



DOWN'S  
HEART  
GROUP

# NEWSLETTER

( Issue No 19 )

## AUTUMN 1998



Another of our video stars, Oliver Hellowell - read about him inside

# Contacts

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# Chairman's Report

## Annual Conference 1998

Well, another Annual Conference has come and gone and I am sure that all those who came along to Sketchley Hill Primary School near Leicester had a thoroughly enjoyable and informative day. The venue was tailor made for us, the weather was glorious, the speakers were experts in their subject and the workshops provided an opportunity for small group discussion and some intensive working on particular issues.

Many congratulations to Sarah Smith our East Midlands Regional Co-ordinator and all her helpers for her impeccable organisation of the whole event.

You can read summaries of some of the sessions in this edition.

## Annual Conference 1999

We are returning to the South Coast in 1999 and have been very fortunate to have secured the use of the Sarah Duffen Centre in Portsmouth, with which many of you will be familiar, as our venue. The Sarah Duffen Centre is part of the University of Portsmouth, and is an internationally renowned centre for research and practice into the development of children with Down's Syndrome. We hope to have contributions by Sue Buckley and Ben Sacks and have also persuaded Nick Archer, Consultant Paediatric Cardiologist at the John Radcliffe Hospital, Oxford to talk to us about the health and medical problems of people with Down's Syndrome.

Make a note in your diary now of the date - 24 April 1999 and look out for further information in our next edition.

## DHG Video endorsed

We thought we had made a good job of our video Heart Problems in Children with Down's Syndrome, and that has now been endorsed by professionals and parents who have viewed it.

We sent out an evaluation form with the 600 copies we have so far distributed asking viewers how well they thought we had met the five objectives we had set for the video. Of the forms returned to date the results are:

Exceptionally well	28%
Very well	54%
Satisfactorily	16%
Not well	1%
Not at all	0%

Worth an A\* grade I would say!

## Chronic Cardiac Conditions

Talking of surveys we are very grateful for all those families with a member with a chronic cardiac condition who returned our questionnaire seeking views about the meeting(s) we are planning to bring these families together, along with outside experts. This has provided us with much useful material on which we can plan a programme. To avoid families having to travel during the winter, and given our crowded programme over the next few months, we have decided to hold these sessions in May/June 1999. Families will be sent further details nearer the time.

## Hospital Visitors

One of our upcoming events is a another training course for hospital visitors. A number of new volunteers have been selected to attend the course and this will be combined with a refresher for existing visitors, to be held in Sussex on 20/21 November.

## Success brings its problems

A combination of increasing numbers of hospital visitors and the publicity resulting from the video and our Topic Notes, means that we are receiving many more enquiries for information and requests to provide speakers, from all sources. This follows through in increased applications for membership. In the first six months of this year we had more new members than the whole of 1997, so we must be doing something right!

In fact we are the victims of our own success as once again we are finding it difficult to keep up with demand with our limited staff and small committee. We are looking at ways of overcoming this and I would make my regular plea that if you work for a company which has a charity fund or budget please let us know as we find that companies and trusts are much more receptive to applications for financial assistance where there is some contact through their employees.

# CHRISTMAS CARDS



This years card was designed by 24 year old Natasha Grange from Romford

**We hope that you like her teddy bear and will help support the  
Down's Heart Group, and raise awareness of our children  
by buying and sending Down's Heart Group cards this year**

Cards are available in packs of  
**10 at £2.15p or 50 at £9.50p**  
**(including p&p)**

and for those who haven't had cards in the past we have limited stocks  
of cards from previous years and can offer you mixed packs  
featuring five different designs (subject to availability) at the same value price

AND

we can also supply books of stamps with your order  
with the profit coming to the Down's Heart Group

There is an order form on the back page of this newsletter

*Please contact us if you would like a sample card and one is not enclosed*

**Prices for overprinting with your own message are available on request**

# Regional Contacts

## Bristol & South West

Avon, Cornwall, Devon, Gloucs., Somerset & Wilts

Sheila Forsythe



Wendy Hellowell



## East of England

Cambs., Lincs., Norfolk & Suffolk

Nicola Desmond



Lindsay Wharam



## East Midlands

Derby, Leics., Notts. & Northants.

Sarah Smith



## Ireland

N. Ireland & Eire

Rosina Brierley



(Dublin Hospital Visitors)  
Marion Delaney



Julie Keating



## London Northern

Beds, Berks, Bucks, Essex, Herts, Middx, Oxon & N. London

(GOS Hospital Visitor)  
Sheila Boniface



(Harefield Hospital Visitor)  
Joanna Simms



## London Southern

Kent, Surrey, Sussex & S. London

Katie Spall



(Guvs Hospital Visitor)



## North East

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

Sally Hardman



## North West

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

Mike Halpin



## Scotland

Mainland & Islands

(Glasgow Hospital Visitor)  
Elaine Thomson



## South Wales

Dyfed, Glamorgan, Gwent & Powys

Chris Stringfellow



## Wessex

Channel Islands, Dorset, Hants., Isle of Wight

(Southampton Hospital Visitor)  
Vickie Richardson



## West Midlands

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

Lynne Holden



## Yorkshire & Humberside

Humberside & All Yorks.

