our team members. Your personal details will not be attached to your story. The stories will be put onto the website of the NHS National Genetics Education and Development Centre. The stories will be used by nurse teachers, by nurses themselves and other health professionals, as well as the general public. If you decide to change your mind about being involved, we will destroy the tape or the written story sent to us. You can also ask for your story to be removed from the web site at any time.

Once we have received your contact details, our Project Officer will get in touch to discuss with you how we can collect your story. If you come to us for an interview to tell us your story, we will pay for your travel expenses and provide some refreshments.

For further information please contact Kalbir Kaur-Mann as above.

LONDON MARATHON 2006

This year's London Marathon is on

Sunday 23rd April

As usual we have runners supporting our work, including 18 year old Jack Pow who will be running in memory of brother Tom who died in 2002.

Please contact National Office on

0845 166 8061

to pledge your support - all runners are searching for as much sponsorship as possible.

The London Marathon is on of DHG's biggest annual fundraisers and thanks go to all previous, current and future runners. Last year our team achieved a massive £8517.50 for the charity.

Vice-chair Chris Stringfellow and husband Bob have attended several marathons to support our runners and recommend it as an exciting day out. Chris says "Last year's Marathon was the 25th anniversary of the Flora London Marathon and as a result there were even more runners and even more people in London.

We set of for Limehouse to find the station was closed and ended up at the Blackwall Tunnel. This was an excellent vantage point but unfortunately we didn't manage to see any DHG runners. From there we moved to Embankment and then we made our way to Horse Guards Parade which is the meeting place.

Unfortunately for us, the police had closed off the entrance in Horse Guards Parade and were directing everyone to the Mall. As a result you had runners and the general public pushing against people trying to leave Horse Guards Parade which lost us 1/2hr trying to get to our meeting place but we did manage it before our runners. All 6 of whom completed in excellent times and we are very grateful to them for the funds raised and hope that they continue running in the future."

Chris Stringfellow



HYDRO ACTIVE IN LONDON

Pat Lucy intended walking the Hydro Active Womens' Challenge pushing daughter Helen in her wheelchair. However, Pat had a scare with her own heart and sensibly decided to take it a bit easier. Teresa (right) took Helen's place and wore a picture of Pat's son, Vin, on her tshirt.

Thanks ladies for taking part.

Sponsor money is still drifting in from the 5k walk/run, so the total will be announced in the next newsletter.



WHAT'S IN A NAME?

After months of asking for a new name for our newsletters we have decided to stick with "Newsletter" and "Newsletter Extra"!

Thanks to everyone who sent in suggestions, we had some unusual ideas and some crazy names as well as many sensible ones, however several people pointed out that with the simple name of DHG Newsletter, everyone knew at once what they were picking up.

Good sense triumphed over creative flair in the end, but now no one has an excuse for not reading it!



BRITISH LONDON 10K

We still need more runners for this fun run which takes place on

SUNDAY 2ND JULY

contact National Office for more details

0845 166 8061



DATES FOR YOUR DIARY

12th -19th February 2006	Children's Heart Week
14th February 2006	Congenital Heart Day National Balloon Launch Parliamentary Launch
21st March 2006	World Down's Syndrome Day
23rd April 2006	London Marathon
2nd July 2006	British 10k London Run
23rd - 27th August 2006	9th World Down Syndrome Conference in Vancouver

CHILDREN'S HEART FEDERATION is made up of heart support groups throughout the UK and Ireland. Some of these groups are based at a particular hospital, some are national and some represent families with children with a particular condition.

Most CHF services are open to all families of heart children including a helpline and email service, respite care grants, family support grants, blood test monitors for home use and computers in hospitals so children can continue their education.

helpline - 0800 808 5000

The CHF helpline supports families by providing information and contact with member groups and other families. CHF also provides information to teachers, doctors, nurses, social workers, students, researchers, journalists and people with congenital heart disease. Answers to the most frequently asked helpline questions are published in a series of information sheets. These can be downloaded from their website.

The Respite Care and Family Support Schemes aim to cover the needs of families in very difficult circumstances. The Respite Scheme will pay for a child to be cared for by a third party while the family can have a break, or for a short break with a helper so parents can relax but the family stays together

The most common requests for Family Support grants are from social workers and hospitals who are trying to help families pay fares to visit their children in hospital. Other requests have included prams big enough to carry an oxygen supply and a washing machine for a single parent with a terminally-ill child.

