



Down's  
Heart  
Group

# Newsletter

Issue 27

Spring 2005



NEWS  
STORIES  
COMPETITIONS  
REPORTS

AWARENESS WEEK  
including  
GRAND  
BALLOON LAUNCH

## Chair and Director's Reports

### Chair's Report

Welcome to our spring 2005 newsletter and what I hope is the first of many to be produced and edited by Sarah; enjoy the read and please, tell us what you think of it and let us know any suggestions you may have for how we may improve.

The New Year truly rings the changes for the Group. Not only has Sarah settled in to her post as 'Information Officer' but Penny has been promoted to 'Director DHG'. Our aim is to build a tighter more focussed organisation in order to provide the support and information our members have been asking for. Over the past 4 years my focus has been to develop our image and reputation, both professionally and within the voluntary sector, and consolidate our position financially. It is from this position of strength that we now seek to move on and grow.

The first changes I hope you will become aware of will be the overall look and feel of the Group and our image. Over the next three months we will be launching our new logo, web site and style, and a new video/DVD, more about that next time. We have agreed an aggressive agenda of work for the coming year and with it comes the need for more funding. I do hope that you will choose to support your Group in our programme of fundraising events throughout the coming year, which kicks off as usual with the London Marathon and should peak in November with Down's Heart Week.

I would like to take this opportunity of thanking all of you, members and affiliates both at home and overseas, who have helped us during the past year for your continued support. I look forward to seeing many of you again during the forthcoming year.

*Cliff Lake*  
Chairman

Cover Photo - Emily Smith and her old pony Bremar Heather enjoy a showing class at the Burbage riding club show

Back Page Photos - Grand Balloon Launch at Surrey Golf and Fitness in Addlestone. See page 4 for full story

### Director's report

Many of you will have noticed a different look to the newsletter the minute you took it out of the envelope, but it's not only its look that has changed, it also has a new editor and it feels a little strange after all these years to be writing a piece for the newsletter, not compiling it. However, I have to admit to some relief too, as with the Group's growth, I have found it increasingly difficult to put aside time to put together each issue, so it was with great delight that I handed the job over to Sarah Smith our newly appointed Information Officer.

Sarah is a parent member who has been on the Committee for many years, so she is ideally placed to fill this new role. As well as editing the newsletter, her many other responsibilities include liaising with cardiac units, maintaining our library of information articles, sourcing new information and press enquiries. She will also have the task of looking after our website when the new updated version comes online later in the year. I am sure that many of you will soon get to know her and appreciate her knowledge and experience.

Her role is part time with some flexibility, but generally she can be reached between 9am and 3pm on Tuesday, Wednesday or Thursday, she also provides additional telephone cover on some occasions when I am out of the office. Staffing at National Office also requires some flexibility but generally there is someone available between 9.30am and 4.30pm Monday to Thursday. At all times when no-one is available to take calls there is the option to leave a message as well as an emergency contact number.

So with all this free time I will now have, what will I be doing I hear you say. Well I haven't quite gone into retirement yet, in fact I have now been appointed Director which brings along new responsibilities and new challenges as Down's Heart Group continues to evolve in order to address the issues affecting our membership. I am looking forward to my part in this growth and development.

*Penny Green*  
Director

## Competition and News

Nowgen, The North West Genetics Knowledge Park launched the Nowgen 2004 Photo Competition in November 2004. A large part of Nowgen's work involves engaging with the public to encourage dialogue on issues associated with human genetics.

The competition has the theme "Human Genetics and Society" and hopes to attract a wide range of interpretations on how human genetics affects and influences life in modern society. The idea behind the competition is to create a novel and stimulating exhibition to display a selection of the photographs.

The exhibition will be launched at the opening of the new state-of-the-art Nowgen Centre in Manchester, planned for March 2005. It will then be taken on tour across the North West of England.

Jon Snow and Lenny Henry have confirmed their support for this project.

