



dhg
down's heart group

Newsletter Autumn 2007

Issue 36



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Chair's Report

It's been ten years since I first met William! He made his entrance onto the stage of life at 8.50am on 24th August 1997 and we were not made aware until a few days later that there was any concern about his condition.

Having confirmed that he had Trisomy 21, we were told we could take him home once they'd done a few more tests to check there were no further complications. To our horror we then discovered that our new baby had a life threatening heart condition.

Following numerous consultations and a cardiac catheter, a cardiologist told us that there was nothing that could be done for William due to his pulmonary pressures. We were stunned when he added that William wouldn't have had a very good quality of life anyway because he had Down's Syndrome. I needed to challenge what I felt was clearly a prejudiced opinion.

I discovered two support groups,

the DSA and DHG, both rich sources of relevant information, but when your child has a heart condition the Down's Syndrome seems irrelevant. Down's Heart Group provided me with information and links to other sources of data which helped me prepare my argument against the decision.

Thankfully my efforts proved unnecessary, as at our next visit, another cardiologist specialising in pulmonary hypertension, agreed that William deserved a second chance. Once the traumatic times of surgery were over, the follow ups and early reviews confirmed a positive result.

In his tenth year, William's entrances have been more theatrical including an appearance on stage at the Magic Circle on Congenital Heart Day and a performance in Pinocchio when he took not only his own bows but contributed to everyone else's. He plays football, captaining his team this year and scoring the winning goal

against his brother. He is also part of a dance group and when asked if he would play the donkey in the nativity, he suggested he'd prefer to be Shrek.

For seven of William's ten years I have been chair of Down's Heart Group. I became involved because when we needed it most, they provided my family with support and information that was easy to understand and extremely informative. I wanted the Group to thrive and grow which has happened, but if it is to survive and develop further it needs the support of more parents and professionals.

We need fresh ideas that trustees can turn into worthy projects and new Committee members to help deliver them. It would also be great to have some people with Down's Syndrome on the Committee guiding us towards the most appropriate choices and best outcomes. Who knows, one day William may even be chairman!

Cliff Lake

Front Cover - Nicky Cheney

Nicky was born on 8th August 1987. It was six months before he was found to have a minor heart problem and fifteen months before we learnt it was a complete AVSD. I was told he could have surgery but it was very risky and in any case he wasn't expected to live longer than a couple of years so we didn't opt for the surgery. Although his first six years were fraught and he was often at 'deaths door', he has survived and is now twenty.

Apart from the AVSD, Eisenmengers and Pulmonary Hypertension he has a large oesophageal stricture. He had repeated surgeries for this - even though the risk of him dying during surgery was high, we had no option as he was getting aspiration pneumonia every few weeks and spent most of those first six years in hospital. The procedures were unsuccessful so he is now fed totally via a gastrostomy (great for all the medication he takes too) and he has an oesophagostomy through which his secretions come out so they don't go into his lungs. At age six he also had a Nissans fundoplication and at the same time his gastrostomy.

Over the years Nicky has been an inpatient at our local hospital, Alder Hey and Great Ormond Street and he is now under the care of the Royal Brompton in London, 170 miles from our home. Professor Gatzoulis told me recently Nicky is stable and could possibly live to be in his thirties or even his forties.

Nicky is one of the less able youngsters and is unable to talk but he is a happy, contented boy who is well behaved and a joy to have around. He leaves school this year and is already attending a very good day centre twice a week where he will go full time in July, he has regular respite at a children's hospice (until December 2007) and at a medical respite facility in the grounds of our local hospital.

He takes all his medical problems in his stride but does not like having blood tests, echo's etc. and will complain loudly!!

Nicky loves going to hydrotherapy, pony riding and on outings, he has

been to America, Belgium, Holland, France and many places in Spain. He is the youngest of my five children and loves being in the midst of his family including his two little nephews.

Thankfully the AVSD repair is very successful now so babies born with it can be successfully operated on.

Pauline Cheney



AGM Notification

**Our AGM will take place at 10am on Saturday 27th October 2007
at the Friends' Meeting House, 16 Queens Road, Leicester LE2 1WP**

There is no need to register but it would be helpful to know you are coming for the provision of refreshments.