In December each year CHF takes a party of heart children, accompanied by a cardiologist and nurse, inside the Arctic Circle to see



children's heart FEDERATION

Father Christmas. In the summer children from each of the groups, enjoy a short break with their families at a holiday centre in the UK. A new project for this year sees CHF starting to work with teenagers, organising weekends away.

Recent inquiries into paediatric cardiac units have shown that care offered to children with heart problems and their families can fall short of what is needed. Children's Heart Federation involved families in looking at how care can be improved through the Parent Empowerment Project. As part of the project, a conference was held and the report "Expectations For The Future – Our Collective Voice" published.

Other publications including "Children's Heart Services – A Guide To Care Standards" written by a working party of parents, nurses and paediatric cardiologists and results of a survey on families' perceptions of services around the time of discharge are also available free from the helpline or can be downloaded from the website.

www.childrens-heart-fed.org.uk

Annual conferences run by CHF have covered issues such as giving bad news, social difficulties and the older child, education, local services, blood tests and bereavement. A report of recent conferences can be ordered from the helpline or found on the website.

CHF ROADSHOWS

April 2006 will see the beginning of a rolling programme of Roadshows aimed at raising awareness of services and support offered by CHF and its member groups.

Each Roadshow will follow a similar format - a free of charge informal parent event in the morning where refreshments will be provided, followed by a professional study afternoon featuring presentations and debate groups. CHF will be charging a fee of £25 for professionals and £15 for students.

Invitations for professionals will be sent out by CHF, but any professional who would like to attend should contact DHG to ensure they are invited.

Representatives from all CHF member groups will be invited to attend the roadshows and talk to parents, so we look forward to seeing lots of you there.

Thursday 27th April the Roadshow will be at the Evelina Childrens Hospital in London.

During the week commencing Monday 22nd May the second Roadshow will be at Alderhey Hospital in Liverpool.

The third Roadshow will be held in Bristol in mid June and the fourth will be in Birmingham in the first week in July.

Other dates and venues will be advertised at a later date.

CHILDREN'S HEART WEEK

SUNDAY 12TH FEBRUARY – SUNDAY 19TH FEBRUARY 2006

This is an awareness week organised by Children's Heart Federation to highlight the needs of children with heart problems, with Valentine's Day being Congenital Heart Day. With two weekends for activities to take place, CHF are hoping to maximise on publicity with Press Releases going out to local and national papers. Please get in touch with DHG Information Office if you would like to hold an event for this week or you have a story that you think the local press could use.

PARLIAMENTARY LAUNCH

On 14th February from 4pm-6pm CHF will be hosting a Parliamentary Launch in the Strangers Dining Room at the House of Commons. There will be a presentation by CHF and its member groups to many specially invited guests, who will include MPs, people from the medical world and policy makers from the Department of Health.

Five speakers will address issues affecting children with heart problems and their families. They will emphasise the lack of movement following the Evaluation of Standards and the Paediatric Cardiac Review and each member group will have representatives present to explain their work. Another hot topic will be the transition from child to adult services and the relevance of the "Every Child Matters" document.

Please help us raise awareness
by contacting your MP

Any MP present in the House Of Commons on 14th February who has received an invitation from a constituent to attend this launch is obliged to attend. Could you invite your local MP?

The event would have far more impact if it was well attended and CHF's awareness campaign would achieve far more. Please contact DHG National or Information Office if you would like a draft invitation for an MP, or feel free to write to your MPs direct.

BALLOON LAUNCH TUESDAY 14TH FEBRUARY

On Congenital Heart Day, many paediatric cardiac units as well as several other venues around the UK, will be launching 144 red heart shaped balloons and 1 pale blue one to signify the ratio of children with heart problems. Local and national press will be notified and all "heart" families are invited to get involved.

Some units are hosting parties and other events arranged by member groups of CHF, others are running stalls in town centres to raise awareness and sell cookies and balloons.

Contact DHG Information Office on 01455 888344 to find out what is happening in your area and how you can participate.

Why not get involved in something different this half term!



Children's Heart Federation
is the umbrella body for charities
representing children with
heart disease and their families.

Each year **one** in every **145** babies
in the UK is born with a heart condition, a
total of about **5,000** per year.

For many parents the knowledge that their
new baby has a heart defect will cause
distress and they will often need support
and information.

children's heart
FEDERATION



DOCTOR NO!