Contact : Ruth Slattery  
Events Co-ordinator  
Nowgen  
7th Floor, St Mary's Hospital  
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<http://www.nowgen.org.uk>

Christel Van Baalen, mum to a four year old girl, Renee who has Down's Syndrome has a business distributing dolls with Down's features through her website [www.downsyndromedolls.co.nz](http://www.downsyndromedolls.co.nz).

The dolls give children an alternative to standard dolls and the features are said to be quite realistic. I'm sure Renee would recommend them!



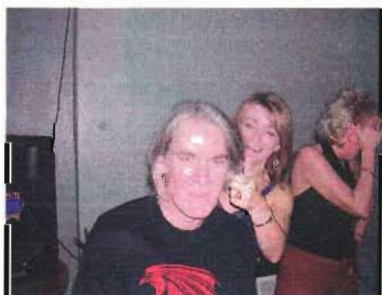
*"I'm not doing it for less than a tenner"*

### The Red Lion Reunion

Stu and Ann McBurney had a bit of a get together with some friends to raise funds for the Down's Heart Group. During the evening someone thought it would be a good idea to "auction" a haircut for Stu. People paid for him either to have his hair cut or not, but in the end poor Stu went home with cold ears and the Down's Heart Group was given £336 as a result. Thanks go to Stu and Ann for organising the fundraising, and for the customers of the Red Lion for being so generous.



*"Here goes!"*



*"I can't bear to watch"*



*"keep smiling"*

### Recycling

Please remember to save all your used stamps for the Group to sell on.  
We also collect ink cartridges. Contact National Office on 0845 166 8061 for more details.

## Balloon Launch

Surrey Golf and Fitness of Addlestone helped the DHG raise £4533.38 on Bonfire Night, when it hosted a firework display and balloon launch organised by member Elaine Archer. The event marked the end of our first Awareness Week, and was the culmination of weeks of hard work by Elaine, whose little boy, Jack, has just had his second birthday.



*Only another 500 to blow up and tie!*

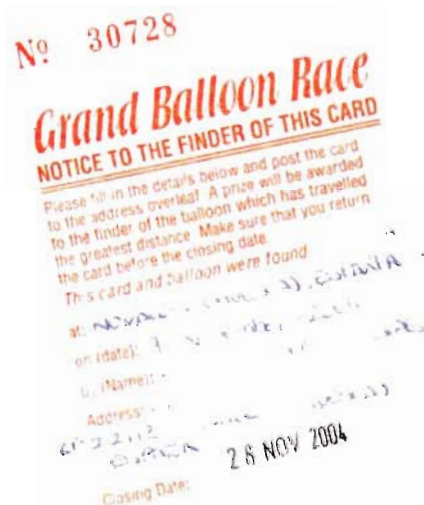
Thanks are due to many people for the success of the night including Toshiba, Marks and Spencer and Tesco for donating prizes; Addlestone ROAB Club for their kind donation; the owners of the funfair which provided yet more entertainment and a donation of £100 and BOC Sureflow who donated some of the helium. We are also very grateful to Hullaballoon and Balloons For Fun whose expertise was greatly appreciated on the night helping to inflate the 1600 red balloons - many sore fingers and thumbs were reported!



*This photo was sent by someone who found a balloon on the road outside their artist loft in France*

There was such a good turnout on the night, that the firework display had to be delayed until everyone was through the gates. The large attendance being down to Surrey Golf and Fitness, who did a tremendous job with the advertising, as well as sponsoring balloons and collecting money on the gate.

There were prizes for the balloons which travelled the furthest, and a small gift for the people who found the three winning balloons. 70+ tags were sent back, many of them with maps, postcards, photos and letters from the finders. The balloon that travelled furthest went 645 miles to Huesca, in Northern Spain. 48 balloons landed in France and one went all of 1.45 miles to Weybridge to secure the "booby" prize!



*The winning ticket*

### PRIZE WINNERS

- |           |   |
|-----------|---|
| 1st prize | TV/video combi<br>Paul Newarke of Addlestone            |
| 2nd prize | DVD player<br>Jeff Linney of New Hall                   |
| 3rd prize | £50 John Lewis voucher<br>Sandra at Snippers Hair Salon |

The money raised will be used to update our video on heart surgery, with new graphics and footage.