Lindsay Allen



(Leeds Hospital Visitor)  
Carolyn Marshall



If you experience any difficulty in contacting someone locally, please get in touch with our National Office who will be able to help you.

**PLEASE HELP US**  
by saving stamps, postcards, ring pulls and Greetings cards

*We have volunteers who are collecting all the above to fund-raise on our behalf, but they need your help!*

Please save used postage stamps (cut neatly from the envelope), postcards (used and unused), ring pulls from drink cans and old greetings cards (just the front picture).

Details of where to send them can be obtained from National Office.

**THANK YOU**

## Oliver's Story

On 5th July 1996, I was lucky enough to give birth to our beautiful baby boy, Oliver Patrick Hellowell. Within twenty four hours we were told he had Down's Syndrome. All the joy of having a new baby was swallowed up by our shock and disbelief, and we were left devastated and heart broken.

I left hospital with Oliver almost straight away. I wanted to come home, to be safe, secure, surrounded by familiar things and to be with my husband Michael and my daughter Anna. We all adored Oliver from the moment he was born and finding out about the Down's Syndrome just made us love him all the more. I immediately decided I would not return to my part-time job and set off to find out everything I possibly could about Down's Syndrome.



**Oliver with big sister Anna before his surgery**

Oliver was not gaining weight very well and a heart murmur was detected when he was five weeks old. At first it was thought surgery was not necessary, but Oliver began struggling with feeding and at two months old after an echocardiogram, we were told he was going to need open heart surgery to correct the three heart defects he had. (An ASD, a VSD and a PDA.)

I began to feel as though I was drowning - how much more could there be? I found myself in tears often and found the thought of our little baby going through this surgery quite unbearable. During the following weeks Oliver deteriorated and found feeding more and more difficult and his breathing rate quickened. Normal bottles became too hard for him as he took too much air, and I found the 'disposable' Avent set invaluable. They have disposable plastic inners which hold the milk and contract as the milk is removed. Oliver managed to drink from these thank goodness, even though it took longer and longer.

At one point when Oliver actually lost weight rather than 'not gaining', we were given Eoprotein as a supplement to add to his milk. This is normally added to breast milk, but as I had trouble expressing, we added it to SMA Gold formula milk and it still worked a treat. Oliver put on seven ounces in ten days which was more than he'd ever managed. Two weeks later at three and a half months old he had his surgery at Bristol Children's Hospital. He was so thin and so frail, yet so very precious.

After three and a half hours in theatre, four days in Intensive Care, and four days in the baby unit we were allowed to return home. His recovery and weight gain had to be seen to be believed. At seven and a half months old, Oliver is a delight to all of us. He is strong, alert, active, happy, beautiful, and extremely chubby! The staff at the Bristol Children's Hospital were all very supportive and caring, and we are very grateful for Sheila Forsythe's support and visits on behalf of the Down's Heart Group.

We know how lucky we are, and we are thankful.

**Wendy Hellowell  
Bridgwater**



**Oliver after recovering from his operation**

*Those of you who have seen the Down's Heart Group video "Heart Problems in Children with Down's Syndrome" may well recognise Oliver as one of our young stars.*

*All Cardiac Units, Paediatric Units and Child Development Centres should by now have received their free copy of the video. If you know of one that hasn't please ask them to contact us to obtain one.*

*The video is also available for members to borrow free of charge, please ask for details.*

# Lauren's Story

Lauren Ferguson arrived on the 24th of September 1994, a day I will never forget, and even today it still feels as if it all happened only yesterday.

I was only twenty when I had Lauren, and already had a son Mathew who was two years old. I didn't have a great pregnancy with Lauren, I was so tired and ill in the first few months and also had two threatened miscarriages. When I was about twenty four weeks into my pregnancy for some strange reason I read a bit about Down's Syndrome, not much but enough.

I went into labour five days early, the staff at the hospital said I wasn't in labour but I was constipated and probably had a urine infection. I was sent to the ward and given a laxative. By this time the pain was just so bad and without realizing I started pushing, then I was sent back down to the delivery room, where my baby daughter arrived. It all happened so fast, I didn't have a labour with Mathew as I had a Caesarean section a month early.

I had just come back from phoning everyone to tell them about my daughters birth, when I was asked to go to the nursery as the doctor wanted to speak to me. As I walked to the nursery something inside told me she had Down's, which was what I was then told - this was something I never ever cried about. At midnight Lauren had to be taken to the Royal Hospital for Sick Children (Yorkhill). I knew it was bad when it couldn't wait until morning. I cried non stop watching her leave in an incubator, and I cried again when I was told about Lauren's heart defect early the next morning. I can't really remember the next few days, so much happened, I saw so many doctors.



Lauren was tube fed, and it wasn't too long before I was feeding and changing her. Lauren's first week of life was spent in Glasgow's Queen Mothers Maternity Hospital, her second and third weeks in my local maternity hospital where the staff in the special care unit were wonderful. All I did was cry, I wanted my baby home with me. The only thing keeping Lauren in hospital at the time was feeding as she was still tube fed. The doctor told me if I learned to pass the tubes I could take her home, so three days later after three long weeks in hospital we were on our way home.