My family and I moved to the UK about 3 years ago. Daisy had been through an horrific ordeal following on from open heart surgery and I wanted to be near friends and family on the Wirral even though I'd been in the Netherlands for 15 years.

The move wasn't easy but we eventually settled and established an excellent working relationship with all of the people involved with Daisy's medical and other needs.

It came as a bolt out of the blue in May 2005 to receive a letter from our GP saying the whole family had been removed from the practice list as, in the event of a medical emergency or the need for a home visit they could not reach us within an acceptable time scale.

We live 3 to 5 minutes drive away! I suspect it may have been a costing issue.

Having worked for the Local Primary Care Trust last year reviewing the new GP contracts, I had the knowledge, tenacity and contacts to contest their decision. Our story was front page news in the Liverpool Echo. We've since had a full formal apology and been reinstated. Policy and procedure within both the practice and the Local Primary Care Trust are also being revised.

The government's white paper "Valuing People" has highlighted the health inequalities experienced by people with a disability and those with a learning disability in particular.

Phillipa Russell from the Disability Rights Commission is eager to hear from anyone who has experienced problems accessing and maintaining healthcare. You can do this through me (contact details available through DHG) or direct to Phillipa Russell (she is a parent /carer herself) at PRussell@ncb.org.uk

Jen Gerritsen

IF SIMILAR HAS HAPPENED TO YOU, PLEASE CONTACT DHG OR THE DISABILITY RIGHTS COMMISSION.

SPOTLIGHT ON SIBLINGS - THE GREEN FAMILY (Part Two)

Following on from Sarah Green's letter in the summer 2005 Newsletter, older brother Ian now shares his thoughts on growing up in a family with a member with Down's Syndrome.

Right, well my little sister has had a go at this so as the big brother of the family, I'd better join in.

I am 3 years older than Rachel. Being a nosey little kid, it didn't take me too long to find out that all was not well with my little sister. Unfortunately for me, my parents were told she wouldn't live long so they tried for another child (and another!) so now I have 3 younger sisters. Those misinformed doctors almost destroyed me!

My poor parents must have found life a struggle in the early years. Not long after the birth of my second sister, (Rebecca), both Rachel and I were in the same hospital at the same time. At least I wasn't in for open heart surgery as well! This was big stuff for a four year old Rachel.

Of course, I learnt that Rachel is just like any other sister. She's just as capable of screaming, complaining, throwing and on the plus side, just as good at hugging and being soppy - although as a bloke, I'm not meant to own up to enjoying this.

Rebecca sort of grew into a mini-mother role and was soon looking after Rachel. In fact, I'm sure her first words were probably a reprimand for Rachel not behaving as expected!

Rachel's Down's is quite severe so she has a very young mental age. As we've grown up, I've seen my family struggling to cope with explaining the menstrual cycle to someone with a mental age of 3 or 4. I've seen the trauma once school ended. School is a wonderful place for the mentally disabled to meet friends and have a laugh. Once it ends, what next?

Luckily Rachel does enjoy watching films. Lord of the Rings remains a favourite although one of the films has an ending that is a little too sad and major tear-sessions can result! And these aren't quiet. For a small person, Rachel can make a serious racket! I have now moved into my own home and the serenity is actually quite disturbing at first. The noise when I do return home is also a shock at first too.

But, she's the oldest of my sisters and, despite a bleak initial outlook, she's still going strong. And I love that.

Ian Green

Sarah, Rachel, Ian and Rebecca Green





MESSING ABOUT IN BOATS!

David Halpin loves sailing as you can see from these photos!



NICKY'S 18TH BIRTHDAY

It's a birthday we were told he would never see due to his inoperable AVSD, Eisenmenger Syndrome, Pulmonary Hypertension and other serious medical problems.

He had a disco at a hotel and about 85 people came including staff from the children's ward, the hospice and his school and friends from Australia and London. Nicky isn't the most sociable of young men but he really enjoyed himself and was on the dance floor and doing the rounds of his friends.

He had over 40 birthday cards, £300 plus presents, so he did very well. I might put the money towards a really nice comfortable wheelchair for him but haven't decided yet.

When I went to pay the bill I was told it had been paid - all £600 of it! The receptionist had been sworn to secrecy and couldn't tell me by whom. I can't believe we have such a wonderful friend who would do that, I wish I could thank them but I'm sure whoever it was knows how much I appreciated it.

