

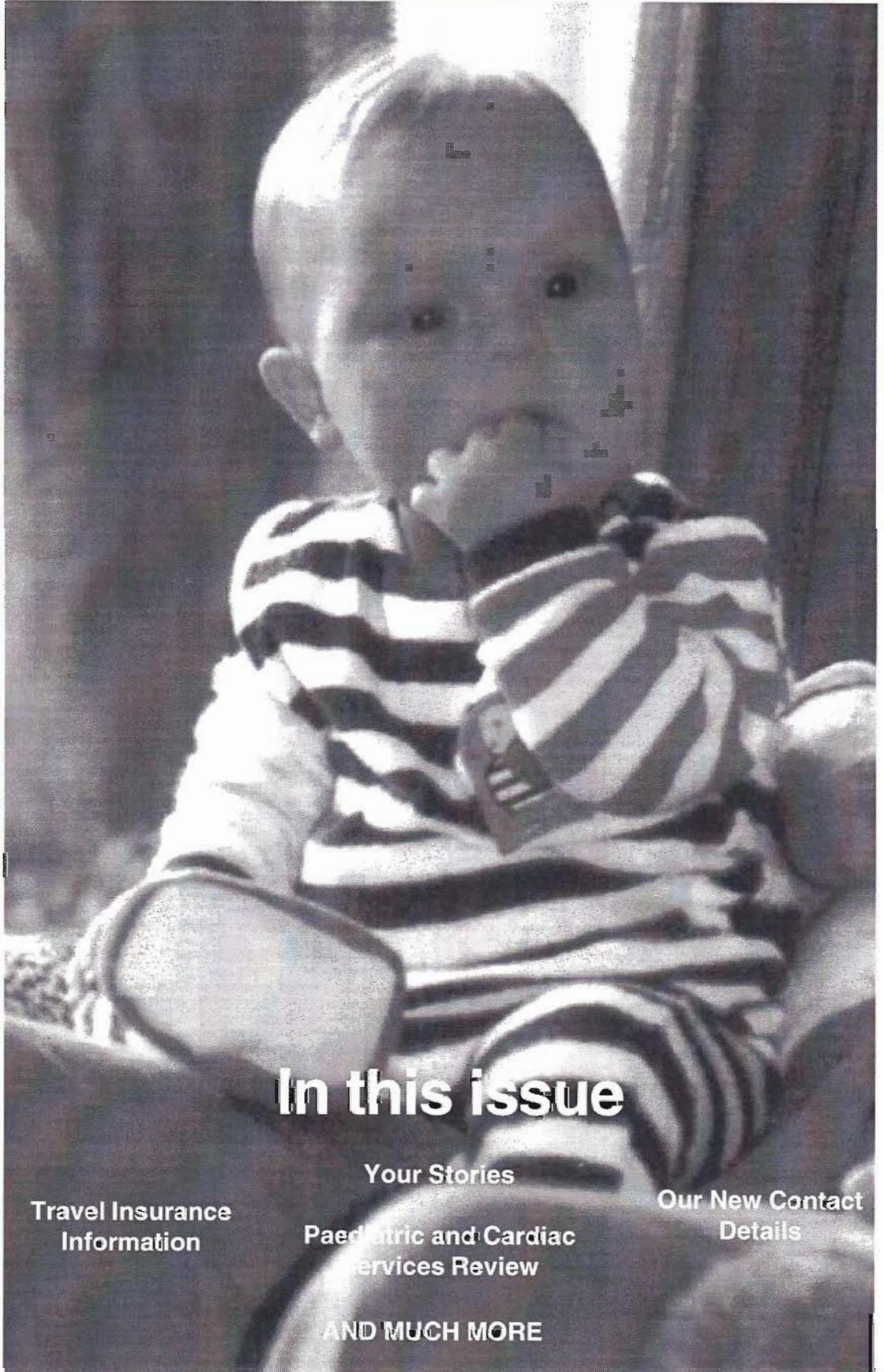


DOWN'S  
HEART  
GROUP

# NEWSLETTER

Issue No 25

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## In this issue

Travel Insurance  
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AND MUCH MORE

# Vice-Chair's Report

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Dear Members

I have been Vice Chairman of the Group for 18 months, but I have been a member for the past 10 years. I have a son, Richard, who is 17½ years old and will be off to College in May 2004. He attended a Special Needs Unit in our local school for Infants and Juniors and then transferred to our Catholic Secondary School with a full time Support Worker. We had nine months of extremely good progress then four years of ill health. Following an operation last July, where he had an ileostomy, we have had an amazing change in health and we now have an adolescent who is free of pain and very interested in the opposite sex!!

It has been an interesting year for the Group following the enquiries and the review boards that have been set up, I was one member of the Committee who attended a cardiac surgery review board set up to improve standards throughout the country. This one saw the paediatric cardiac consultants of the South West presenting an overview of the status of their services and how they are aiming to be. All areas have a long way to go to achieve their goals, but at least they were honest in their assessment of where they are and how they are trying to achieve their aims. These reviews are taking place across the country. However, it was very disappointing to see that there were very few parents prepared to come and listen to the initial reviews set up by the Children's Heart Federation. These reviews exist to present the findings and future needs of the Cardiac Services. It is apparent that we will not be getting a Cardiac Surgeon back in Wales as he/she could not work in isolation again. We will keep you updated as things progress on this matter.

Following the Annual General Meeting last September, we have gained extra members for the Committee and we welcome them greatly for coming on board as we do need the bodies to keep going. The next conference is in the process of being organised, but if you, the members, have any particular ideas of what you would like us to arrange please let us know. We do our best to change ideas and views each year, but we would welcome any suggestions and input from you. We would like to give you what you want!!

Finally we must say a grateful thanks to our Marathon runners. Penny and children, and myself and my husband Bob had an enjoyable day in London cheering them on. This will probably be our last weekend away from the fold as we had left Richard in the care of his sisters for the first time for two nights and he proceeded to develop a night sweat and an asthma attack!

Don't forget to get the children working on their Christmas card drawings for our Christmas cards please, all drawings appreciated.

*Chris Stringfellow*

## Note from the Editor

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As you can see from above, our Chairman Cliff Lake has been rather busy with work commitments recently and didn't have any free time to write a report for this newsletter, so I have persuaded our Vice-Chair Chris Stringfellow to put pen to paper. Chris has been involved as a volunteer for many years now, and as a trained nursing sister and working health visitor, she provides an invaluable medical viewpoint at Committee meetings.

We are fortunate to have a Committee whose members have a broad spectrum of talents and experience, but we are always glad to receive offers of extra help from amongst the membership. If you have a talent or experience that you think we may be able to put to good use, please let us know. Currently we would particularly like to find someone with graphic design experience to offer advice regarding our new publicity material.

So if you have a few hours to spare, a talent we could use, or an idea that we might develop, and you would like to help us improve our services and keep our costs down, please give us a call - we'd love to hear from you.



### Front Cover

Daniel Merchant in whose memory we have recently received a donation. This photo was taken the day before his first birthday.

# ANNOUNCEMENT



## We have new contact details!

You can now call us on our new local rate telephone number

**0845 166 8061**

which means you will only pay for a local call no matter where you are phoning from in the UK

You can also email us at ***info@dhg.org.uk***

or visit our website on ***www.dhg.org.uk***



## *Christmas Card Competition*



*YES! this is the Summer issue of the newsletter,  
but we need to start thinking about designs for the 2003 Christmas Card.*

So get your children busy with their felt pens and paint and they could be the lucky winner whose design will appear on this years cards and be the recipient of a small prize.