Copies of the accounts and Annual Report will be available at the meeting, or if you would like a copy, please let us know in what format (hard copy or email) and we will send them out to you around the date of the AGM.

Nominations for Honorary Officers and Trustees should be sent to National Office to arrive no later than 13th October 2007. Forms available upon request or send a written nomination proposed and seconded by two members (each member family has two voting rights). It must be signed and dated by both and also by the nominee to show their acceptance.

Under the terms of our Constitution, both the Chair and Vice-Chair are due to stand down this year, but they may stand for re-election. We also have vacancies for Honorary Secretary and Treasurer as well as other Trustees. We would welcome nominations for new Board members and we now have provision to elect up to 25% of the Committee from associate rather than full members. Being on the Committee isn't an arduous task, we meet about four times a year with phone calls and email correspondence in between, so this is an ideal opportunity to get involved and help to shape and ensure the future of DHG. If you would like to know more, why not call Penny Green on 0845 166 8061 for a noncommittal chat?

Please note that there is no creche facility available at this meeting.

To save on postage costs this is the only AGM notification you will receive

Christmas Cards

Due to limited finances there are no new DHG card designs this year, but there are still great opportunities for you to help raise awareness and support our work.



We have packs of 10 cards featuring previous DHG designs at the bargain price of £2 each (packs will vary but will contain at least 5 different designs).

Cards are 105 mm x 148 mm approximately and the greetings inside vary. 100% of the proceeds go to DHG.

Order form on page 11

You can purchase cards from Creation Greetings who have over 70 designs available.



They are printed with our logo and 50% of the price is donated to DHG. Please call and ask us for a leaflet or you can order online by visiting

[www.creationchristmascards.co.uk/
downsheartgroup](http://www.creationchristmascards.co.uk/downsheartgroup)



Don't forget to get ALL your Christmas stamps from us!

They are exactly the same as you'll get at the Post Office, they cost the same, but we make a small commission on our sales.

We do ask that you buy at least one pack of DHG cards (past experience shows it's safer to send the stamps that way) but you can order as many stamps as you like.

Information DVD's

"Going into Hospital" is an information DVD available for people with learning disabilities. It is all about going into hospital and it shows people with learning disabilities what happens, who the people are and explains the important information that everyone needs to know.

This is just one of the current catalogue of fifteen titles available from Speakup who have been making information films for people with learning disabilities for over twelve years, providing them with the information they need to live more independent lives.

All are produced by and for people with learning disabilities working in partnership with media professionals. They are clear, friendly, good quality films on subjects ranging from parenting skills, tenancy agreements and opening bank accounts to bereavement, bullying, abuse, life planning, health and much more.

Visit www.speakup.org.uk for more information. From there you can order, download an order form or watch full length samples of the DVD's - so you can decide before you buy!

Speakup is run by and for people with learning disabilities, everyone gets paid a proper wage and is learning the skills needed to have a job.



Elizabeth

Elizabeth has an unrepaired AVSD which is now Eisenmengers. She is twenty seven years old, even though the heart specialist at Manchester Childrens' Hospital, Pendlebury told us that if she did make it to five she would not reach her teens!!!



Elizabeth has attended a special school and then Derwen College as a resident. She has recently been given a council bungalow and despite our initial worries, she has settled in very well as an independent person. Her home is located some seven minutes walk from our home.

Liz has a kitten (Sweet Pea) and a Personal Assistant who is paid through the Direct Payment Scheme. She is getting help from Occupational Therapists who are teaching her to cook. Despite being in quite a lot of chest pain, Elizabeth has a good quality of life. She has pain medication in the form of Codeine Phosphate and uses Oxygen regularly from a concentrator installed at her home.

I would be happy to be in contact with anyone who would like to know more about our life and Liz.

Sandie Ollier

YOUR LIFE

Brogan

Hi, I had my daughter Brogan on 14th November 2006.

I didn't find out that I was pregnant till six months gone!! I never used to believe people that said they didn't know they were pregnant, I thought how could they be so daft!!! Then there I was with two sons age eleven and six. I was very shocked.

It was a weird pregnancy, I can't explain it but knew something wasn't right. I used to wake up in the morning and say to my husband, "I don't feel pregnant" and that was at eight months. The last two weeks, well weeks 36-38 as Brogan was born at 38 weeks, were really strange. She stopped moving and I would only have two or three movements a day. I kept going up to the hospital, but you know what its like, you don't want to be too much trouble!! Thank God I acted

on instinct, as I do believe Brogan wouldn't be here now if I hadn't.