Many thanks to Elaine for all her effort, it was worth those sleepless nights!

## Sarah's Story

Sarah lives at home with her Mum, Dad, younger sister Katherine, her dog Holly and her cat Ivy. She was born on 24th June, 1982 in East Berkshire and her medical condition is described as Down's Syndrome with an inoperable heart defect - AVSD (now with pulmonary hypertension and Eisenmengers).

Her first three years of life were spent in and out of hospital on constant drugs to control her heart failure. Feeding was difficult as sucking was too much effort and made her breathless; we had tube feeds. Spoon feeding and solids were introduced earlier rather than later. Early years were quite fraught with constant trips to hospital. However, we have always been determined for Sarah to get the most out of life, as far as possible, and we had a Portage teacher visiting home from about age 1.

Sarah started school at a local special school part time from the age of 3. Everything was a little late - she famously decided to walk unaided for the first time in a crowded rugby club aged 4! (She did not repeat this at home for Mum for another week).

Sarah was firstly under the care of Hammersmith Hospital, and was then referred to GOSH - whose care we found to be excellent - Sarah has told everyone that Dr. Phil Rees is THE best doctor in the world! She went into GOSH for tonsil/adenoids removal, and several sets of ear grommets.

Due to Dad's work we moved up to West Yorkshire in 1997, which unfortunately coincided with a deterioration in Sarah's health - now on medication of amlodipine / digoxin tablets and overnight oxygen therapy. Our moving day involved "signing on" with our local GP so we could collect a prescription of oxygen cylinders from the chemist!

Sarah is now seen by the cardiac team at the Leeds General Infirmary (whose care we have found to be excellent) once a year for a check-up. This is in a newly set up adolescent clinic for congenital heart defects, and we are also in touch with a liaison nurse if needs be, in between appointments.

Sarah settled in very well to our new home and new school - quickly making new friends. (Her social skills have always been her strongest point). The last four years have gone

extremely fast, Sarah's health has remained stable, and she is due to leave her school this summer and goes in September to a local F.E. College where she has enrolled for an "Independent Living Life-skills" course - which we are all hoping will go well. Sarah has been attending the college this year one day a week to get accustomed to her new surroundings and new friends. She can't wait to be there full-time!



Sarah is enjoying her teenage life: she loves to go ten-pin bowling, visiting the cinema, horse-riding, and going to discos to 'flirt' with the boys. When she is not too tired she goes to a youth club too. Pop music is a firm favourite with her. On days when she does not feel so good, she will listen to her music, whilst resting.

As a family, we have found the Downs' Heart Group a great life-line. Over the years we have had nothing but positive feedback and helpful assistance, putting us in contact with similar parents over a common problem, and advising on all the new medical details, etc. We have shared the highs and the lows and received help with understanding medical jargon into simple language, etc.

Sarah and her Dad were even lucky enough to visit Lapland and Father Christmas courtesy of the Downs' Heart Group, and as a family we cannot speak highly enough of you all. You really are doing a wonderful job for all your families! Thank you.



*(Photos showing Sarah painting the school common room and with some of her artwork)*

### Experiences of growing up with a sibling affected by Down's Syndrome

*A report by Charlotte Riddick, Trainee Genetic Counsellor, on the findings from her study including input from her workshop at the Down's Heart Group Conference in 2004*

My study aimed to allow siblings to express their views on their experience of growing up with a sibling with Down's Syndrome. While this group are not generally at increased risk of having a child with Down's Syndrome, their perception of this risk and their views on having children and on having screening for Down's Syndrome in a pregnancy were hoped to be explored. As few studies have directly looked at siblings, especially regarding their concerns with regards to becoming parents, it was hoped to allow their views to be heard.

Semi-structured, in depth interviews were undertaken with 7 individuals who have or had a sibling with Down's Syndrome. These were analysed and emerging themes compared and explored.