Pauline Cheney

HOW INAPPROPRIATE?

National Office has been in contact with a parent who has received a letter relating to Disability Living Allowance in which they are described as the "registered keeper" of their youngster with Down's Syndrome.

As this was a standard letter rather than one individually written to this family the main concern is how many other families have received similar letters.

DHG would like to hear from anyone who feels that the wording in any letters received from official bodies are as bizarre, hurtful or just totally inappropriate.

DOWN'S SYNDROME RESEARCH FOUNDATION
 announce their
 BRIGHT BEGINNINGS FOR CHILDREN WITH DOWN'S SYNDROME
 CONFERENCE
 to be held on
 31st March and 1st April 2006
 at
 Kennedy Conference Centre
 Institute of Child Health
 30 Guildford St
 LONDON WC1N 1EH

topics include;

- Why we need specialist Down's Syndrome clinics
- How to break the news to parents
- Latest news on research and health issues
- What's happening next - Improving the future for Down's Syndrome
- Open forum for questions and answers

for more information visit
www.dsrf.co.uk

FLEDGLINGS

Fledglings is a not-for-profit organisation which helps parents and carers of a child with special needs to find simple, affordable solutions to practical problems.

Fledglings offer a free product search service to locate toys, clothing, developmental aids and other items which may stimulate the child's development or give relief to the carer. Once Fledglings has located a suitable product, they are usually able to supply it at a competitive price.

The organisation has to date been operated largely by a volunteer workforce, made up of 'professional' volunteers supported by parents and carers of children with special needs and disabilities.

Fledglings can search for, order and demonstrate products to help with a child's specific development and learning needs. They specialise in finding those unusual items which may not be easily available or those designed specially for children with special needs.

Fledglings produces a regular newsletter with information about products. The organisation gives demonstrations to parent groups, schools etc. and can offer advice on possible sources of funding for large, expensive but essential items.

Fledglings can help families communicate their collective needs for special products to manufacturers.

For more information contact Ruth at

**Fledglings
6 Southfield
Ickleton
Saffron Walden
CB10 1TE**

Tel 0845 4581124

www.fledglings.org.uk

DANIEL'S STORY

Daniel and Natasha were born on 23/01/92 at 37 weeks. Neither of them would feed so nasal gastric tubes were used. The problem was they were then overfed and were very sleepy.

After a week a junior doctor said they wanted to do some chromosome tests on Daniel but didn't tell me why. I was extremely weepy, I didn't know what was going on.

A couple of days later the twins were moved to special care, where Natasha quickly got better. Daniel hardly even moved. The paediatrician sat us down with Daniel and explained that he had Down's and a heart murmur.

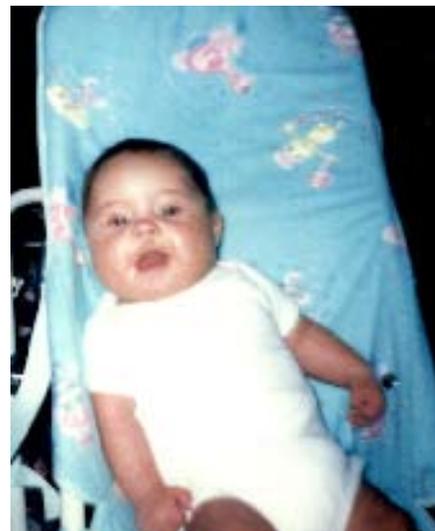
I think I cried for weeks before I pulled myself together and started to work really hard with Daniel to get him bottle-feeding. I would dress him up smart and became so proud of him. Then there was another bombshell – Daniel had two holes in his heart and a missing valve and would need surgery before his first birthday.

By five months Daniel was in a baby walker and saying "mama" and "omar", a word my Dutch friend taught him.

29th July was the date of Daniel's surgery. Daniel was really noisy, I had never known him like that before, it was as if he was trying to tell me something. I found it hard to sign the consent form and when my husband took him down to theatre, I couldn't bear it. Daniel went into theatre at 8.30am and was back in ITU by 2.30pm when we were allowed to see him. He was wired up for sound and on so many drugs.

As the days went on Daniel began to deteriorate. The doctors were baffled, suspecting meningitis, but his liver was very enlarged, he was yellow and bloated and he had to be put on an artificial kidney. He ran a fever and was on so many drugs. When they tried to wean him off oxygen he had a fit.