As soon as she was born I knew immediately that she had Down's Syndrome, but was more shocked that she was a girl. I had a really sympathetic midwife who came in after I'd had Brogan and said "Big shock." Thinking she meant having a girl, I said "Yeah!!" Then she said "I had a baby girl who had Down's Syndrome, she died at six months." I mean is this what you want to hear?

As I said before, Brogan is our chick and we wouldn't change her for the world!!!! We have a worrying time ahead as she has to go to Great Ormond Street Hospital for heart surgery on a large VSD but we are sure she will pull through.

Bobbie Ambrose

Alex

Our Son Alex is four. In the past I have spoken to you with worries and problems, at the time I was totally devastated with what we were facing. Our family has been nearly torn apart with all the added strains, but I can honestly say now that things are getting better. Alex is a fighter and we have remained a family throughout.

The sheer pressure it puts on a family is tremendous, we have all suffered, but now we see that Alex has grown stronger and overcome most of his weaknesses. He remains gastrostomy fed and still refuses to feed orally, but he is walking and babbling, trying to put words together. We are working on his communication skills and social interaction but he is a fantastic character, with a lovely sociable personality. He wants to learn and is into everything, he's settled well in nursery and has had his statement now since two years old.

Since having his Tetralogy of Fallot's operation at four months old we have only had a couple of blips where he

has had more blue spells. We know he continues to have a hole in his heart, but keep a close watch on him and he soon lets us know when he is getting tired. We know the signs, he may just sit quiet, his head goes back and he will go into a quiet daze, he often gets thirsty and is constantly licking his hands, or he gulps very loudly.

If you'd told me three years ago that my son would be where he is today I'd never have believed you. He is the apple of my eye. He has inspired me so much, taught me so much and made me appreciate life so much more. Our other children have learnt from him and become so much more patient and understanding.

Knowing that I was having a child with Downs Syndrome was a privilege to me, then he was born and was very poorly. After surgery we were told to expect him to die - my hair was falling out with shock. I prayed to God to pass my strength to Alex, he survived against all odds, then he still could not feed. There was problem

after problem, too many professionals getting involved, coming to our home, it was as though we were owned by the services that helped Alex.

Then he started to get stronger and I had the courage to stop people coming into our home. We had time together as a family for the first time in two years. It has been a roller coaster ride, just like you say in your magazines. It's an amazing journey of ups and downs and hanging on in there, but we are still here to tell the story and will be as long as we've got Alex.

Children like Alex open our eyes into a whole new dimension, an amazing world of learning at a slower pace, of exploring every tiny detail that everyone else just takes for granted. He's a very bright boy and I'm very proud of him. These children have so much potential locked away inside of them, just actually bursting to get out, but when they are ready.

I feel so lucky to have a child with Down's Syndrome. I'm so proud and people I meet are always intrigued and have so much time for him. It can be hard work at times, but aren't all children?

Tracy and Andrew Gordon

Letters

Chelsea

I thought I would send a few pictures of our beautiful daughter Chelsea who is full recovered after her surgery to repair Tetralogy of Fallot and an ASD. She spent only seven days in Birmingham Children's Hospital and has gone on to make an amazing speedy recovery.



She is a very placid loving and cheeky girl who gives us so much pleasure.

Chelsea had surgery on March 6th 2007 just shortly before her first birthday and now at fourteen months old she is trying to crawl. Her determined nature shows us that she will get there very soon.

I am just so thankful to all the staff at the hospital for the care they showed her. We are looking forward to a brilliant future for Chelsea now that her surgery is behind us.

Andrea & Darren Ledger



THANK YOU

We've had a good response to our appeal for funds in the last issue but we still need **YOUR HELP!**

So if you haven't got round to doing something yet, there are several good opportunities in the coming months to show your support and really make a difference.

We don't like asking our members for money - our aim is to help **YOU**, but currently our very existence is threatened. We're sure that if you value our work and want us to be there for you and other families in the future, that you will want to help DHG in any way that you can.

Why not have a look at some of the things people have been up to in the past months and get some ideas. It's not about putting your hand in your own pocket (although that's fine if you want to), but about helping put DHG in a position where other people know about our work and want to support us too.