A mixture of impacts and experiences of having a sibling with Down's Syndrome were reported by the group. Siblings in this study all described many positive impacts such as an increased acceptance of others, closer family relations, and independence. Many would not have wished their childhoods to be different and had close relationships with their sibling with Down's Syndrome. Another effect some described was the perspective it gave them on their own problems.

In this study some participants also described negative impacts that they thought their sibling having Down's Syndrome had had on them. Associated with care and responsibility was having to stay in and look after their sibling when they wanted to go out with friends. It must be noted, however, that this was only perceived to be negative in teenage years. Associated with how their sibling was treated, was lack of attention from parents, bullying, and having to fight against discriminative education services. These were not common experiences, however. Those who felt a lack of attention from their parents at home also described hiding their problems from the family so as not to cause any additional stress.

#### Implications for practice

- Reassurance to parents that most children do not view having a sibling with Down's Syndrome negatively, however, parents should be aware of cues for problems.
- Parents should allow time for the siblings to talk about their own life interests, especially in teenage years.
- Openness in the family should be encouraged to be able to talk about anything and discuss feelings.
- Option of external support for siblings with an opportunity to talk about fears and realise they are not alone.

#### Other topics covered in Workshops

##### How do you tell your children their brother or sister has Down's Syndrome?

While some parents felt concerned about this, most had found their children understood and were accepting. In my study whether they were told at day one or whether they worked it out themselves in a biology lesson, they were very accepting of the situation and the way in which they found out.

##### How do you divide your time and attention?

Many parents felt it was hard to divide their time because their child with Down's Syndrome did need more attention. Others felt that their child who did not have Down's Syndrome demanded a lot of attention themselves. One suggestion was to set aside a time each day to spend with the sibling by themselves. Again, from my study those who felt their sibling with Down's Syndrome received more attention, understood why this was and would not have wanted it to be different.

I hope those of you who attended the conference found it helpful to discuss some of the issues together and draw ideas and support from other families.

### Competition

Just when you thought you'd seen the last of him for a few months, a reminder that we need Christmas card designs ready for 2005. So, climb back in the attic or raid the recycling bin to retrieve all the fantastic artwork done during the run up to Christmas, and see if you have anything suitable.



There is a prize for the winner, as well as having your design on the front of Christmas cards that are sent out across the world.

Forward your artwork to Penny at National Office, with your name, address and age.

Printing needs to be done in the summer to meet deadlines - **so don't delay, send today!**

### NEW YEAR, NEW IMAGE!

The time has come for the Down's Heart Group to have a bit of a facelift., so we have taken a good look at our corporate image and although we cannot be as ruthless as Trinnie and Susannah, over the coming months you can expect to see subtle changes to our logo and literature, bringing us into 2005.

The website is also being redesigned and will have a new look and up to date details of events as well as a facility for online donation.

The newsletters will be back to regular slots throughout the year and these too are going to be revamped.

We are able to make these changes with the assistance of a grant from the Children's Heart Federation.

### Tom Pow Ayres Memorial Golf Day

This special Golf Day took place on 1st October 2004 and as Tom would have been 18 on October 13th everyone raised a glass of champagne in his memory. It was a fantastic day, well attended by people who knew, or knew of Tom and it was such a success that people are already asking about next year's event.

In a letter to the Group Tom's family say "Obviously, we would rather not have to have the Memorial Golf Day, but while we do, we will always be glad to hand over the funds raised to the DHG in memory of the support you gave to us, and to enable that support to continue for other families"

Thanks to everyone involved, £1600.00 was raised for the Down's Heart Group and we would like to say a huge THANK YOU to Keith Turner, of Turner Trophies for his generous support.

### AWARENESS WEEK FUNDRAISING

Whilst the balloon launch was the biggest event of Awareness Week, many other things were happening too:

Ellie Hunter from Grangemouth wrote letters to her children's schools. She received a £150 donation from one school and a teacher donated £5. She has also been given some used stamps for the DHG.

Sarah Smith, (your new editor), had a coffee morning with raffle and a "girls night in" which raised £99 in total.