Within half an hour I was out with my baby in her pram. I felt like the proudest mother in the world. When anyone asked about Lauren I told them the truth. For a few months her heart defect was pushed aside until around Christmas time when we visited the cardiac clinic. It was only our second visit there when surgery had to be brought forward. What a shock. Lauren was only weeks old and weighing almost nine pounds. How could a baby have heart surgery and live was all I wanted to know.

As soon as we left the doctors room I ran as fast as I could

with Lauren in her pram wearing only a nappy and vest. I ran out of the hospital into the bitter cold night crying, two nurses came after me, taking us into a side room. One dressed Lauren and the other gave me some tea and reassured me that it was for the best. I already knew Lauren would die slowly without surgery.

Then the day came, 20th February 1995 when I had to take my baby to Yorkhill Hospital for her surgery on the 22nd, not knowing if she would live or die. Just before 1pm they came to take Lauren to theatre, it was a lot harder than I thought to let her go, the nurse told me to give her a kiss goodbye. I wouldn't - it felt as if by kissing her she wasn't coming back. By this time I wasn't only crying but screaming I cried for hours not caring who heard me, I went into shock it was a total nightmare, about five and a half hours later she was out of theatre and on her way to I.T.U. The surgeon Mr Pollock came to see me, he said everything had gone well and that he had never seen a hole so big in a baby so small, words

I will never forget. I went to see her and passed out. My poor baby, what a mess she was in. I was sent home in a taxi.

A lot of children go home a week after surgery, but three weeks later Lauren was still on a ventilator and still sedated. I knew something was wrong when we were taken to a small room and told that Lauren still had a hole and need more surgery. I did a lot more crying when we were told the risks were higher on a sick baby and that Lauren was a very sick baby. She finally came off the ventilator and was back on the ward for about three more weeks. Then on March 28th she was christened, the day before she went for a cardiac catheter, and

finally on 5th April back to theatre for more surgery. I didn't go into the hospital that day, I couldn't face it.

When Lauren arrived back in I.T.U, Mr Pollock telephoned me at home and said everything had gone well and they expected Lauren to come on in leaps and bounds within the next few weeks. Yet again, three weeks later Lauren was still on the ventilator. Then suddenly she was off it. The next thing I knew she was back on the ward on the Thursday. By Monday I was allowed to take her out within the hospital grounds, on the Tuesday I took her into Glasgow shopping for new clothes. When we got back to the hospital the doctor was doing his rounds and out of the blue he asked me when I was going to take Lauren home. I cried some more. On Thursday 5th May, Lauren came home.

Since then a few of the babies I knew have died, two who also had Down's. It wasn't until they died that it hit me just how lucky we are with Lauren - most of all we love her for who she is.

**Sharon Ferguson  
Airdrie**

# Naomi's Story

Naomi was born at Leighton Hospital, Crewe at 2.11 pm on 18 August 1997 - an emergency Caesarean as she was in distress, her heartbeat was slow. When I came round from the general anaesthetic, I was told that Naomi was in the special care unit - she needed oxygen and her heartbeat was erratic, but this was probably due to the trauma of being born so quickly. I was taken to the maternity ward. After about an hour, the paediatrician came to speak to Roger and myself, accompanied by a nurse from the special care unit.

He explained that he was almost certain that Naomi had Down's Syndrome. He said that this would have to be confirmed by chromosome analysis and that there was always a chance that he could be wrong. However he had never been wrong in the past and the signs were that she had Down's - she also had two holes in her heart and needed to be transferred to Alder Hey, Liverpool to the cardiac unit.

I was wheeled to the special care unit on my bed to see my baby and spent about ten minutes looking at her lying in the incubator, unable to hold her, but relieved just to be able to see her. We spent the next hour in shock, it was so hard to accept that our new baby was struggling.

Naomi was transferred to Alder Hey at 7pm that evening, Roger followed the ambulance, my dad went with him. My mum stayed with me while we waited for news and the only thing that kept me going for the next five hours, was the fact that we had not been asked if we wanted to have Naomi baptised before she was moved. This to me was the only hope that things were not too bad. Roger came back from Alder Hey at midnight, upset. She was very ill, and the coming days would be critical.

On Wednesday, I begged the staff at Leighton to let me go across to Liverpool to see Naomi. They eventually gave in as I was so desperate to see her. I held my baby for the first time and remember thinking what small hands she had. The consultant came to talk to us and explained that Naomi had a complete AVSD and that further scans would be carried out over the next few days, but for the moment we had to concentrate on keeping her stable and encouraging her to feed. Dr Kitchener spent a long time with us, drawing diagrams to help us understand the problem and asking if we had any questions, but at that time it was all so new to us that we didn't have anything to ask - we just needed to concentrate on taking in all this information.

I was discharged from Leighton on Friday and went straight to Alder Hey with Roger and our elder daughter Sarah. The nurses were keen to get Naomi to feed from a bottle and I fed her for the first time, she didn't take much but just the small amount that she did take was an achievement. Dr Kitchener saw us again and explained that Naomi would initially need a PDA ligation and pulmonary band. This was carried out when she was three weeks old. Ten days after her operation we took her home - she was a fighter and had recovered from the operation much quicker than anyone dared hope. She needed daily medication - digoxin, frusemide and amiloride.