So whether it's holding a coffee morning, asking your boss or the kids school to support an event, suggesting that colleagues make a donation rather than send Christmas cards or changing your internet search engine, there's bound to be some way that you can help.

Don't forget to ask friends and family to support DHG too!

Motorbike Madness Update

Despite coming off his bike on the motorway between Leicester and Birmingham, organiser Wayne Brown made it to Leeds. Admittedly it was in a car and with five broken toes, but nonetheless he finished.



Apart from this little mishap it was a brilliant day. The site of all the bikes caused quite a lot of attention,

especially when they passed through the middle of Leicester at midday and I had the perfect viewing point from my car as I brought up the rear.

Thanks to those who turned out to wave us on our way. Apologies to anyone who missed us - a two hour wait for Wayne's bike to be recovered wasn't in the schedule but no-one would leave him behind. Most of all, THANK YOU to all the bikers who came along and to Wayne and his family for all their hard work. The event raised over £1500.

I'm happy to report that Wayne is making a good recovery and has used his enforced rest to update the website and start planning next year's run.

For details and more photos visit www.motorbike4charity.co.uk

Penny Green



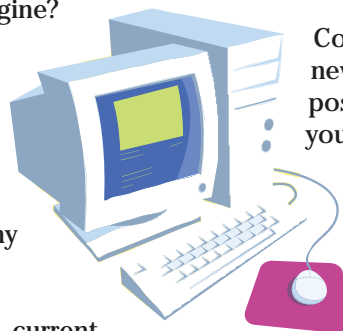
Do you have internet access?

Are you using **Everyclick.com** as your internet search engine?

So far we have raised £486.19p thanks to the 141 registered DHG supporters, but we know that more than twice that many members have email.

We could double our current £30 a month income if they all signed up. And what if everyone recruited one more supporter from

amongst their family and friends!!!



Could you help us save newsletter printing and postage costs by accessing your copy online? We send an email notification when a new issue is available and can always provide a hard copy if you ask.

To sign up just give us a call or send an email to info@dhg.org.uk.

Awareness Week - 27th October to 4th November

A great opportunity to arrange a fundraising event and raise awareness of our special youngsters and the importance of the work DHG undertakes.

It doesn't have to be big or make a fortune, make it fun and you'll be surprised at how much you can raise and we'll be grateful for whatever help you can give us!

Skydiving ladies

Thank You!

To everyone who responded to our appeal for funds in the last newsletter.

Without your help we probably wouldn't still be here to produce this issue.

Pictured here is Suzanne Adams, one of two of our female members who've recently taken the dramatic step of jumping from a plane to raise funds for DHG.



to be smiling, although I'm not so sure that her children, Rachel and Jamie, would have been quite so happy to see their mum floating through the air!



Both Suzanne and Georgie Freeland reported that it was a fantastic experience. Suzanne certainly seems

Many thanks to both ladies who each raised around £700 in sponsorship for their bravery.

Have you made a donation to DHG in the past six years and are you or your partner a UK tax payer?

If so then we can probably reclaim the tax on your donation no matter how small. Just complete the Gift Aid Declaration Form on page 11 and post it to us - we'll do the rest.



Would you like us to reclaim the tax on any donations you may make in the future?

Simply complete the Gift Aid Declaration Form on page 11 and post it to us - we'll make sure we claim the Gift Aid on any donations until you notify us otherwise.

To make a Gift Aid Declaration you must pay tax at least equivalent to the amount being reclaimed in each tax year. Donations drawn on joint bank accounts can be assumed to be from the account holder who has completed a Gift Aid declaration if only one of you is a tax payer.



Dan loves the theatre

Many thanks for the latest copy of the DHG newsletter, it prompted me to write and give you an update on our son Daniel and his wonderful progress.

Dan appeared on the cover of the Spring 1998 magazine (with his story inside) and later again on the cover in Summer 2005. With help and support from yourselves at the time, he has gone from strength to strength.