Stu and Ann McBurney went to a reunion and "auctioned" a haircut. This raised £336. Well done!

*We are hoping to put some fundraising ideas together, as well as some guidelines as to how to achieve maximum results without too much of a headache. If you have any ideas or tips for success, or would like to organise a fundraiser please contact Elaine, Penny or Sarah.*

## Lewis' Story

I was 32 expecting my fourth child and went along for my 20 week scan, only to be told that he could not see everything and to come back in 2 weeks for another, which I thought was ok as I already had 3 healthy children and this pregnancy was just like all the rest. So I went back when I was 24 weeks and this time I could tell that something was wrong.

The sonographer told me that the baby had a hole in the heart and also that the baby had club feet. I was absolutely devastated and he asked me to come back the next day for a more detailed scan. So back I go the next day only for the midwife to tell me that the baby has Down's Syndrome, which I did not know, and had not been told the day before. It all came as a big shock to me as I had also been told this on my own, as my partner was at work.

I went from High Wycombe Hospital to the John Radcliffe Hospital, Oxford, for a more detailed scan where they confirmed that the baby did have Down's Syndrome by doing a nuchal fold scan, and the heart defect was AVSD which is common in Down's babies. I also had an amnio there at the same time, just to confirm in my own mind that what they were seeing and saying to me was correct. I also saw the cardiologists at this time so as you can see I had a busy and hectic time. As well as seeing all these people I was trying to take in the news that they were telling me about my baby.

We decided to keep the baby as I couldn't have had a termination just because the baby had Down's. It would be something that we would all adjust to. Because I had also spoken to the cardiologists and they had told me that the holes were repairable and that the operation is quite common that also put my mind at rest. I got on with the rest of the pregnancy with no other complications except for heartburn and cramp.

Lewis was born 2 weeks overdue and I had to be induced. The paediatrician was present at the birth because of the heart problem as they didn't know how Lewis was going to be and whether he would need assistance to breathe. After he was born he was taken straight to the special care baby unit where we stayed for 4 weeks in total. Lewis was on

oxygen and after 2 weeks they took him off to see how he would cope and he didn't, so they started him on Digoxin, Frusemide, and Spironolactone, and put him back on the oxygen. I also had to get used to giving Lewis the medicine and we also needed oxygen put into the house so that we could come home and get back into a routine of family life for me and the rest of the children.

The four weeks in SCBU was not what anyone of us had expected or had been informed about before and so was a bit of a shock for all of us. I stayed with Lewis all the time he was in SCBU as I was breast feeding him which I persevered at after having been told that Down's babies don't often take to the breast. These feeds had to be supplemented with Infantrine given to him every other feed to help him to put on weight for his impending operation.

The operation would take place before Lewis was 6 months old, we had been told, but before then he had to gain weight and grow.

The operation took place in Oxford on August 30th 2001 and was the worst day of my life. As Lewis was taken down for the operation he looked back at our faces as if to say "don't leave me here". I cried my heart out and we drove back to High Wycombe to wait for the phone call to tell us that Lewis was out of surgery. It was the longest 3 hours ever, it seemed to be all day. By the time that we got back to Oxford which is about half an hour away from us, Lewis was in intensive care all wired up to a ventilator, with tubes and wires which seemed to be everywhere.

The staff were absolutely brilliant and told us everything that was going on and what they were doing. Lewis seemed so fragile and helpless, I was frightened to touch him. It took me about 2 days before I held his hand again and I felt helpless because I could do nothing. We used to sit by his bed for hours just watching him and talking to him, hoping that he could hear us and we would get some kind of response, this seemed to take a long time because of all the drugs he was on.

After 2 weeks Lewis was still on the ventilator, so they scanned him and found that the mitral valve was leaking



## Lewis' Story Continued and 2006 World Congress

and decided to operate again the next day. This time it didn't seem so bad as we were not staying at the hospital all the time. Lewis was taken to the operating theatre in the morning as he was the first on the list and because we had the other children to think of, it took our minds off the waiting.