Over the next few months, we had monthly visits to Alder Hey for scans and consultations. Everytime that Naomi's breathing sounded slightly "rattly" I worried, and visited my GP several times to ask him to listen to her chest - each time

it was clear. My GP was very supportive and spent much time talking to me - explaining that Down's Syndrome did not automatically mean that we would have a severely handicapped child. With the right stimulation and support from us, she would reach her full potential. We felt more positive over the next few months. Naomi was not the floppy, listless baby that we had been told to expect. I suppose that doctors give you the worse possible scenario so that you are prepared. But she fed well, started to smile and recognise me, Roger and Sarah, and we just got on with being a family.

In December, Naomi had a cardiac catheterisation. Dr Kitchener spoke to us about the results. There was some doubt as to whether Naomi's left ventricle was large enough to be able to function efficiently when the holes were closed. In January she had two very detailed scans and the decision was made that the left ventricle was in fact big enough. We were given a date of 11th February for her operation. Two days before this, Naomi came out in a rash. We went straight to our GP who said that it was only a viral rash but that we needed to inform Alder Hey. The operation was cancelled - it was not worth taking the risk.

The rash disappeared within twenty four hours! We were given a new date of 18th February. We went to hospital for admission at lunchtime and were immediately told that there was a shortage of beds on Intensive Care. However, we were admitted and went through the process of preparing for the operation - we discussed the risks and signed the consent forms and went to sleep that night, prepared for Naomi to go to theatre at lunchtime the next day.

At 6am we were told that it was doubtful if Naomi would be operated on, but I thought "well, if she doesn't go today, at least she will be first on the list for tomorrow - we're here now". At 10am a doctor came to see me to explain that there were no Intensive Care beds and that the surgeon was due to go on leave the next day, so we would have to go home and would get a new date for surgery. I sat and wept, we had got so worked up to this operation and now it was not going to happen. Everytime anyone spoke to me I just cried at them. I can laugh at this now, I must have seemed like an hysterical mum, but at the time I just thought I could not cope with going through this whole preparation process again.

The new date was set for 11th March and we began the process of pre-admission clinic again. On 3rd March, Naomi went to Alder Hey for a routine check up. During the previous two to three days we had noticed that Naomi's breathing was becoming more laboured and she did not look as well as she had done. Dr Kitchener saw her and decided to have her admitted immediately - her saturations were only 75% and she was very blue. I still feel guilty that I had not taken her to our GP earlier. She spent the next week in a head box until her operation date.

The day before the operation we saw the anaesthetist, a doctor and the perfusionist. The risks were explained - this operation had about a 95% success rate. We signed the consent forms. On 11th March, Naomi went to theatre at 8.30am. She had only been gone for one and a half hours when we had a telephone call to say that the surgeon needed to speak to us. Before beginning the operation, the



# Reports from the 1998 Annual Conference

## The Green Paper & It's Implications

### John Wallis, President of the Association of Educational Psychologists

Undoubtedly one of the primary concerns of all parents is their children's education, but this is perhaps of even greater concern to parents of children with special needs. So I had been looking forward to hearing the views on the Green Paper of such an expert in the field of special education as the president of the Association of Educational Psychologists, John Wallis.

When John opened his talk by suggesting an alternative title 'Further Empowerment of Parents in the aftermath of the Green Paper', I had a feeling that I was about to hear a new interpretation of it's implications. I was to be proved right.

He was wearing his carefully selected education tie, one covered with pictures of children and worn to educational meetings where a reminder might be needed that EDUCATION is about CHILDREN - a point sometimes forgotten when discussing policies, documents, resources etc.

John reminded us that the whole history of special education is about parents saying "this is what is needed". Only thirty years ago most children with Down's Syndrome were assessed and deemed inadequate without any parental involvement in the process, and looked after by the Health Authority. Thankfully now all children are considered educable. Who set about the change? PARENTS. All special education exists because parents fought for it.

To turn to the Green Paper, John pointed out that it is only the second major look at special education in the last fifty years (the first being the Warnock Report which led to the 1981 Education Act). However, for the first time it acknowledges that parents and families of children with special needs face exceptional pressures. The second chapter is "Working with Parents" - no other document puts this as high on the agenda.

Education is a partnership between parents and LEAs, and is most effective where there is a relationship between parents and schools built on trust, mutual respect and an acknowledgement of different roles. John told us about his work in an assessment unit for children whose parents had disagreed about what was right for the children. After six months, in three cases out of four the psychologists agreed that the parents had been right, and in the remaining one out of four, the parents accepted that the psychologists had been right. John had drawn two conclusions from this :