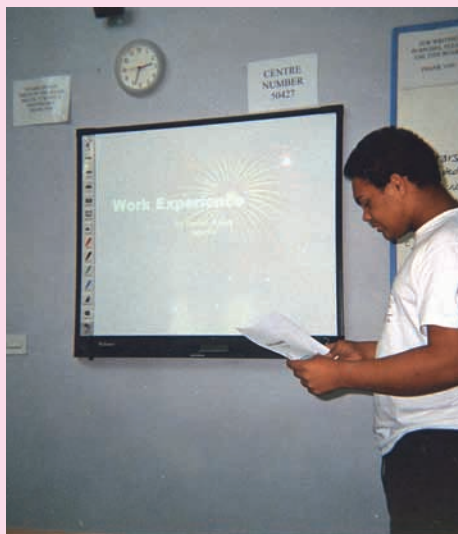
He attends the City Academy in Bristol, took GCSE's last year and has a pass in drama plus other pass certificates. He has had work experience in various places including our wonderful Old Vic Theatre.

He will be leaving school shortly, but before that he has a part in the school production of Bugsy Malone playing 'Knuckles'.

In September Dan has been offered a foundation course in drama at our local college / academy of arts.

When Dan was young we were so overwhelmed by his diagnosis and concerned for his future, now seeing the positive effect he has on others and the good friendships he has built up, I had to put pen to paper to encourage and inspire others.

Pauline Bryan



Dan is pictured making a presentation about his six weeks work experience at The Old Vic Theatre in Bristol.

Bex's new heart valve

Yesterday my daughter Rebecca, or Bex as she prefers to be known, was twenty. I find it hard to believe that it's almost twenty years since I met my soon to be adopted daughter for the very first time. She was just six weeks old, still in the neo-natal unit of our local hospital, and it was with some nervousness that I picked her up for our first cuddle. She was tiny, floppy, topped with the most amazing shock of ginger hair and came with the reputation of the most difficult to feed baby with Down's that they'd ever known!

Most difficult to feed baby they'd ever known!

It wasn't quite love at first sight, but this amazing child soon worked her way into our hearts and we accepted that we would be facing difficult times together as she would need major corrective surgery for Fallot's Tetralogy. So just before her first birthday, after an increasing number of alarming "blue episodes" and a failure to gain more weight, we were admitted to hospital for a total correction.

This was a difficult time for us all, both during the hours Rebecca was in surgery and in the days after in Intensive Care. Although the correction was successful, there had been considerable difficulties when taking her off the heart bypass and it was several days before the surgical team could feel that she was out of the woods.

She seems to run well on batteries!

It was a much-improved child we brought home from hospital and of course we hoped that heart wise, we were over the worst of our problems and wouldn't have to face such traumas again. There's no harm in hoping is there? Two years later we were

back in hospital as an emergency as Rebecca had dramatically developed total heart block and needed to have a pacemaker fitted. This effectively dealt with the problem but since then Rebecca has had two replacement pacemakers, however, she seems to run well on batteries!



It was round about the time of the second replacement when Rebecca was in her early teens that we were asked to consider having her pulmonary valve replaced as it was almost certain to start causing her some problems in the not too distant future. There was some merit in having the operation while she was well and relatively strong. She was so happy and full of enthusiasm for life that we decided it was better to wait

and of course hope that she would be one of the few who didn't need a replacement valve. The prospect of open-heart surgery and all the risks and suffering it involved was daunting to put it mildly.

Falling asleep at school

About four years ago we began to notice a gradual change in Bex. She began to fall asleep at school and was really tired at the end of the school day. We thought this might just be the demands of being in a large comprehensive school where she worked hard and there were no obvious physical symptoms apart from tiredness.

Then on holiday we were on one of our favourite coastal walks, when I realised that Rebecca was struggling and breathless in her efforts to complete the walk. On several occasions she opted out of activities; things were obviously not right and more surgery suddenly loomed large in our minds.

New valve replacement procedure via catheter

A couple of months later Bex was in hospital for catheterisation to confirm the need for a valve replacement. After the procedure the cardiologist called me into her office (quickly telling me there was nothing to worry about - the speed with which your heart can reach your boots is amazing!) She confirmed that replacement was essential but then asked if she could explain a little about a new procedure

that was being developed to replace the pulmonary valve via a catheter rather than surgically. Although this was still "on trial" the advantages were obvious and we were keen to explore this possibility to avoid the risks and suffering that were inevitable with open heart surgery.