After our phone call we raced straight over and this time he looked much better than before. His colour was better, he wasn't needing as much oxygen and we hoped that this would be our last operation and we wouldn't have to do all of this again. After the weekend Lewis was off the oxygen, weaned off the drugs still feeding through a tube but we could cope with that, and was up on the ward which meant that he would hopefully be coming home soon.

In fact he came home a week after his second operation,

still on a little bit of medicine but nothing compared to what we were on before and this time there was no oxygen which was a huge relief. Within 2 weeks of coming home Lewis was feeding from a bottle (which he started to do before we left hospital) and was on no medication except for lactulose for constipation. It was heaven.

His scar healed up beautifully but we still had to keep him off his front for 3 months which was very difficult for a very stubborn baby who always wants to do things his way.

Lewis is now 2 years old and we have cardiac check ups once a year now which is great. He is crawling at great speed but not walking but that will all come in time. He has been through so much in his life already, he is our inspiration and light of our lives. He brings us all so much joy and laughter and is a real character.

## 9th World Down Syndrome Congress

The 9th World Down Syndrome Congress will take place in Vancouver from 23-27th August 2006.

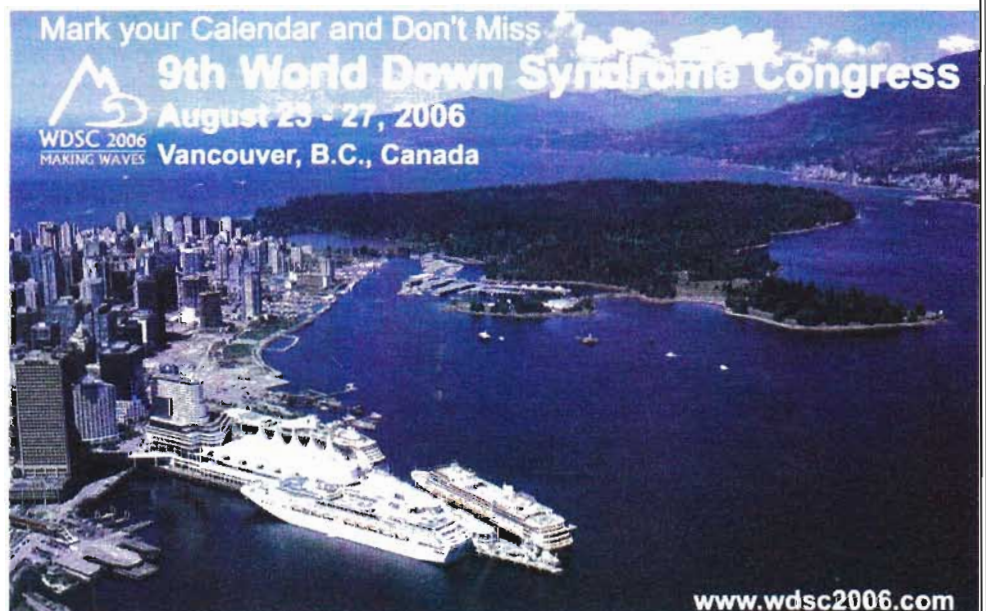
The conference programme will feature keynote presentations, special theme sessions, poster presentations and selected papers on various topics including motor, language, social and cognitive development, neuropsychology, health issues, education, advocacy and social policy, family concerns and world issues for people with Down's Syndrome.

Keynote speakers include Dr. Siegfried Pueschel & Dr. Alan Baddeley

Visit the website or contact :

World Down Syndrome Congress  
c/o Venue West Conference  
Services Ltd  
#645-375 Water Street  
Vancouver  
B.C.  
Canada V6B 5C6.

Tel. 1-604-681-5226  
Fax. 1-604-681-2503  
Email: [wpsc2006@venuewest.com](mailto:wpsc2006@venuewest.com)



## Sweatpea's Story

Amanda, or Sweetpea, as we called her, was born on Tuesday 21st August 2001 at 3.05pm at Falkirk Royal Infirmary. Apart from having extremely cold, cyanotic feet she looked the picture of perfection. I was transferred from the labour suite to the ward, and waited for my husband to bring our other three kids in to visit their new little sister.