1. Parents know best
2. There is no such thing as an unreasonable parent.

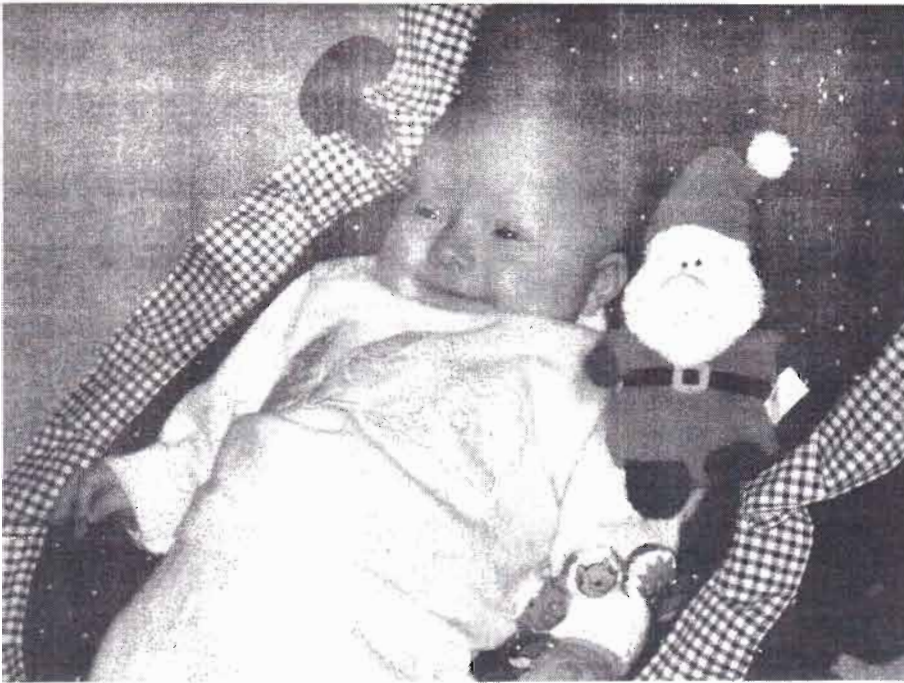
I found myself hoping that officials at the DFEE and education ministers share this view, especially as the response to the Green Paper has been so strong.

I was surprised that so far little reference had been made to inclusion or statementing. Until this point I had heard discussions and read articles about the Green Paper, but in the main they had been in the context of mainstream versus special schools or units, and children's legal entitlement to the provision that they need, given the proposed cut in the number of statements issued. John did not discuss these issues in any depth. He did suggest that if the education system is sufficiently flexible and well resourced, and with attitudes between parents and professionals built on mutual respect, then it should follow that more children can be included in mainstream schools. He would support this, if parents want it. However, there is no mention of finance in the Green Paper and many problems in special education provision are due to lack of resources. At present there are one hundred and fifty six LEAs all following their own policies. It is obvious that small authorities find it difficult to implement some policies because of resource implications. The Green Paper suggests a new role for special schools as "centres of excellence" offering a wider range of experiences for children than is currently available, within the resources available. This could mean that centres of excellence and expertise are not developed in mainstream schools, and make inclusion more difficult.

Where does this all leave our children with Down's Syndrome? John gave us his view that the term 'Down's Syndrome' is irrelevant unless it gives information that affects the way the educational needs are met - it is the individual child and his/her needs that are important rather than the label, and each child should have an individual programme for meeting those needs. Yes, I thought, I agree, provided that the schools have sufficient information and a full understanding of the effects of Down's Syndrome on the learning process.

Special education is just a part of education. All education is about achieving high standards, and so anything which leads to raising education standards should improve special education.

John concluded by giving us his personal view that as parents we should have nothing to fear from the Green Paper. It is a consultation document, not law, which has provided us with a good opportunity to express our views and be listened to. The reaction to the paper has been very great, with thousands of responses to the DFEE. If parents views are valued as highly as suggested, then we should welcome the fact that the Green Paper has given us a chance to influence future law



Dr Kitchener spent a long time answering our questions. We got to my question. She explained that Naomi's heart was now doing a job that it was not in fact designed to do. Naomi would need to have the second part of this procedure - the Fontan at about two to three years of age. The fontan procedure has only been carried out over the last twenty years and people who had this procedure as infants are now experiencing some difficulties in their early-mid twenties. We left hospital feeling depressed - although Naomi was well and we were happy about this, there was always something to knock us back down again.

For a month, I felt that I could not even speak to any mums with babies the same age as Naomi - for the first time, since she was born I kept asking "Why? Why Naomi?"

surgeon had done another scan and had decided that the holes were too big to be repaired, therefore a completely different procedure would be carried out. Naomi had a bilateral cavo-pulmonary shunt. We had a call at 2.15pm to say that she was out of theatre and in ICU, we could visit in about half an hour. The surgeon came to talk to us and explained the operation. We asked why they could not close the holes and he said that Naomi would not have survived - I could not take it in. We had spent seven months preparing for one operation, and I could not accept that she had now had a completely different procedure. He began to say something about Naomi's long term outlook, but seemed to stop short.

The next day, I questioned one of the ICU doctors and he explained that her long term outlook may not be as good, but that we should discuss this with the consultant. But on a general note, he said she will still swim, ride a bike etc, but would not have the stamina that other children have. We decided that this was probably what the surgeon had been trying to say and did not mention it again while we were in hospital.