Entries must reach us by **30th June**, so there's plenty of time to get those artistic talents flowing.

### **RULES**

The competition is open to all Down's Heart Group children and their siblings.

Entries should be on a sheet of white A4 paper and contain the DHG logo somewhere in the design.

Please ensure the entrants name, address and age is shown clearly on the back of each entry.



# Duncan's Story

My husband Colin and I were thrilled to be pregnant after four years of infertility and two attempts at IVF. The pregnancy was completely normal - we had a nuchal fold test and the twenty week anomaly scan was fine.

A few days before Christmas 2001 when I was 31 weeks pregnant I had a late scan. My consultant saw a "double bubble" in our baby's tummy which a sonographer confirmed. We were sent away from Christmas having been told that it may be that the baby had drunk too much liquid and not to worry and that we would have another scan in two weeks. We didn't worry, having no idea what the significance might mean.

Two weeks later the double bubble was still there and we were introduced to the idea of Duodenal Atresia and the link to Down's Syndrome. We were told that three out of ten babies with this problem would have Down's Syndrome. A bit of a shock but there were still seven out of ten babies that wouldn't. We were then scanned again the same day by a doctor in the scanning unit and she spent a lot of time looking at our baby's heart. She found what she thought was an AVSD - which, we were informed, alone gives an eight out of ten chance that the baby would have Down's Syndrome. As far as I was concerned - never having been very good at maths - that gave us an eleven out of ten chance that our baby had Down's Syndrome, as well as two serious health problems. We were devastated.

We were referred to the John Radcliffe Hospital in Oxford to see a neonatal heart specialist, where at an appointment the next day, all our fears were confirmed. We were treated with the utmost honesty, empathy and compassion by all the staff we came into contact with. We were, however, horrified to be informed that we could abort our baby at up to 33 weeks because of the probable Down's Syndrome. We couldn't even consider it - particularly the mechanics of what would happen to the baby if we took that course of action - and immediately and emphatically refused.

The Doctor who told us of this course of action obviously did not support it, but said it was something she had to tell us about. She was also able to inform us that the Duodenal Atresia could be successfully operated on very soon after birth and that repair for the AVSD has a 95% success rate nationally and it is slightly higher than that at the John Radcliffe Hospital.

We were also told that although the doctors could not be sure our baby had Down's Syndrome they would be very surprised if he hadn't. The only way to be sure was to have an amniocentesis, but as so few are performed so late in pregnancy it was impossible to tell us what the risks of the procedure were, and we decided not to go through with it and prepare for this birth as though our baby would have Down's Syndrome.

Our continuing pregnancy was regularly monitored at our local hospital in Reading. Again staff there could not have been more helpful or supportive. We took time to assimilate the news ourselves and tell our families and friends so that everyone could be as prepared as possible. Colin was fantastic right from the beginning and said "He is our baby and we will love him". I was not so sure. We knew nothing about Down's Syndrome, had had very little contact with anyone with Down's Syndrome and had a

very negative view from the little contact we did have.

Our consultant at the Royal Berkshire Hospital put us in touch with a family with a two year old boy with Down's Syndrome who lives in our area. It was with much trepidation and clutching a box of posh biscuits and nervous smiles we went to visit them at their home. We needn't have worried. Ned is a wonderful little boy. He charmed us both and soon had us down on the floor playing with him. His parents and brothers and sisters are obviously besotted with him and told us he brings huge happiness to their family. They are convinced that every home should have a child with Down's Syndrome! We left with great relief, elated to think that our boy could be as marvellous as that.

We arranged for our baby to be induced ten days early at the John Radcliffe Hospital Oxford, so that he was in the right place for his specialist care and that there was less risk of us being separated if we delivered at Reading and then had to be transferred. We knew he would have to have an operation for his Duodenal Atresia within 24 hours or so and that we would not be able to feed him until it was done. We would probably go home with him before his heart op at about 12 weeks.

Best laid plans and all that - Duncan had his own ideas about when he wanted to arrive and I went into labour two weeks early,



travelled to Oxford and gave birth after a very straight forward labour. Duncan looked very healthy and weighed in at 6lb 6oz. After about 20 minutes he was taken away to Special Care where he spent the night prior to having his operation. The doctors were not convinced he had Down's Syndrome at that point as the only characteristic he had apart from his health problems was a large sandal gap between his toes.

Duncan had his operation for Duodenal Atresia when he was twelve hours old. The operation itself was straight forward but

he suffered a reaction for some unknown reason and needed to be given vast amounts of fluid to maintain his blood pressure. He blew up like a little Michelin Man. He was in Intensive Care for eight days rather than the planned one. After three days the Down's Syndrome was confirmed via blood test. He had numerous heart scans. He was diagnosed with a complete AVSD and a slightly narrowed Aorta. However his heart was coping extremely well and he was showing no symptoms of a heart problem. After three days he was fed intravenously.

After his eight days on the paediatric Intensive Care ward he was moved to the childrens ward where he started small doses of spironolactone and frusemide because his breathing had become a little laboured. He was on tiny amounts of oxygen and was not going to be allowed home until he was able to cope without it and was feeding well, and had lost all the excess fluid. By the time he had lost it all he looked very skinny! He was now being fed expressed breast milk via a naso gastric tube.

Facilities for parents at John Radcliffe hospital were fine. I was allowed to stay in my maternity room whilst Duncan was an in patient which was great as it was a single room with en suite. Colin could have taken a bed in a dormitory for parents attached to the childrens ward, which also had a kitchen and lounge, but either chose to go home or have a camp bed in my room.

After a further week we were transferred to Royal Berkshire Hospital in Reading - it was so nice to be able to go home at night occasionally! It was impossible after such a long time to get Duncan to breast feed - although believe me I tried - and he started to bottle feed, and eventually after a further week he managed without any oxygen at all. We were discharged on the first day Duncan actually gained weight when he was three weeks old.

Despite his dodgy start Duncan has now caught up and weighs 16lb 5oz at six months and looks very bonny. Feeding since discharge has never been a problem and he loves solid food. His heart is being monitored by a consultant at John Radcliffe Hospital and his drugs were stopped completely at three months with no discernable effect. I have never yet seen him go blue - touch wood. It appears that the hole between the pumping chambers of his heart is small enough to enable him to cope with it very well.

His heart operation is on hold. While he is developing well and showing few symptoms his consultant advocates leaving well alone



### *Instead of Christmas Cards*

I am writing to tell you how we managed to raise money and perhaps others can try this. I work in a local hospital and instead of buying Christmas Cards for all members of staff, we drew Christmas trees. To these everybody stuck one card addressed to everyone and they put in a box the money they would have used to buy cards. £100 was raised and due to the help you have given to us, we are donating the money to you. We hope you will be able to use it to help other parents.



Enclosed are pictures of Jessica, Molly & I with some of my colleagues. Jessica is nearly three and had open heart surgery when she was seven months old. She has survived many episodes of illness and lights up the lives of everyone she meets. She is our little ray of sunshine. Molly is sixteen months and has doubled our trouble and our joy.