Just before August Bank Holiday 92 we were told that Daniel was

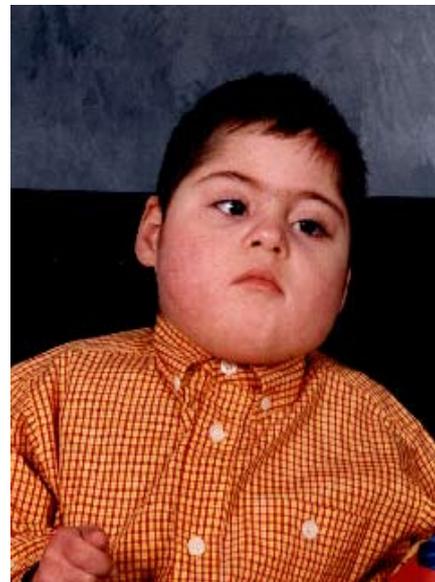


Daniel at 5 months old

not going to make it and had he been Christened? I was so angry, it seemed as though everyone was giving up on my little boy. We were even asked if we would consider donating his organs.

On the Wednesday we took Natasha to the hospital to be with her brother one last time. We put her on the bed with him and it may be a coincidence but Daniel started to improve. We kept Natasha at the hospital with us and by Friday Daniel was off the ventilator and his drugs. By Saturday he was back on the ward but he wasn't the same child. We were told that Daniel was brain damaged through lack of oxygen to the brain at some point during his liver and kidney failure. My whole world felt like it was crumbling.

Daniel was hardly moving, never cried and was now partially



Daniel at 10 years

sighted; only seeing shadows. I set out to get Daniel what he was entitled to, Portage, physiotherapy and specialist playgroup. It was hard work having to devote so much time and energy to Daniel; he now not only had Down's but was severely mentally and physically handicapped and had epilepsy.

I requested Daniel's medical notes and phoned Dr Jennifer Dennis, who specialises in Down's. After talking I was able to come to terms with the fact that there had been so many problems after surgery and that Daniel's body basically hadn't been able to cope with it all. I would urge any parents out there to weigh up the pros and cons and to ask lots of questions and be prepared for possible problems.

By three and a half years, Daniel could say "Ma" when he felt like it. He couldn't do anything for himself and we had been told he would never walk or talk. I had to be optimistic for him; everything he did was a real bonus to us. We and the professionals all worked so hard with him and Daniel became a happy and content little boy. It was all a constant struggle but it was worth it.

Daniel continued to thrive until he was ten and a half when he contracted pneumonia. He was in hospital for a week and it was awful. I had his twin sister and his two year old brother, Joshua to look after, but Daniel was upset every time I left him and he refused to drink for the nurses.

I was told that if he had another bad chest infection he may not pull through and I ought to think about whether I would "keep him on life support or switch it off". Needless to say I was shocked, upset and angry to be told this.

Daniel recovered and everything was normal apart from the night sweats he was now having. His paediatrician had started him on various drugs for asthma and I'm not sure whether, along with his other medication this had something to do with the sweats.

On 1st June 2003 I went into Daniel's

room to find him fixated with something on his bedroom wall, I kept a close eye on him all day, as he didn't seem quite himself. The next day we saw the paediatrician, who prescribed antibiotics for another chest infection, and an increase in his other drugs.

The next day was completely normal, Daniel was awake when I went to bed, watching his lights and listening to his pan pipe music as usual. When I went into Daniel the next morning my world fell apart. Daniel was in the same position as the night before, his lips were blue but he was still warm. My partner did CPR whilst I dialled 999. The paramedics tried for ages to get him breathing until I eventually told them to stop, my baby wasn't coming back. I was interviewed by the police for foul play. Daniel was buried and his death certificate listed probable causes of death. I had no idea why he had died, I was in denial and as there had been no post mortem I had no proof as to why he died.

Life for me became extremely difficult. I was depressed, angry at everyone, blamed everyone for Daniel's death, I had no energy and felt that I was in a bad dream. Eventually I contacted Compassionate Friends and poured my heart out to another bereaved mum. This really helped.

By September 2003 I couldn't bear to be at home any longer - I applied for two jobs working with adults with learning disabilities, mental health issues, challenging behaviour and physical disabilities - what a challenge! I was doing what I needed to do to get over Daniel's death. I have succeeded in various courses and achieved an NVQ3 in Care.