After they had left after 8pm, I breastfed Amanda, or tried to, as all she wanted to do was sleep. As I thought she seemed so settled, I tried to get some sleep as I was absolutely shattered. However, I had no sooner drifted off, when a midwife came, grabbed Amanda out of her cot and pressed the emergency buzzer at the side of my bed. I will always remember the words "Did you not notice her change colour?" I carried a guilt complex around with me for months as I knew that if I had been wakened, yes, as an ex-nurse I would have noticed the colour change and the breathing become laboured.

She was whisked along to the nursery and then taken downstairs to SCBU, where she was ventilated. One minute we had a healthy baby, the next bedlam had been let loose! The paediatrician told us he felt sure it was her heart, but he didn't know exactly what, as he wasn't a specialist, so Amanda was then transferred in a transit incubator to Queen Mother's hospital at Yorkhill in Glasgow. There, the consultant took us into a side room and told us about Amanda's heart problems and that she had been born with Trisomy 21. Big deal! The heart problem should have taken all precedence in that conversation!

Amanda's heart problems consisted of Tricuspid Atresia, a very rare heart condition which if not treated within the first year and a half of life, can result in death. It basically means that the Tricuspid valve is either malformed or is non-existent. She also had an Atrial Septal Defect and a Ventricular Septal Defect, but on top of this the Mitral Valve had a lot of regurgitation. This all meant that Amanda wasn't getting enough oxygenated blood going to her lungs. We were told that she would need many operations to improve her chances of survival.

After about 2-3 days at Queen Mum's she was taken off the ventilator and transferred to the cardiology ward at Yorkhill Sick Kids. She was on nasal oxygen and had her oxygen saturation levels recorded for about another week and was allowed home on sats of roughly 80% when she was two weeks old. At that point in time, while we had her

home, it was difficult at times to remember she was so ill.

She had to be rushed back into hospital two weeks later when she had several apnoea attacks - one while the Health Visitor was holding her. She remained hooked up to monitors and oxygen until she had her first operation on 1st October. She had a PA banding, which is a ligature that goes around the Pulmonary Artery.

This, they hoped, would reduce the amount of mixed blood that was going into Amanda's lungs. However, after several attempts at trying to get her off the ventilator, we seemed to be going nowhere at all. Then at the end of October, Amanda had a cardiac arrest, while on CPAP, which is halfway between ventilation and nasal oxygen via prongs. It was only at this point really that I came to grips with the fact that I had a little girl who might not survive - as the doctors were later to drum into us many times.



We were then offered an operation to repair her Mitral Valve. We knew that there were more odds against her not making it, as this operation is normally performed at 5 years of age. However, we wanted her to have the best fighting chance, so we signed consent. She made it back after a very lengthy surgery, lasting nearly eleven hours all inclusive. This was in November.

At the start of December we were told that there was no hope. However, our wee fighter proved them wrong and came off the ventilator, CPAP, and was transferred on three litres of nasal oxygen back up to the ward. We felt on cloud nine! Our baby was back! We spent Christmas with her in the family flat supplied by Ronald McDonald House. Everything was going well and she was to be discharged home on portable suction and oxygen, hopefully allowing her to get bigger and stronger, and for the right atrial pressure to go down allowing them to think about her next operation.

However, tragically on December 31st, Amanda caught RSV, a flu type respiratory virus that makes the airways to the lungs swollen and inflamed and in Amanda's case making it virtually impossible for oxygenated blood to pass through. She fought as hard as she could and managed to survive the virus, but the scarring caused by it was still there. She went into secondary heart failure and her liver became extremely enlarged. Her kidneys became affected, too, as her urine output was getting worse despite getting massive doses of Frusemide.

## Sweetpea's Story Continued and News

On 31st January, we were again taken into a side room and this time we were basically asked how we would like Amanda to die. I felt like screaming "Not at all!!" but all my fight had gone. We knew that on Friday 1st February we would have to allow the medical team to switch off her ventilator.