**Fiona Drummond, Errol**

and monitoring every three months or so, allowing him to grow bigger and stronger. It may be that he doesn't have it until he is four - we have to wait and see how he copes as he gets more mobile. While we obviously want it fixed and it would be nice to get it out of the way, we are not looking forward to going through the trauma of an operation again.

In the meantime we are enjoying our beautiful baby boy. He has the most fantastic and infectious smile and is an absolute joy to us, our family and friends.

From listening to other people's experiences we have learnt that we were very fortunate to find out all about Down's Syndrome and Duncan's health problems before he was born, enabling us and the hospital staff to prepare for his birth in practical and emotional ways. It was a really joyous time in spite of the difficulties, and could so easily have been very different. We believe that all women should be offered a scan at 30 weeks as 20 weeks is too early to identify anomalies.

We have enclosed a photo of our darling. Fantastic isn't he?

**Kate Stonehouse. Reading**

**Printer Cartridge  
Recycling  
can earn funds for DHG**



*Did you know that empty laser, inkjet, fax and photocopier cartridges can be recycled for money?*

We can put you in touch with a company who will :

- supply free storage boxes for collection and return of used cartridges
- arrange free next day collection at your convenience when you have 10-15 cartridges for recycling
- send us a prompt and administration free payment for the cartridges you have saved

Could you have a box at home and ask neighbours and friends to give you their used cartridges?

Would your boss let you have a box at work? You could use it for the office printers and staff could bring cartridges in from home.

Perhaps your local school would consider having a box and letting parents know about the scheme?

*If you can help us raise funds in this way,  
please give us a call for more information.*

# Allira's Story

Allira Grace Bowhay was born on 1st August 2002. This little bundle of life was born by emergency Caesarean at Southend Hospital. I had gone to my local hospital for a routine ultrasound to check on her growth. My placenta had not been functioning effectively and so at 9.25am I was having an ultrasound and at 11.08am Allira was born. What a morning!!!



She was taken straight to the Special Care Baby Unit. For two weeks she stayed in an incubator and then her last week in Special Care she was in the normal hospital crib. She was very jaundiced and needed other treatment.

At 20 weeks pregnant - the usual scan had detected some form of heart defect. The ultrasound manager told us they suspected it was a hypoplastic left heart. The manager was a little reluctant to discuss this with us, instead referring us to the internet to do our own research. An appointment was made at Kings College Hospital for a foetal cardiac scan.

We were devastated. We went home and I remember just weeping. Both Stuart and I asked the usual - why us? It was not fair - how are we going to cope? Well I have learnt a lot since then and so far we have coped. We did a lot of reading in those few days and made some decisions. Regardless of the outcome, we were going to have this baby and fight for this life.

At Kings College, the cardiologist explained that there was a problem - I imagined the worst possible scenario, worse than what we had originally been told. However he explained that Allira had Atrial Ventricular Septal Defect (AVSD). He was most helpful in drawing diagrams to explain this condition. Basically our baby had no central wall in her heart and would require surgery. We had another scan a month later and again it confirmed the AVSD. As this defect is very common to children with Down's Syndrome we were also offered an amniocentesis. We decided not to have one, simply because it would not change the outcome. We were however given an anomaly scan to check how the baby was developing.

Two weeks after Allira was born we went to the Royal Brompton for an echocardiogram - there the AVSD was confirmed as being a complete AVSD with some valve damage. We were told a little about the operation and the rate of success. We were then told she would have surgery at 3-4 months old. Whilst there we were given a number of leaflets to read - including the one for the Down's Heart Group and some about her particular defect. These proved very helpful. We found it helped to take this information away and read at home where we were able to process the information

more fully.

A week later Allira was discharged from the Special Care Baby Unit of our local hospital. She came home with a nasal gastric tube, four hourly feeds and an apnoea monitor. Her medication consisted of Frusemide and Spironolactone twice a day. The thing I noticed the most was her hands, which due to her poor circulation were always cold. Stuart and I got used to seeing her looking blotchy, bluish, bloated with cold hands and feet. We had a film developed that contained pre and post surgery photos and it was amazing to see how good she looked post surgery.

I had a paediatric community nurse who would visit to change her nasal gastric tube although Stuart had to put the odd one in when she would pull it out. Allira had very little energy and rarely cried - if she did, she would summon up what little energy she had and shout once! The good thing was she liked to suck - her hands and her thumb when she found it. We were very lucky that she never lost that sucking reflex and we never really had a problem with Allira feeding. Allira continued to put on weight and fed well with her nasal gastric tube.

Two weeks after we had her home we got a call from the Brompton Hospital to tell us Allira had been scheduled for surgery on the 26th of September. We were surprised it was so soon. We had prepared ourselves for her to have this at 3 - 4 months old not 2 months old.

We contacted the Down's Heart Group and made use of their video which helped to prepare us for surgery. I was unable to watch it all the way through without crying and I wondered what impact open heart surgery would have on this little eight week old baby. However we found what we saw very informative and helpful.

Once at the Brompton we were informed the night before exactly what the surgery would entail, risks and outcomes. It seemed too much for a little baby to tolerate but we decided to go ahead with surgery. The next day at lunchtime she was taken to the operating theatre - we were able to walk down with her to theatre and stay until she was anaesthetised. What an experience - I found that upsetting but the next three to four hours were the worst.

We decided to wait in the hospital and we saw her return from surgery - it had taken about three hours and the surgeon was positive about the success. During that time we were taken on a tour of the ICU and spoke to some parents. We found this very helpful - it stopped us being so stunned when Allira came back from surgery with wires and drains out of her chest.

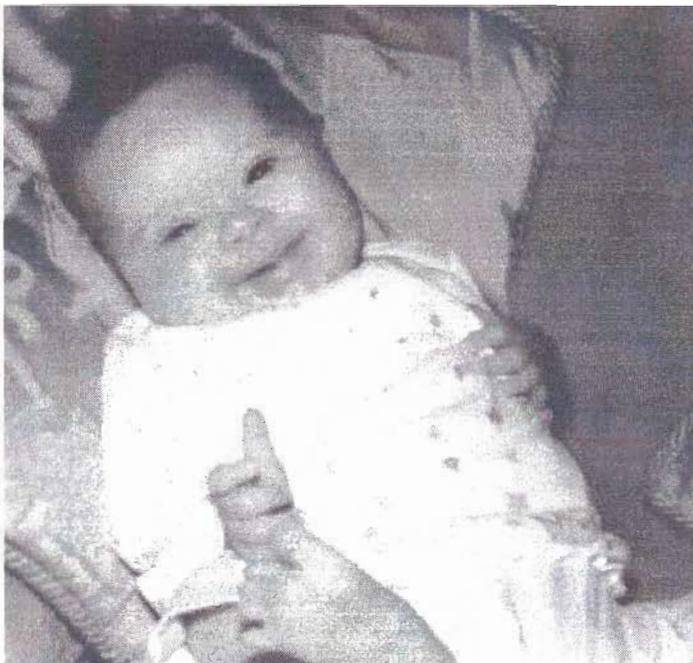
She stayed three weeks altogether in the Brompton - her surgery was complicated by the patch lifting which meant another open heart operation four days after the original one - this one took as long as the first. She then managed to have all the complications - fluid on her lungs that needed further drains as well as an air pocket which developed through her being moved so much with a chest drain. Once everything was sorted - she was out of ICU for the last time and home within four days.