After some time with various letters, test results and measurements being sent to Professor Bonhoeffer at Great Ormond Street, we were delighted to hear that he was willing to attempt the new procedure on Bex. Obviously he couldn't guarantee success, nor would we have the reassurance of this procedure having been completed many times.

Should this fail, Bex would need open heart surgery

With the help of our cardiologist we considered the pros and cons of going ahead. If it was successful, the advantages of minimal trauma and risk reduction were obvious. Should this fail, Bex would need open heart surgery but this option would still be possible; so all in all it wasn't a difficult decision to go ahead, especially as the procedure was little more traumatic than having a cardiac catheter.

In September 2003 Bex and I travelled to London, where we met Professor Bonhoeffer and his team for the first time and any questions we still had were dealt with. We were given a full explanation of what would happen during the procedure and what course of action would be available if things didn't go according to plan. Bex had not been able to have a MRI scan because of her pacemaker, but from the information available from the other tests it seemed that she was at the upper limits for the size of valve that was to be used. So it was not certain that a new valve could be inserted.

Off to theatre

The next morning Bex was taken to theatre, where she was met by Professor Bonhoeffer and one of the

cardiologists from our "home team" who had travelled to London to see this new procedure.

Although the procedure took longer than was anticipated and there was difficulty in getting the valve into the right position, I was soon reunited with a complaining and irritable daughter. The team was delighted with the result and there was great rejoicing at Rebecca's bedside by all the adults involved. Rebecca was rather too busy being sick to appreciate our delight!

Spectacular bruising in a place that she couldn't show off

The next day Bex felt sore and still rather sick but all the scans and tests showed that everything was as it should be and so we were able to take the train home the following morning. With the exception of spectacular bruising in a place that she couldn't show off and a touch of soreness, Bex had few after effects from the procedure and was back at school, firing on all cylinders within a fortnight. Since that time she has been extremely well, full of energy and hasn't fallen asleep over her schoolwork once!

The relief at being able to avoid the trauma of a conventional valve replacement was huge and we are so thankful that Bex was able to take part in the trials. Very recently we were back in London, this time on the happy occasion of celebrating the 100th valve replacement and I was able to thank Professor Bonhoeffer for his skill and the care he showed us. I think, for him, the reward was probably seeing so many of his patients looking well and happy.

THANK YOU Professor

So, to the Professor and his team, an enormous thank you from Rebecca (number 28) and her Mum.

Julie Payne

Our holiday in Switzerland

Caroline has Down's Syndrome, congenital heart problems and pulmonary hypertension. She is on nebulised Iloprost and uses oxygen at night. On the 21st March she reached the age of thirty five! She is an amazing and wonderful person who lights up the lives of everyone she meets.

We like to live life to the full and travel is one of our most favourite pastimes. With the advantage of low cost airlines we try to visit cities in Europe whenever we can afford it. Recently we booked a trip to Geneva and unfortunately Air Products do not cover Switzerland for providing holiday oxygen. I phoned the PHA-UK helpline and I was advised to email the PH association in Switzerland.

Although they spoke very little English they were able to put me in touch with Pangas, the Swiss equivalent of Air Products. They were extremely helpful and efficient and organized for the concentrator to be delivered to our hotel prior to our visit and picked it up on the day of departure. It was such a relief to know that Caroline's medical needs would be in place.



As you can see from the photos we visited the Alps and all had a wonderful time. The hotel staff were friendly and as our homeward flight was not until 9pm they allowed us to use our room for as long as we needed.

We arrived at the airport feeling relaxed and delighted with our holiday. Then suddenly we were horrified to learn that our flight home was cancelled and that there would be no further flights to Belfast until two days later. Many passengers were becoming irate and making plans to fly to other UK airports but it would still be too late in the night to catch a connecting flight to Belfast. What were we going to do with no oxygen for Caroline? Panic started to creep in.

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When we reached the desk and reported our plight, the desk attendant summoned her manager who lead us into his office where we discussed our options, or lack of them! It was after hours so we could not get through to Pangas and did not have their emergency number. The manager painstakingly tried all avenues until he found a pharmacy that was open and who could provide us with cylinders for the night. He arranged the collection of the oxygen and a taxi to take us to a beautiful airport hotel where we spent the night. Next morning we flew to Belfast via Liverpool, all compliments of Easyjet. Needless to say, we have been singing their praises ever since.