I feel that Daniel has been at my side every step of the way. He is talked about a lot and his photos are all around the house. His love surrounds our world.

Maria Downie,
proud Mum of Daniel Hartas

WISE WORDS

David McConnell has recently launched "Wise Words", a set of DVDs to help children with learning difficulties learn to talk and read, using a medium they love - television! David is hoping to develop more DVDs in the future and welcomes ideas to be incorporated. So far the DVDs are

- One syllable words
- Two syllable words
- Three syllable words
- Two word phrases
- Three word phrases

Each contains 50 words or phrases which are written on the screen and then pronounced slowly and clearly, giving the child the chance to repeat them back at a speed they can cope with. Then there is a clip of the word such as a bus going down the road for "bus" or a boy kicking a ball for "kick the ball". The word or phrase is then written over the clip and again pronounced clearly twice.

For more information or to order a free demo disk go to

www.wisewords.org.uk

21st March is

**WORLD
DOWN'S SYNDROME
DAY**

**Put it in your diary and
celebrate!**

If you are wondering how they decided on the date, it was because it can be written 21.3 which is also another way of writing Down's Syndrome or Trisomy 21.

Clever!

HILLWALKING

Britain has some beautiful areas with dramatic scenery and there is nothing quite as exhilarating as standing on top of a peak surveying the world below, but for some families health and mobility difficulties make walking in the hills virtually impossible, whilst for others, the safety aspect of taking youngsters on steep and uneven ground is rather daunting.

Outdoor pursuit centres and hillwalking companies are beginning to cater for people with learning difficulties and often the whole family can participate at whatever level they are comfortable with.

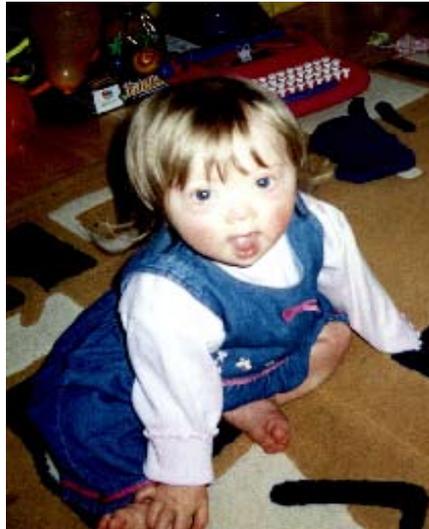
David Matthews runs such an organisation. He has a wealth of experience in leading walking, climbing and other outdoor activities. Better still he has a wealth of experience in taking people with learning difficulties on his excursions and equally importantly, he is trained in useful things such as mountain rescue!

www.hillwalks.co.uk

is full of information about each route David uses. Bookings are taken for groups or individuals and David can be hired to lead walks or climbs to suit the individual. This company specialises in the Lake District, Yorkshire Dales and Snowdonia.

Contact David on 07867 594135 or email d.matthews@hillwalks.co.uk

Perhaps you can recommend other companies or have been hill walking with someone needing extra help? Write in or call 01455 888344 with your experiences. DHG members would like to hear all about it.



Megan at 16 months

MEGAN'S STORY

Megan was born on 19th February 2001 at Queens Park Hospital, Blackburn. At a day old they told us that she may have Down's Syndrome and I asked them to check for heart problems - I am a nursery nurse working with special needs children so I knew it was a possibility. We were told there was something wrong and that she would go to Alderhey by ambulance when she was a few days old.

The doctor there ran tests and tried to explain the problem but we were so shocked that we couldn't take it all in and despite seeing the Echo and being drawn diagrams we just couldn't get the technical jargon. The cardiac nurses gave a clearer explanation although we were not told much about Megan's future, only that she needed surgery at about three months old.

We only saw the one doctor, we didn't feel the need for a second opinion, and we never felt pressed into opting for surgery. It was clear that without surgery Megan would not be here now.

Megan went down with pneumonia which led to her stopping breathing. She wasn't drinking, she was always cold and she started to look blue. She was in hospital for five weeks on a ventilator and her operation was moved forward as a result. She was on medication, drips and had four blood transfusions before surgery.

Megan was in the operating theatre for six and a half hours and was on the bypass machine so long we were told it was touch and go. Despite all the other problems the surgeon was pleased with the operation.

We have another child so it was really hard whilst Megan was in hospital for those twelve weeks. Luckily we could use the Ronald McDonald house to sleep and as a break from the ward.