In some ways I was glad that Allira was so young so that she really was not that aware of what was going on - sure she felt pain and cried but comparing her to other ones who come in and knew what was ahead of them - it was a little easier for me as a parent not having to explain it all to her ahead of time. Having accommodation in the hospital was so helpful though. Being able to pop and see her in the middle of the night if I was worried was great.

In the three weeks that Allira was in hospital I was given an insight

into the NHS and the workings of hospitals. The following advice would have assisted both Stuart and I immensely:

1. Never consider Doctors to know your child better than you. If something does not look right do not be afraid to speak up and keep speaking up until you are satisfied with the standard of care your child is receiving. Take your concerns to staff higher than the staff you are dealing with - your child's life may depend on it.
2. Don't be afraid to ask questions and continue asking until you are happy that you understand exactly what has happened and is happening with regards to your child's care.
3. Never assume all nurses are devoted to their work. There are some who are brilliant and are in fact in the right place doing the most amazing work with very little recognition. Value them -they are more precious than jewels.
4. Be prepared to basically assume care for your child once they return to the ward. If you are there - you do it. I found this frustrating as I just wanted to take Allira home and be back together as a family. This was made even more difficult as my husband had to go back to work and that meant leaving me in London for days on end. I found it hard without that support.
5. We found it important to be on the ward with Allira during hand over - that is when we learnt a lot. What sort of day she had had and what possible things could be faced in the hours to come.



Finally after three weeks in hospital, Allira came home. She was feeding from a bottle - no tube to obscure that cute little face. She took to the bottle with relish - sucking each one dry!!! She had a number of medications - Frusemide twice a day (for about eight weeks), Monogen (special formula) for six weeks, an iron formula that she needs to have for about three months and Captopril three times a day.

Allira had a check up at the Brompton about three weeks post discharge where she had an ECG, and echocardiogram and a chest x-ray. They were happy with her progress, however, it looks like she may need a further valve repair. We have a further check up in the New Year at the Brompton to check the state of the valve. We should have a clearer idea as to whether she definitely needs further surgery or not.

There have been so many changes post surgery - she can cry - BOY can she cry!!!! The one that is my favourite - she has warm hands. She is full of beans and is madly trying to do everything at once. She has made good progress weight wise and in terms of her development. She is feeding well and we have begun weaning at four months. She was so ready to move on to solids. We are taking it easy - just one feed of solids for the first month and then she moved onto breakfast and lunch of solids.

At this stage we have very few visits to the family doctor. She has been able to start her immunisation programme although we had to wait for six weeks post surgery before she could have any immunisations. She is a little behind others for that as her first lot were due the week she had her surgery.

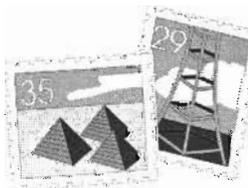
We are still only a small part through our journey with Allira but the difference post surgery is amazing. No doubt there will come a time when we will have to explain the scar on her chest and her limitations (if there are any), but for now she is just our little girl who is growing and developing every day before our eyes.

#### UPDATE

On the 9th of January we attended an outpatient's appointment at the Royal Brompton. We were not looking forward to this appointment as previously we were told that it was highly likely that Allira would need further surgery. I was not sure I would cope with this all over again.

Imagine our elation when we were told the moderately leaky valve was now a trivial leak and that she was looking 'fantastically brilliant' to quote the cardiologist. No more medicine, no operation in the near future and an outpatient appointment much closer to home in eight months.

*Lisa Bowhay, Danbury*



***We still want even more stamps!!!***

*Thank you to everyone who has sent in their postage stamps - especially those of you who didn't include a name and address. Christmas is a time when people get lots of letters, and this obviously prompted many of you to send them off to us as we received a steady flow of packets in the following weeks, and continue to do so.*

*On April 5th the 9 packets of stamps filled the postman's bag - thank you to the Grant family from Cleveland.*

*We have several groups and companies collecting as well as individuals so we are getting a good supply, but we could always use more! Why not ask your friends and neighbours to collect for us? Or what about your work or local school!*

*When you have a reasonable number, pop them in an envelope and post them off to National Office. (NB It's usually cheaper to split them up into smaller lots which can be sent 2nd class post, rather than one big packet which tends to cost more).*

# Alfie's Story

Alfie James Dickinson was born on 2nd September 1999 two weeks early after a pregnancy clouded in worry after the routine blood test showed a 1:20 chance of our baby being born with Down's Syndrome.

Alfie's dad, Mark and I were totally ignorant of what Down's Syndrome 'really' meant. We had negative ideas probably due to the fact that these children had in the majority been hidden away from normal, ordinary life in which we had been brought up.

After the birth and the quick diagnosis and confirmation that he had Down's Syndrome we were also told Alfie had a hole in the heart that would probably close in the short term. The term for his heart defect was an 'ASD' Atrial Septal Defect - many children have this defect and it goes undetected for many years.

A couple of months later I visited Alfie's paediatrician on my own and was told the hole had not closed and would need surgery to correct. This would probably be surgery through his groin and a device fitted to close the hole (a balloon device). I was shocked as, being such an optimistic person and the fact that Alfie had shown no symptoms of a heart defect, I really thought the hole would have closed. An appointment was made to visit the Freeman Hospital in Newcastle to have various tests.

At the appointment in Newcastle Mark and I were told the hole was about 16mm and would need open heart surgery to correct -

either to stitch the hole together or patch the gap between the two upper chambers. This operation would be best undertaken at a preschool age, simply to prevent Alfie missing any length of time away from school.

As Alfie approached 3 years old we visited the Freeman Hospital again and we were told the hole was actually about 23mm and we were asked whether we would like to get surgery over with earlier rather than later. Mark and I agreed we would.



Alfie's surgery took place on Friday 8th November 2002 at 10am and the great thing was that we only had a few days to prepare. We received a telephone call on 5th November to say there was a slot available and did we want it. 'Yes' we did although there were many natural emotions to contend with.

Alfie's surgery was very straight forward with no complications. The operation took approximately two and a half hours; he spent 24 hours in Intensive Care and then went to the Children's Ward where he and all the family were very well looked after. Mr Hasan was the surgeon and I knew Alfie was in very capable hands (Mr Hasan's handshake was the gentlest I have ever experienced too!).

Alfie had no post-operative complications and was home the following Wednesday morning (he could have actually been discharged the evening before if I had not left the hospital with my four and a half year old son Sam an hour before).

Alfie will miss nursery and playgroup for 2 weeks and swimming for 6 weeks. He needs to avoid anyone with an infection but basically does not need wrapping up in cotton wool (which he would not be happy with anyway). The only aspect I worry about is lifting him - we can't scoop him up under his arms at present and we must alert other family and friends to this.

We are so thankful to staff at the Freeman Hospital and his local Consultant Paediatrician, Dr Wyllie, at Middlesbrough for regular check-ups.

Mark and I certainly have not come across any form of discrimination from any medical, educational or social fields which makes us very happy.

Alfie is a cheerful, endearing young man who never complains and his family are pleased this important chapter of his young life is over.