Naomi was taken off ventilation four days later and returned to the ward the following day. Once again, she made an amazing recovery - it took longer than last time and she had a slight setback when she developed sickness and diarrhoea, but we took Naomi home on 30th March. Naomi still has digoxin, frusemide and amiloride, she also takes warfarin and has a ventolin inhaler. On our trips to the chemist we come home with a shipping order.

A week later she had a routine check-up with Dr Kitchener. The day before this, Roger and I sat down together and wrote a list of questions. My main one being about Naomi's long term outlook as I felt that we had not found out enough about this.

Naomi had a scan and chest x-ray - everything looked good.

It is now early June. Naomi had a check-up at Alder Hey on 28th April and they did not need to see her for two months - a record, we had never gone this long before - we felt like parents must feel who have been given an all-clear for their child.

We now have other appointments to keep us busy - physio, anticoagulant clinic (we've had quite a problem getting Naomi's INR stable), paediatric check-ups. We are also due to start hydrotherapy and portage very soon. We have only praise for the staff at Leighton Hospital and Alder Hey - everyone we have come into contact with has been supportive and helpful. Also, our GP, Dr Llewellyn, the physiotherapist and paediatrician at our local hospital, who again, have spent much time with us and given us much support.

No matter how Naomi is in the long term, we are determined to give her the best life can offer. She is a happy baby and has brought much joy to our family. Her big sister adores her. We could not imagine life without her. We could not imagine her being any different.

**Louise Hough**  
**Northwich**

**Do you have a story  
about your child's birth,  
surgery or life and  
achievements?**

If you would like to share your story, please  
send it in to us

*It would be helpful if you could include a photograph -  
please state if you wish it to be returned to you)*

regarding the education of our children with special needs. Having listened to John Wallis, I felt encouraged by his optimism. He had given me a different perspective on the Green Paper. Only time will tell if the consultation exercise was truly genuine, and we have been listened to.

**Lindsay Allen,**  
**Yorkshire & Humberside Regional Co-ordinator**

### **Medical problems**

#### **Dr Jenny Dennis and Dr Liz Marder**

Dr Dennis and Dr Marder handled the wide diversity of questions with reassuring ease. Firstly they took questions from the floor, then having grouped them loosely into subjects, dealt with these one by one with some lively discussion from the floor.

The subject of those unoperated members with Eisenmengers was discussed, with description to explain the problem, the effect on oxygen saturation levels in the blood, and where families might look for the most appropriate treatment if the young person were to be discharged from a paediatric unit at age 16, the suggestion being made that referral be made to one of the GUCH (grown up congenital heart) Units being set up around the country.

The work of the Down's Syndrome Medical Interest Group was mentioned, particularly in relation to its work in producing medical protocols which include guidelines to prove cardiac status of a new born by the age of six weeks. It was also suggested that they might be able to assist with regard to the question of heart lung transplants.

Further discussion centred around medical problems in teenagers, associated problems such as Coeliac disease and Epilepsy, which is apparently more common in children with Down's Syndrome but usually easily controlled with drugs. There was a good deal of interest in mobility and foot problems, with the recommendation that any children with these problems should be seen by a podiatrist or Orthotist regularly.

Skin problems were discussed, the suggestion for dry skin being to moisturise regularly with whatever is useful for your child such as Oilatum or E45 and to avoid bubble bath and rough soap.

During the limited time the two doctors managed to cover a wide range of problems and provide useful help and suggestions from their vast wealth of knowledge.

**Penny Green**  
**National Administrator**

### **Integration : The Teachers View**

#### **Felicity Gill and Rachel Rees-Jones, Thurlaston Primary School**

Felicity and Rachel gave a very interesting and thought provoking workshop based on their experience of a child with Down's Syndrome who has attended their small village primary school for the past three years. Felicity, the head-teacher, had moved to the school fairly recently from a larger town school and had a wide range of experience. Rachel had a degree in Psychology and six years of teaching experience. Their school adopts a very positive ethos on including children with special needs.

Rachel led most of the workshop and focused on three main areas :

1. The problems they anticipated before the child came into school.
2. What actually happened.
3. The future.

#### **1. Anticipated Problems**

- a) The child's safety - the school was an old building which had been extended and had several narrow entrances, and they were concerned that the child might run out or get lost.
- b) The effect on the other children - they might have less time and be distracted by the child.
- c) The effect on the child - may be "over mothered" by the other children and did the school have the right resources to cope?
- d) Finding the right adult helper for the child.

#### **2. What actually happened**

There were a few problems with some aspects of behaviour initially, such as hiding under the tables or in the cloakroom, generally distracting other children and refusing to do certain things, which were made worse by the familiar problem of

recurrent colds causing tiredness due to disturbed nights.

All the other children were very supportive towards the child and were good role models which helped to advance the child's behaviour.

The child had full time ancillary help, fifteen hours of which were provided by the Local Education Authority and the remainder supplemented by the school. The teacher and ancillary met together every week to plan the child's Individual Educational Programme, and discuss any problems.

Since starting school the child had made excellent progress and their self-confidence had grown tremendously. The child has moved on from reading mechanically to reading with understanding, and was confident to take messages around the school which helped with language development.

Having the child in school provided an opportunity for both adults and children to learn that everyone has different abilities and to develop an understanding of people with special needs.