When cheap flights to Pisa were advertised, I immediately researched the availability of a holiday oxygen supplier. Air Products do not supply this particular area of Italy but gave us the contact number of the local supplier. However, they were not as efficient as Pangas in their efforts to help and the cost for a four-day trip was exorbitant, so we had to abandon that venture!

After speaking with Grant on the PHA-UK helpline, we are seriously contemplating the purchase of a mobile concentrator as it will save us a lot of hassle and phone calls!

Sheila Artt

Since this article was written Sheila tells us that a portable oxygen concentrator has been purchased and the family's travels continue, including a recent trip to Biarritz.

We would like to thank Pulmonary Hypertension Association for giving permission to reprint this article which originally appeared in their Summer 2006 newsletter.



PHA aims to make the lives of patients, relatives and carers easier and more able to cope with the challenges that Pulmonary Hypertension imposes. Their website aims to provide information about all aspects of Pulmonary Hypertension including clear explanations of what it is, how it is diagnosed and what can be done to treat it.

Support Helpline : 0800 3898 156

www.pha-uk.com

If you prefer not to cut up your newsletter you may photocopy the forms on this page

Order Form for DHG Christmas Cards

Orders can be posted to Down's Heart Group, PO Box 4260, Dunstable, LU6 2ZT or made over the phone on 0845 166 8061

Name: packs of 10 cards & envelopes @ £2.00p £..... -p

Address: books of 12 1st class stamps @ £4.08p £..... -p
 books of 12 2nd class stamps @ £2.88p £..... -p
 NB. Minimum order one pack of cards to place a stamp order please

Postcode: postage & packing £..... -p

Contact No:

Email:

SUB TOTAL £..... -p

I enclose a cheque or postal order payable to Down's Heart Group

or Please charge my debit or credit card

Name on card

Card No

Issue Valid from / Valid until /

Postage & Packing	
1 - 3 packs	£2.00
4 - 5 packs	£3.00
6 - 7 packs	£4.00
8 - 10 packs	£5.00
Over 10 packs, please use the cost for 10 plus the extra	

Please consider rounding your payment up

I would also like to make a donation £..... -p

FINAL TOTAL £..... -p

Postage shown is for UK 2nd class.
Please contact us for other options.



Gift Aid Declaration for donations to Down's Heart Group

Registered Charity Number 1011413

Please post the completed form to Down's Heart Group, PO Box 4260, Dunstable, LU6 2ZT

Name: Please delete as appropriate

Address: I would like to Gift Aid all donations I have made in the past six years and on future donations until I notify you otherwise.

 or

Postcode: I would like to Gift Aid all donations that I have made since / / (enter date you became eligible to make a declaration) and on future donations until I notify you otherwise.

Contact No:

Email:

To qualify for Gift Aid, what you pay in income or capital gains tax must at least equal the amount that will be claimed against all eligible donations you make in each tax year.

Please notify us if you wish to cancel this declaration or you no longer pay sufficient tax

Signed: Dated: / /



dhg

down's heart group

Charity 1011413

PO Box 4260
Dunstable
LU6 2ZT

tel : 0845 166 8061
email: info@dhg.org.uk
website: www.dhg.org.uk

contact or answerphone
always available

(24 hours in emergency)

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Dr. Graham Stewart
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Sarah Boston
David Graveney

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2A Langdon Park
Teddington, TW11 9PS
0845 230037

www.downs-syndrome.org.uk

**the down syndrome
educational trust**
<http://www.downsed.org/>

The Down Syndrome Educational Trust
The Sarah Duffen Centre
Belmont Street
Southsea, Hants, PO5 1NA
02392 824261

www.downsed.org

Down's Syndrome

SCOTLAND helping people realise their potential

Down's Syndrome Scotland
158 - 160 Balgreen Road
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0131 3134225

www.dsscotland.org.uk



Down Syndrome Ireland,
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Old Naas Road,
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00 3531 426 6500

www.downsyndrome.ie

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



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

www.childrens-heart-fed.org.uk



British Heart Foundation
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London
W1H 6DH
08450 70 80 70

www.bhf.org.uk



Grown Up Congenital Heart Patients Assoc..
Room 5, Saracens Business Centre
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www.guch.org.uk

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