**Linda Dickinson, Middlesbrough**



Many thanks to everyone who supported our work by buying their Christmas Cards and stamps from us. Thanks to your combined efforts we sold 8600 cards, 39 mugs, 1476 first class stamps and 5148 second class stamps, which resulted in a profit of £2300.

- *Our treasurer Phil Thorn once again beat all the other Committee members with sales of 1000 cards, 300 first class and 600 second class stamps.*
- *And member John Carter was once again our most successful salesman with sales of 860 cards and 200 first class stamps.*

We are especially grateful to all those people who rounded up their payments to include a donation. Including the tax we can reclaim from those who Gift Aided their donations, these amounted to £975.53.



# *Travel Insurance advice for people with Down's Syndrome and a heart condition*

We are often contacted by members who are having trouble obtaining travel insurance due to their child's heart condition, so we have done some research and now have a list of companies that should be able to assist.

Obviously availability and cost will depend on individual circumstances, and it is worth contacting a few different companies to see who offers the best policy for your requirements and the best price. Most companies will need full information about the heart condition of the person with Down's Syndrome, and may request a letter from the cardiologist.

This is a list of companies that we understand offer cover for preexisting medical conditions. We cannot recommend any of them and would be glad to hear comments from anyone who uses their services.

**WARNING** - Some Insurance Companies take on new policies without asking medical questions, relying on a clause in the small print which says that they will not cover preexisting medical conditions. Please be aware that under such a policy, any claim as a direct or indirect result of your child's congenital heart disease would not be honoured. In such cases it is irrelevant whether you were accepted (disclosing existing illness) and have paid the premium.

All existing medical conditions **must** be disclosed and accepted by insurance underwriters for you to be fully covered.

To travel abroad without Insurance that covers you for preexisting medical conditions could be catastrophic financially. For instance, if **you** had to pay for an Air Ambulance to get you home from Spain you would need a minimum of £8,000.

If someone is taken ill whilst abroad, the Medical Emergency Service will contact their doctor to check their medical conditions before confirming payment for hospital treatment or repatriation.

If you have a non travelling sick relative, you may not be covered if you have to cancel or cut short your holiday due to their illness.

An E111 certificate does **not** cover cancellation of your holiday or the cost of getting you home.

All members of your party should be covered under one policy. If you split cover because of one person's preexisting medical condition it will affect the Cancellation cover for the other members of the party.

All Clear Plus  
6 Floor  
Regent House  
Hubert Road  
Brentwood  
Essex  
CM14 4JE  
Tel : 08707779339

Direct Line  
Tel : 08452468704

Free Spirit  
Stanstead House  
Rowlands Castle  
Hampshire  
PO9 6DX  
Tel : 01483255888

Holiday Services  
1 Charnwood Drive  
Ripley  
Derby  
DE5 3NB  
Tel : 01773747426

Leisurecare Insurance  
107a High Street  
Cricklade  
Wilts  
SN6 6AE  
Tel : 01793750150

Medicover  
Medical Screening  
P O Box 142  
Alton  
Hants  
GU34 3LX  
Tel : 08707353600

Tesco  
Tel : 08453008800

Venture Sure  
68 High Street  
CHISLEHURST  
Kent  
BR7 5AQ  
Tel : 0208 295 1234

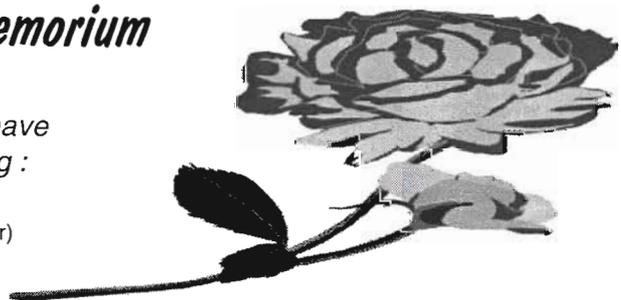
Worldwide Travel  
Business Centre  
1-7 Commercial Road  
Paddock Wood  
Tonbridge  
TN12 6YT  
Tel : 01603487699

## *In Memorium*

*Since our last newsletter, we are very grateful to have received donations in memory of the following :*

**Daniel Merchant** - Aberystwyth (who appears on our front cover)

**Amy Wild** - Farnham



# Family Fund Information and Publications

Hopefully all our members are aware of the existence of the Family Fund who can provide grants for families living in the UK and caring at home for a severely disabled or seriously ill child.



## Family Fund

They can give grants related to the care of the child, for example:

- clothing and bedding
- driving lessons
- holidays and outings
- transport expenses, moving home or hospital visiting costs
- washing machines, tumble dryers and fridge freezers

There are certain criteria that families must meet to qualify for a grant, but provided they continue to do so, they can apply again once each year.

A leaflet giving a description about how the Fund can help and how to apply including an application form is available on the Family Fund website at [www.familyfund.org.uk](http://www.familyfund.org.uk) in:

- Arabic, Bengali, Chinese, Gujarati, Hindi, Punjabi, Russian, Spanish, Turkish, Urdu, Vietnamese, Welsh
- Large print

### Information Sheets

The Family Fund also has a number of helpful Information Sheets which are available at no cost to parents and carers. These are available to all families even if those who do not meet the grant criteria.

#### Bedding and clothing

Information about help with continence supplies, special clothing for children with physical disabilities and addresses of advice and information agencies.

#### Behaviour and attention difficulties

Information about sources of support available from professionals, voluntary organisations and parents groups to parents and carers of children with behavioural and attention difficulties.

#### Benefits checklist

Details of benefits and other financial help for disabled children and their carers. Updated every year in May.

#### Education

Information about special educational needs, where to get advice, information and publications, and useful guide to 'Ed-speak'.

#### Equipment

Includes details of how to get equipment for daily living, health care equipment, buggies and wheelchairs. It gives information about the Fund's policy on equipment and lists a number of organisations who give information and advice.

#### Holidays

Information about arranging holidays for families with disabled children with sources of advice and information.

#### Transport

Details of help with transport, cars, adaptations, wheelchairs, access, and information and advice agencies.

#### Taking Care (126 pages) July 2002

Based on research about how families cope with caring for a severely disabled child, this book was written by and for parents. It contains a useful Resource Directory with information on how to get in touch with services, laws relating to disabled children and useful books and organisations.

#### Your life, your future

A brief, lively guide to opportunities and choices for young disabled people including sections on planning for the future, speaking up for yourself, getting support and lots more.

#### After 16 — what's new? Choices and challenges for young disabled people is available online at [www.after16.org.uk](http://www.after16.org.uk)

This website gives details of the opportunities and services available to young disabled people in the UK after leaving school. It provides detailed information on getting your views across, money, learning choices, daytime activities and work, housing, getting around, health, leisure and holidays, friends and beyond, you and the law.



## I Dreamed

*I dreamed he'd be born beautiful and healthy.  
He was.*

*I dreamed he'd tell me that he loves me.  
He tells me every day.*

*I dreamed he'd be bright and funny.  
He is - his humour is wonderful.*

*I dreamed he'd ride a bike, catch a ball and  
wrestle with his big brother.  
He does and his brother loves it.*

*I dreamed he'd have big birthday parties with  
lots of friends and cake and presents.  
He's had six.*

*I dreamed he'd one day get on a bus and go  
to kindergarten.  
He did it yesterday - my heart full of love and  
my eyes full of tears.*

*I dreamed he'd make us proud.  
He has and he's inspired us.*

*Dean has Down Syndrome.  
I never dreamed that.*



**Amy H. Opalk**

## Oxygen/Air Products Information



*This very useful article appeared in the Spring 2003 newsletter of the Pulmonary Hypertension Association UK.*

For those of you needing oxygen and organising a holiday, either in Britain or abroad, it is a big challenge. However, that need not be so, there is a way of organising oxygen and concentrators with very little work on your part and at a reasonable cost.