The teachers noticed that as the children progressed through the school the maturity gap was widening, and it was taking the child longer to complete most tasks, which was sometimes frustrating for the other children. They also found some areas of the curriculum, such as science, were becoming difficult to adapt to the child's level of understanding.

However, they felt the placement had been very successful so far, due to the excellent relationships between the child, ancillary and teachers, helped by enormous support from the child's family. Rachel stressed the importance of full-time ancillary help and support in the classroom for the teachers benefit as much as the child's.

### 3. The Future

The teachers were hopeful that the placement would continue to be successful as the child moved up to Key Stage 2 later in the year, and in order to achieve this they felt the child would continue to need full-time ancillary help and the good relationships between teaching staff, the child, and the family would need to be maintained. The situation would need regular assessment and they needed to acknowledge that although there would be setbacks, not to take these personally and continue to build on all the positive things.

They were concerned that class organisation at this level was more intense, and the curriculum, which was becoming more demanding, might be harder to adapt. The maturity gap would be widening further which would make friendships more difficult and it was suggested to encourage any child with special needs to have several friends, rather than rely on one "best buddy".

Those who attended the workshop were very appreciative of the open and honest way in which Felicity and Rachel had shared their experiences to help us understand more about integrating a child into mainstream schooling.

**Sheila Boniface**  
**Bexhill-on-Sea**

### How to get the most out of your child's assessment - John Wallis, President of the Association of Educational Psychologists

We were enormously fortunate in having John Wallis to talk and advise us on how best to approach this bureaucratic world of the statutory assessments. He covered the process of assessment, choosing a school and appealing against statements in the statutory assessment.

John started off his talk by laying some clear foundations when starting the statutory assessment: - Parents must be prepared to be responsible and open to other views - that might mean that what you want at the beginning of the process may not be what you want at the end. - Being prepared to listen, to be advised, to make choices in the interest of your child - may have the affect of changing your approach throughout the process - that's being open and responsible. John also emphasised the need for developing good relationships with representatives of the LEA and that as a result you would be more likely to get what you want.

Everyone has a right to ask for a statutory assessment at any age.

#### How to go about it:

1. Identify key people who are important - if you are not sure who they may be - ask.
2. From the start establish your rights as an EQUAL partner - that is you are not going to be patronised or dictated too but you are going to be an active partner, after all you know your child, establish that is to be your pattern within the process. All parents have a right to be present when advisers undertake their assessments, e.g. educational psychologist, speech therapist, medical advisor etc.

3. Equal partnership must be fair and firm, so don't make assumptions that your child is going to be put down - assume good will from the outset. However be prepared to challenge and if you think it appropriate ask for a second opinion. Parents can provide their own private advice but be warned that this can be expensive.
4. John advised to get the best out of the relationship parents should be fair, listen, be reasonably polite and accept views as they may be valid - you don't have to agree - you may not like what you hear - but the relationship should be based on trust from both sides.
5. Keep written records of all you dealings with any of the authorities e.g. dates, times, names of people spoken to on the telephone or at any other time. Keep copies of anything you write, make notes of discussions over the telephone. If comments on the telephone are significant get written confirmation - you may need to confirm this back in writing saying that unless you hear within 14 days you will assume they agree with the written account.

#### Choosing a school:

1. Parents have the right to state a preference of school - LEA has to give reason why preference can not be met. Naming a school in the first statement may not be in the child's interest and it may be best to complete the statement on need before determining a school.
2. If the statementing process has been completed but you are in dispute over its content with the LEA you can go to the SEN tribunal. LEA's are expected to act reasonably in resolving issues. Tribunals mostly take note of parents wishes therefore few cases taken to a tribunal are lost.
3. Children under 5 years commencing the statementing process will be reviewed after 6 months, thereafter the review is annually. The LEA should anticipate the changes that will need to be met within that year e.g. taking into account appropriate schools.
4. Your LEA should provide you with names of schools in your locality. You also can ask for information from the schools. e.g. prospectus, governors annual report, OFSTED report and summary. SEN policy, discipline policy. Talk to other parents, visit the school and observe the way in which they talk and handle the children in class. Ensure you know what you are looking for prior to the visit and ask the question of teaching staff and ensure you get an answer.
5. You can ask for extra time before showing a preference for a school.
6. Say what you think, ensure that you play it on your terms and not their's but above all be organised.

#### Appeals and Complaints:

1. Any complaints about a school not adhering to a statutory statement or not being prepared to accept your child in their school, should initially go to the head teacher, then the governing body who has to deal with the complaint and if not satisfied the complaint should be referred to the LEA, Director of Education. All LEA's have a complaint procedure.
2. You can also go to your local Councillor who represents your ward or to a councillor on the Education Committee. If you are still not happy you can take it to the Ombudsman for your LEA . and of course to a SEN Tribunal. Your last resort would be to take it further to the Secretary of State.
3. The DFEE have produced a book about how to complain to SEN Tribunal, which will identify the grounds on which you can appeal.

Well, having listened to John's very informative and practical information I was left feeling that with all these people being employed to ensure parents get their rights our children should be in safe hands but maybe there is still a considerable amount of discrimination within the education establishment. I do hope that these notes may go some way in helping you.