The hardest part was trying to explain what was happening to our other kids. When we first told them of Amanda's problems at the end of November, one of the other mums, Elaine (who became a great support to us, despite her own son being ill at the time) told us to tell them "Amanda's wee engine", (her heart) isn't working properly and nobody can repair it." In the end we decided to be straight up front and let them know exactly what was happening, which was very hard to do at the time, but neither of us regret being so honest with them.



We made Amanda's room look really homely - we had fresh flowers everywhere, kiddies' posters on the wall and CDs playing softly in the background.

After all our relatives had come to say their goodbyes, the doctor came in to take Amanda off the ventilator. She died peacefully within ten minutes in my husband's arms, while Dido's "My Love's Gone" was playing in the background. We then gave her a bath and changed her into her favourite outfit - her denim dungarees.

It was all very dignified and we don't regret releasing Amanda from the pain she was in at that point. Our time with Amanda was a treasured gift that neither of us regrets for a moment, despite all her problems. We knew all the risks of the operations she had and the ones she hopefully would have got if she had survived, but if we had to do it all again, we would still give consent for them to be done.

Our Sweetpea is sorely missed, but has made such a huge impact on our lives that she will be with us forever.



Down's Syndrome Scotland have published a range of books and tapes about complex issues such as keeping well, getting older, dementia and death. These books use pictures and simple text, but are still quite "grown-up".

Contact : Down's Syndrome Scotland, 158 -160 Balgreen Road, Edinburgh, Lothian EH11 3AU or phone 0131 3134225

### TO LET - Holiday Home (sleeps 6)

Bristol Children's Heart Circle has a holiday home at Lakeside Holiday Park, Burnham on Sea, Somerset which is available for rent by members of other heart groups.

A most attractive site with a club, large children's play area, a swimming pool and a coarse fishing lake. The site is opposite the town's swimming pool and a short walk from the seafront. An ideal resort for a relaxing holiday.

Prices vary from £150- £190 per week, depending on time of year. Available Easter to October. Short breaks or long weekends (outside school holidays only)  
Ring Des and Judith Langdon or [REDACTED]



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Contact or answerphone always available  
(24hrs in emergency)



**Founder**

Linda Walsh

**Patrons**

Sarah Boston

David Graveney

**Down's Heart Group Policy Advisors**

Sister Mary Goodwin

Dr. Phil Rees

Dr. Rob Martin

Dr. Graham Stewart

Dr. Claus Newman

Dr. Rob Tulloh

**Legal advisor**

Brian Auld



**Chair**

Cliff Lake

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

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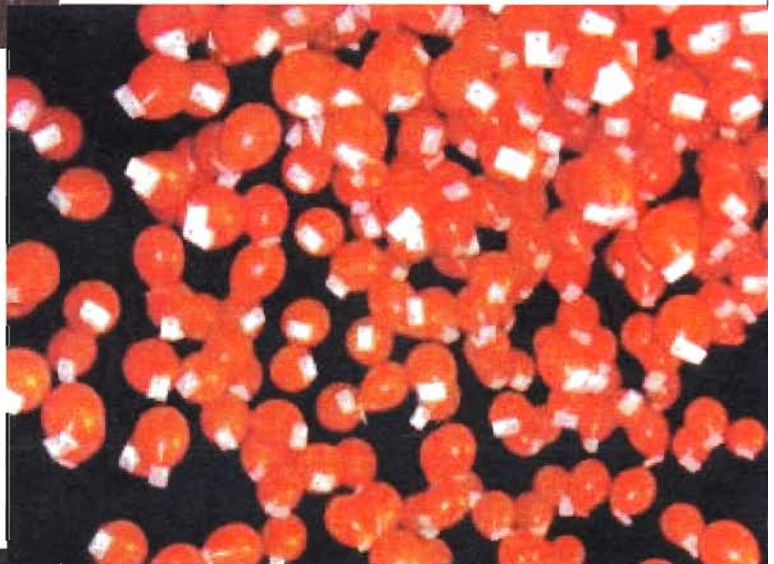
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