Air Products have been providing a service, in which they arrange for delivery of a concentrator and all your oxygen requirements to your holiday destination.

Their service includes:

- Arrange for oxygen to be made available at your hotel or apartment
- Choice of liquid, gas or concentrators
- All the disposables you need
- Provide a contract with the local supplier

*The Holiday Oxygen Service is available throughout the UK and Eire. They also provide holiday oxygen rental in some areas of Spain, France, Germany, Portugal, Belgium, Italy and South Africa. To take advantage of this service call Air Products on free phone 0800373580, they will send you a pack that includes leaflets with advice on living with oxygen therapy, going on holiday with a lung condition and a list of airlines who supply oxygen and the cost. It also includes an order form, price list and VAT relief declaration.*

## Mosaic Down Syndrome

The UK Mosaic Down Syndrome Association has a new website and support group for parents of children with Mosaic Down's Syndrome. Besides email support they have an online chat every Sunday night. For more information visit their website

[www.mosaicdownsyndrome.org](http://www.mosaicdownsyndrome.org)

The International Mosaic Down Syndrome Association are looking to recruit volunteer new parent contacts who can assist parents of children with Mosaic Down Syndrome. Their online membership at present stands at 150 and they are looking to increase this. For more information please visit

[www.mosaicdownsyndrome.com](http://www.mosaicdownsyndrome.com)

**N.B.** Very similar URL's so please read carefully.

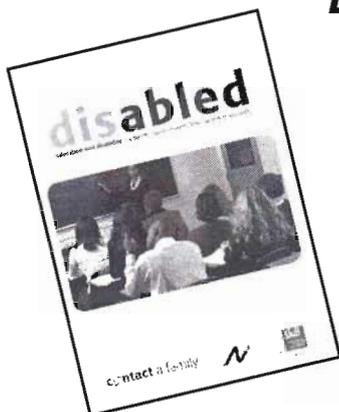


## 8th World Down Syndrome Congress

1 - 5 October 2003  
Singapore

*"Down Syndrome :  
Global Progress in a Changing Era"*

more info at [www.downsyndrome-singapore.org](http://www.downsyndrome-singapore.org)



## 'Disabled - education and disability - a parent's guide to rights from nursery to university'

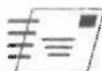
*a new publication from Contact a Family*

Families can contact the Freephone Helpline for a free copy on:



**0808 808 3555**

between 10.00am and 4.00pm Monday to Friday



**helpline@cafamily.org.uk**

Minicom: **020 7608 8702**

Please note that as the pack was funded by the Department for Education and Skills in England, some of the information relating to special educational needs does not apply to Scotland, Northern Ireland or Wales. Contact a Family have unfortunately been unable to secure funding for a similar publication for the nations.

For education advice in Scotland, Wales or Northern Ireland, please either call the Helpline or contact their national offices:

Scotland 0131 475 2608 [scotland@cafamily.org.uk](mailto:scotland@cafamily.org.uk)

Wales 029 2049 8001 [wales@cafamily.org.uk](mailto:wales@cafamily.org.uk)

N. Ireland 028 9262 7552 [nireland@cafamily.org.uk](mailto:nireland@cafamily.org.uk)

## Fund Raising Coffee Morning

Leading up to Christmas 2002 our office Staff Penny and Lynda were invited to the Hamilton Court retirement complex in Leighton Buzzard, where Lynda's father, Ted Watson, has been a resident for the last five years.

Organisers Christine Taylor, Peg Jackman and her husband Peter are very active charity supporters and regularly take the opportunity of turning the weekly coffee morning into a fund raising event. Hamilton Court has been collecting stamps for us and it was suggested that perhaps the Down's Heart Group could benefit from one of their gatherings.

About 30 of the residents came to the coffee morning where gifts had been collected by Peg, Christine and Peter. Raffle tickets were sold during the morning and a variety of prizes

ranging from vouchers for the local Butcher, books, toiletries, food hampers and of course the obligatory cuddly toys were won by delighted participants.

A thoroughly enjoyable morning was had by all and it gave Hamilton Court a chance to meet Penny and Lynda and put faces to the Charity they have supported for several years. It proved to be a very successful fund-raiser and a total of £118.50 was made from the raffle and donations, together with the profit made from selling packs of our Christmas Cards and stamps.



### Flora Light Challenge for Women

This year's Flora Light takes place on Sunday September 14th at 10.30am. As well as the previous venue of Hyde Park, London, this year there will also be a race in Birmingham City Centre.



Some of our year 2000 entrants with Tom Pow who inspired them to take part. Sadly Tom died last year, and is sadly missed.

This is a 5 kilometre fun run ... or walk ... for women, and has previously been a successful fund-raiser for the Down's Heart Group. Entry costs £12 of which £5 goes to your chosen charity, and you also get a finishers goody-bag which includes a finisher t-shirt and medal.

If you would like to be part of the DHG team, please contact National Office for one of our Official Entry Forms and sponsor forms - there is no minimum required sponsorship, every little bit helps! **Places are limited so give us a call soon!**

## Awareness Fortnight

2nd - 15th June 2003

The beginning of June sees two very important awareness weeks for our members.

**2nd - 8th Jun  
Down's Syndrome Awareness  
Week**

and

**7th- 15th June  
Heart Week**

This year the British Heart Foundation will be focusing on congenital heart disease during heart week, so both weeks are of particular relevance to the Down's Heart Group.

So why not hold a coffee morning fund-raiser some time during the two weeks and help raise awareness and some funds for the Down's Heart Group.



## TSG on the ball helping children hit by 'double whammy'

Sincere thanks have been given to TSG(5) for a successful charity event that raised over £4,000 to help families of children with Down's Syndrome and heart problems.

Organised by Sergeant Paul Turney, a Charity Summer Ball saw numerous London businesses and TSG officers give their support by buying tickets or offering goods and services for auction.

Sgt Turney said the idea to fundraise for independent charity, the Down's Heart Group, was due to the support and care they had given to former TSG officer PC Gary Lawless.

### Valuable

"Gary's son Hugh has had numerous operations since birth and we all know that the group were very supportive of him and his family," said Sgt Turney.

"From his personal experience

we knew we were helping a charity that does extremely valuable work."

Raffle ticket sales and the auctioning of goods such as a DVD player donated by Tesco or rides on the London Eye, raised £4,585.48.

"We had expected to raise around £2,000 but everyone was bidding very high and really got behind the fund-raising on the night," said Sgt Turney.

Chair of the Group, Cliff Lake, was overwhelmed by the amount raised - the most substantial single donation received in their 13-year history.

Mr Lake said the money was "absolutely marvellous" and would directly benefit work to support the parents of babies who are diagnosed as seriously ill.

"Parents receive a sort of double whammy," he said.



"They not only find out their child has Down's Syndrome, but that they have a life-threatening heart disease.