She remained on medication for quite a while after she came home, but we only see the heart specialist every two years now and Megan requires no medication. She still has a small hole but this hasn't caused any problems so far.

Megan is now four and attends nursery school five mornings a week. She should have started school in Sept 05 but we have kept her at nursery for another year. She is a very happy and sociable little girl and smiles and waves at everyone.

Her speech is not good but we are working on it with help and we are sure it will come in time. She loves singing nursery rhymes and "plays" lots of instruments. Megan loves water and it is hard to get her out of the bath!

Overall Megan is a very happy girl without a care in the world. She can be very demanding and have tantrums but she has her own personality and we wouldn't change her for the world. She is a happy, healthy and lively little girl and we love her lots.

Julie Hodgkinson



Megan at 4 years

WHAT ABOUT US?

Young people with learning disabilities may be particularly prone to anxiety and depression and may be four times more likely to experience emotional problems than young people generally. Young people with learning disabilities who are included in mainstream schools can feel isolated and experience bullying. Without careful planning and proper resourcing, their experiences, in terms of teaching, learning and social activity can be unsatisfactory.

The What About Us Research Project aims to help young people with learning disabilities by working with pupils, students and teachers to develop more positive approaches to educational inclusion in mainstream schools and colleges. The project will explore ways of overcoming barriers to involvement in terms of the

- curriculum and teaching and learning
- social and extra-curricular activities
- pastoral care and tutorial support
- planning for transitions, including the future after full-time education

The project will use a participative action research approach, working directly with young people with learning disabilities in clusters of case study sites in three different areas of England. Each cluster will include a college, two mainstream secondary schools and, where appropriate, a linked special school or unit.

The research aims to

- investigate how young people with learning disabilities experience inclusion using their own perspectives
- listen to the views of families and non-disabled pupils and students
- find out what supports and threatens the emotional well-being of young people with learning disabilities in mainstream schools and colleges
- develop better ways of working, designed and approved by young people themselves.

The project's findings will be reviewed and refined to generate recommendations for future policy and practice. The project's outcomes will be widely disseminated through:

- report and summary of key findings
- guidance for staff
- support materials aimed directly at young people with learning disabilities and their families.

These materials, together with a series of regional seminars, a media campaign and direct engagement with policy makers at the national level, will be designed to influence policy and practice.

The intention behind the project is to produce benefits for young people with learning difficulties in mainstream schools and colleges in terms of:

- improved opportunities for educational and social inclusion;
- more effective education for personal and social development;
- enhanced quality of life and emotional well-being.

The project will run from September 2005 to September 2007. Richard Byers of the University Of Cambridge Faculty Of Education will lead the research, with input from Jill Davies of The Foundation for People with Learning Disabilities.

"AFTERLIFE"

"Afterlife" is a DVD released last July, starring Paula Sage as Roberta, a talented young artist with Down's Syndrome. It was released theatrically in 2004 but many regional cinemas were not able to screen it and so there has been huge demand for a 'home' version.

"Afterlife" stars Lindsay Duncan as May, a mother and carer who finds out she has terminal cancer when she falls and sprains her ankle. Her family - daughter Roberta (Paula Sage) who has Down's Syndrome and son Kenny (Kevin McKidd) must make decisions and take responsibility for Roberta's future.

Paula Sage has since secured a part in a mainstream Soap Opera and continues to inspire people with Down's Syndrome as one of few UK actors with Learning Disabilities.

Images of "Afterlife" are available from Soda Pictures' website www.sodapictures.com or for more information contact;

Alexandra Perry, Press and Marketing Assistant
Soda Pictures
3 Rupert Court
London
W1D 6DX

Tel 0207 287 7100

YOUNG MENCAP AWARD

Last November a panel of judges, including investigative journalist Donal MacIntyre chose ten year old Zoe Mace as winner of the first Young Mencap Award.

This new award is in recognition of young people's efforts in helping others understand learning disability. Zoe came to Mencap's attention when she made two classical CDs to celebrate the life of her sister, Jodie, who had Down's Syndrome. Sadly Jodie died last March. The Cds have raised money as well as awareness of learning difficulties.



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TW11 9PS
0845 230037

**the down syndrome
educational trust**

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

The Down's Syndrome
Educational Trust
The Sarah Duffen Centre
Belmont Street
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For general information on heart related issues you might like to contact:



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52 Kennington Oval
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