"Cardiac conditions fall into many complex categories and part of our work helps make the information as simple as possible to understand."

The group also supports parents whose children have inoperable heart defects as well as bereaved parents.

Funds will be used to produce a video for people with Down's Syndrome and a cardiac condition.

Sgt Turney gave his personal thanks to everyone who contributed and made the event such a success.

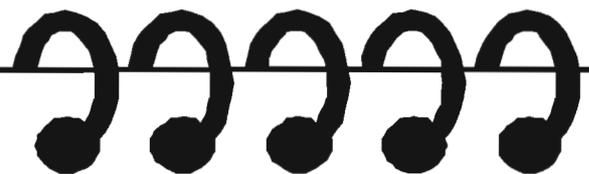
*This article by Elizabeth Collins appeared in the November issue of 'The Job', the newspaper for the Metropolitan Police Service.*



### London Marathon 2003

All eight of our runners in this years London Marathon on Sunday April 13th finished the 26 miles, and I am sure that you will want to join us in thanking them for all their efforts on behalf of the Down's Heart Group.

We look forward to reporting on their success in the next newsletter.



### 3 Peaks Challenge

*Does the idea of climbing Ben Nevis, Scarfell and Snowdon within 24 hours and at the same time raising funds for the Down's Heart Group appeal to you?*

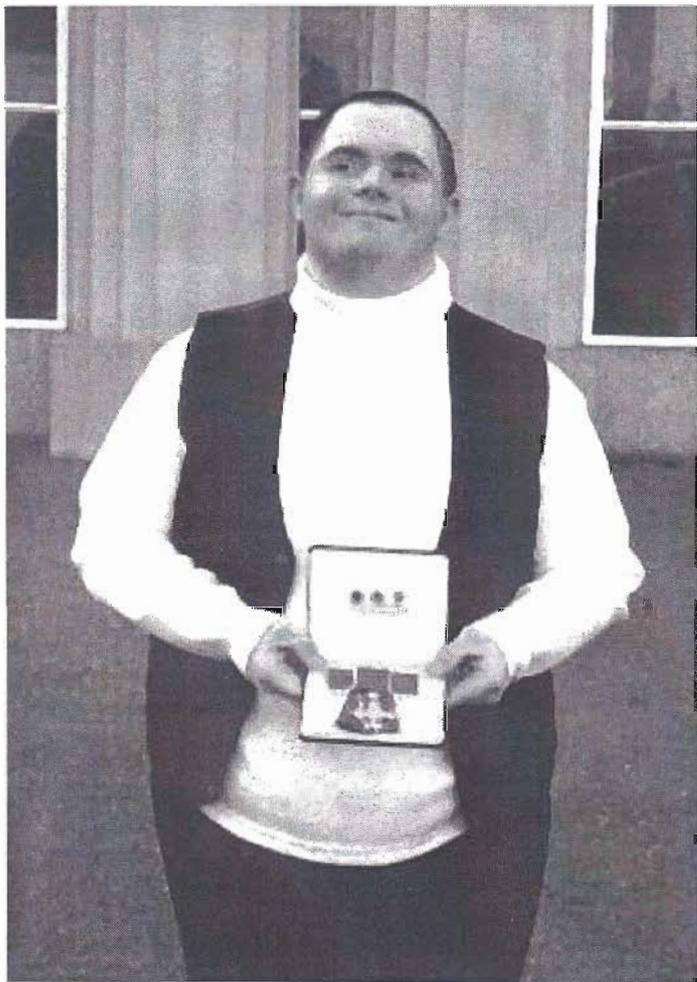


We have been approached by a supporter who would like to organise a 3 peaks challenge for next year, and we need to hear from anyone who would like to take part or to help with the planning or on the support team. Please contact Penny at National Office on 0845 166 8061 for further details.

# Your Letters

Dear Down's Heart Group,

I have been a reader of the Newsletter for many years and admired greatly the children/young adults whose bravery and perseverance is told over and over again. This has prompted me to write to you with a story about my own son, as although it is not a medical story, I felt it needed to be told and might perhaps bring him a little of the admiration I believe he deserves.



I have three sons, two in their thirties, who have given me five lovely grandchildren between them, and then my youngest, Nicky. He is 21, has Down's Syndrome and although he has had heart surgery in the past, as I said before, this is not a medical story.

Ever since Nicky was 2 years old I have been involved with working with children with special needs. Firstly at Addington Special School in Woodley - the school that Nicky himself attended until he was 19. I have been a classroom assistant there, had a stint as a Governor and for many years was chair of the school's Parents/Friends Association.

Simultaneously I began to work for Reading Mencap, driving their Sunshine Coach (a period which lasted some 15 years) and organising their Easter and Summer Playschemes, as well as serving on the main committee (a post that I still have). Being a single Mum, the commitment has sometimes been difficult, but with the support of my family and friends I have been able to offer help to many of our parents/carers who sometimes find their lives a little difficult.

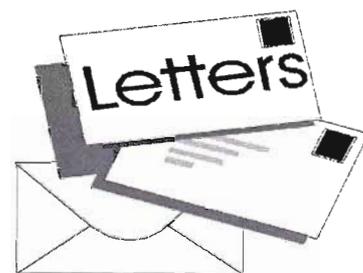
To cut a long story short, in 2001 I was very honoured to be awarded an M.B.E. in the Queen's Birthday Honours list for my work with children with special needs, and whilst I am treated as a star by many as a result, I feel that Nicky is the real star. He has spent much of his childhood helping at jumble sales, fayres, collection days, playschemes and attending meetings etc. and never once has he complained or moaned, just amused himself quietly and accepted that this was his way of life.

As you can see from the photograph, he was the proudest of all when I received my award. And the M.B.E. I collected last December was for him as much as for me. HE REALLY IS NO 1 IN MY EYES...AND THE BIGGEST STAR OF ALL!

I hope you feel you can publish a little of this story. I know it would make Nicky extremely proud and happy to see his name in a nationwide publication.

Keep up the good work you all do - you bring a lot of joy and comfort to a lot of people

**Barbi Takyar M.B.E.**  
**Reading**



## Let us have your contact details

We quite often get offers of DISCOUNTED or FREE tickets to places and events, but we need to contact members very quickly.

If you want the chance to be included in events like these, please ensure that we have up to date contact details for you.

**TELEPHONE - MOBILE - EMAIL & of course ADDRESS**

# Developments affecting Paediatric and Congenital Cardiology

This item appeared in the Children's Heart Federation Update, in response to the publication of the report of the review of Paediatric and Congenital Cardiac Services.

## Does size of units matter?

The Paediatric and Congenital Cardiac Services Review Report recommended standards of a minimum number of procedures (both surgical and catheter) that centres should carry out. The reasons for these proposals are:

### Each centre should have a minimum of three cardiac surgeons performing congenital procedures.

It is understood that professionally it is considered that on average a minimum of two paediatric operations a week should be undertaken to maintain skills and avoid occasional practice. While there has been no formal survey anecdotal evidence suggests that parents when asked 'What experience do you think the surgeon operating on your child should have had?' usually quote at least two operations a week. If centres undertake less than 300 operations either the standard of three surgeons or that of minimum of two operations a week would be compromised.

Surgeons should avoid occasional practice and devote a minimum of four operating sessions a week, on average, to the congenital service. While no numbers of operations are quoted in this standard it would be reasonable to think in terms of at least three per week from four sessions. This standard related to both paediatric and adult congenital.

Where a centre has a programme of open-heart procedures on children under one year, at least two of the surgical consultants should be significantly involved with the programme and the centre should perform a minimum of 80 such procedures per annum on average. National statistics show that the ratio of open to closed procedures is about 3:2 (ie for each three open heart operations undertaken by a unit on under ones they will, with an average population undertake two closed operations.) This means that the minimum of 80 open operations will be accompanied by 53 closed, totalling 133 operations.

National statistics show the ratio of all operations on under ones compared with over ones is about 5:4 (ie for every five operations on under ones there will be four operations on over ones). This means that 133 operations on under ones will be accompanied by 106 operations on over ones, totalling 239 operations.

The recommended standards are:

- Each centre providing a paediatric surgical service should carry out a minimum of 300 paediatric surgical procedures per annum, on average, sensibly distributed between the surgeons to avoid occasional practice.
- Each centre should have a minimum of three cardiac surgeons performing congenital procedures.
- Where a centre has a programme of open-heart procedures on children under one year, at least two of the surgical consultants should be significantly involved with the programme, and the centre should perform a minimum of 80 such procedures per annum on average.
- Surgeons should maintain results within an acceptable range of UK average demonstrated by the ongoing national audit of surgical procedures.
- Surgeons should avoid occasional practice, and devote a minimum of four operating sessions per week, on average, to the congenital service.

The Government is not persuaded that these standards are necessary, as all surgical results in centres are acceptable and counter-propose:

- Set the number of minimum procedures at 100 - which would serve as an indicator that a given unit might be approaching the limits of safe surgery and that action should be taken to ensure that a sufficient level of each procedure was being performed to ensure surgical safety
- Set no minimum standards and rely on the combined effect of the other standards to assure quality and safety
- Continue with all centres operating as now but underpinned by the audit system the Review Group recommended to ensure high standards are maintained and that any significant variations within the outcome range were investigated through peer review to ensure the high standards continue.

## National surgical procedures

This table shows the average number of paediatric cardiac operations per centre per year over the period 1998/99, 1999/2000, 2000/01. The figures in the table have been averaged over three years. Due to rounding some rows do not sum.

Unit	Total Open	Total Closed	All Operations	Number of Consultant Surgeons
Great Ormond Street	386	132	517	4
Brompton	301	117	419	3
Guy's and St Thomas	205	62	268	2
<b>South East</b>	<b>892</b>	<b>311</b>	<b>1204</b>	<b>9</b>
Birmingham	383	85	468	2
Leicester	101	73	174	2
<b>Midlands &amp; East</b>	<b>484</b>	<b>158</b>	<b>800</b>	<b>4</b>
Liverpool	231	131	362	1
Newcastle	93	62	155	2
Leeds	180	56	236	2
<b>Northern</b>	<b>504</b>	<b>249</b>	<b>753</b>	<b>5</b>
Bristol	143	70	213	2
Southampton	148	59	208	2
Oxford	71	45	115	2
<b>Southern &amp; West</b>	<b>362</b>	<b>185</b>	<b>537</b>	<b>6</b>
Belfast	61	22	84	2
<b>TOTALS</b>	<b>2303</b>	<b>914</b>	<b>3219</b>	<b>26</b>

## Rationalisation of catchment areas

During the Review it was found that the geographical coverage of the paediatric cardiology centres has developed piecemeal. For example, 20 District General Hospitals have more than one centre running outreach clinics, and there are more than thirty outreach clinics held by centres which are outside their natural catchment area. The areas in which the centres will be responsible for the clinical network need to be defined. It needs to be clear who is responsible for standards of patient care and family support in each area, services should be accessible, and resources should be used to best effect. Rationalising catchment areas will assist with ensuring the viability of the maximum number of centres.

The proposed standards are:

- Specialist centres should work with local paediatric or cardiology services so that as much cardiac diagnosis and care as possible is provided in a network of locally accessible outreach services. The patient and family should be asked to travel to the specialist centre only when essential.
- Each specialist centre should provide outreach clinics in a planned network of designated paediatric and cardiology units within a defined geographical area.

## National Contacts

### National Office



Email : [info@dhg.org.uk](mailto:info@dhg.org.uk)  
Website : <http://www.dhg.org.uk>

Contact or Ansaphone always available (24hrs in emergency)

<b>National Administrator</b>	<i>Penny Green</i>
<b>Admin. Assistant</b>	<i>Lynda Hale</i>
<b>Founder</b>	<i>Linda Walsh</i>
<b>Chair</b>	<i>Cliff Lake</i> [Redacted]
<b>Vice-Chair</b>	<i>Chris Stringfellow</i> [Redacted]
<b>Treasurer</b>	<i>Phil Thorn</i> [Redacted]
<b>Secretary</b>	<i>Position Vacant</i>
<b>Legal Advisor</b>	<i>Brian Auld</i>
<b>Policy Advisors</b>	<i>Sister Mary Goodwin</i> <i>Dr. Rob Martin</i> <i>Dr. Claus Newman</i> <i>Dr. Phil Rees</i>
<b>Patrons</b>	<i>Sarah Boston</i> <i>David Graveney</i>

**LETTERS AND ARTICLES REPRODUCED  
IN THIS NEWSLETTER EXPRESS THE  
OPINIONS OF THE AUTHORS, AND ARE  
NOT NECESSARILY REPRESENTATIVE OF  
THE VIEWS OF THE DOWN'S HEART  
GROUP.**

## Regional Contacts

**For your information details of our regions  
are given below.**

### **Bristol & South West**

Avon, Cornwall, Devon, Gloucs, Somerset & Wilts

### **East of England**

Cambs, Lincs, Norfolk & Suffolk

### **East Midlands**

Derby, Leics, Notts & Northants

### **Ireland**

N. Ireland & Eire

### **North East**

Cleveland, Cumbria, Durham, Isle of Man & Tyne & Wear

### **North West**

Anglesey, Cheshire, Clwyd, Gtr. Manchester, Gwynedd,  
High Peak, Lancs & Merseyside

### **Oxford**

Berks & Oxon

### **Scotland**

Mainland & Islands

### **South East**

Beds, Bucks, Essex, Herts, Kent, Middx, Surrey, Sussex  
& London

### **South Wales**

Dyfed, Glamorgan, Gwent & Powys

### **Wessex**

Channel Islands, Dorset, Hants., Isle of Wight

### **West Midlands**

Hereford, Worcs, Salop, Staffs, Warwick & W. Midlands

### **Yorkshire & Humberside**

Humberside & All Yorkshire

For other information about Down's Syndrome, you might like to contact:

The Down's Syndrome Educational Trust  
The Sarah Duffen Centre  
Belmont Street  
SOUTHSEA  
Hants.  
PO5 1NA  
02392 824261

Down's Syndrome Association  
155 Mitcham Road  
Tooting  
LONDON  
SW17 9PG  
02086 824001  
(Regional offices in Wales, Midlands  
and N. Ireland)

Down's Syndrome Scotland  
158 - 160 Balgreen Road  
EDINBURGH  
Lothian  
EH11 3AU  
0131 3134225

Down's Syndrome Ireland  
41 Lower Dominick Street  
DUBLIN 1  
EIRE  
00 353 1 873 0999