**Katie Spall**

**London Southern Regional Co-ordinator and Hospital Visitor for Guy's & G.O.S.**

## LAPLAND TRIP

Once again the Down's Heart Group has been allocated a place on the Children's Heart Federation Christmas trip to Lapland on Sunday 13th December.

We can nominate one heart child along with his or her parent or carer to go on the trip. The flight is from Gatwick, where you will have overnight accommodation provided on both Saturday & Sunday evening together with a festive meal on the Saturday night. It is a very long and cold day, for which reason we are looking to nominate a child over the age of eight.

For further information, or if you would like your child's name to be include in our lucky draw, please contact Penny Green on 01525 220379 by **5pm on Monday 19th October**.

## Members News

Thank you so much for sending the tickets for the children's ballet 'Mrs Harris goes to Paris'. Matthew really enjoyed it and drew this picture of it. It shows the dress of Mrs Harris's dreams, (left to right) Mme Colbert, Fauvel and Natasha and three seamstresses.



Matthew has a great love of theatre and especially RED curtains and he was not disappointed. He has near total recall of events and even the fire exit was not to be missed. He remembers everything in minute detail.

This was a new experience for him and I am very grateful to the Down's Heart Group for giving us this opportunity.

**Angela Weaver  
Cuxton**



I am enclosing a cheque for £25, which our daughter Ruth raised in a local fun run, which was a mile and a half around the village of Rippingale.

As you have been so helpful since we recently joined your group and you have sent us some very useful information, we decided to send you the money that Ruth raised.

We will be in touch again to let you know how every thing goes next week when Ruth has her op.

Once again thank you for all your help and understanding.

**Julie Maxfield  
Dunsby, Lincs**

*Ruth had successful surgery on July 20th this year, you can read her story in our next newsletter*

My name is Digby James Townsend. I live at Great Thirkleby I am 17 years o'd. I support Manchester United FC

When I was a baby (nearly 2 years old) I had a patent ductus corrected it is fine now.

I went to Thirsk School When I was 15 or 16, I did some work experiences are at Blue Cross Animal Centre I was doing feeding dogs and cats. In Thirsk School for my work experience I was helping the other staff in Thirsk Library and in school and of course the canteen. I was enjoyed doing it. At Thirsk School I got 2 GCSE's in Art and French, and numerous Units of Accreditation. I also did a computer course in the evenings and got 2 parts (word processing and data base) towards my CLAIT certificate.

In my year in Harrogate College (CONTEX Course) I have gained my English Speaking Board certificate and also I have my work experience in Harrogate's Sainsbury's Supermarket PLC, The Resource Centre, Solberge Hotel, Northallerton.. On Monday's we were doing the computer work towards our certificate. We went to a trip at the Low Mill going to caving ETC. I have gained my Basic Food Hygiene certificate and one is the First Aid certificate.

I enjoyed speaking at the Downs Syndrome Conference, (N. Yorkshire Branch)

Thanks,

**Digby**

*I was among those present at the North Yorkshire branch conference. AT the end, we were privileged to view a video recording of the work that had gone on in the drama workshop during the day. Digby was a very vocal member of the cast of young people who had staged their own production of 'Titanic', which was much enjoyed by the audience. - Editor*

***Isn't it lovely to see items  
from the young people  
themselves!  
And about their lives and  
achievements.***

We would like to include more items like these in the newsletter, so please send us your news, pictures, stories etc.



## Members with Chronic Cardiac Conditions

Mrs Sandra Redman manages dental treatment for referral to Queen Elizabeth Children's Hospital, Hackney, London. Sandra read of concerns for the dental treatment of our children in the Spring newsletter and hastened to contact us to tell us about all the effort that goes into creating an inviting and fully involving atmosphere for children within the hospital, dispelling fear and anxiety as much as possible. She is constantly looking to improve things and has asked for any ideas and suggestions that our members might have to lessen the inevitable traumas of dental treatment. Please think of any ideas for what your child might like to see and do during a visit for treatment and send ideas for Sandra via National Office.

Updates about vasodilation continue to come our way, and pose further questions for consideration. A change of centre has meant that one of our members is currently receiving venesection on a "little and often" basis, related rather more to how symptomatic he is rather than, as previously, his haemoglobin count only. This is aimed at maintaining a reasonable blood supply to extremities and relieving painful headaches, finger ends etc.

I must say at this point that I am writing this away from home, and in the process, I have left the carefully crafted menu ideas Jane sent me, behind at home. I will include these in the next newsletter, but in the meantime I can report that I have taken her advice and am adding garlic to accompany the onion that Alex already has in his food. Garlic and onion are both reputed to improve the condition of the blood and aid digestion, so hopefully it all helps, anyway Alex seems to like it.

**Wendy Tucker**  
**Representative for those with chronic cardiac conditions**

*The following is an extract from a letter written by member Angela Weaver to the Down's Syndrome Association in response to a letter published in their Winter 1997 newsletter from Wendy Tucker.*

I am prompted to write by reading Wendy Tucker's letter in the winter issue concerning the difficulties experienced with her autistic son who also has a congenital heart defect. How I feel for her. My own son, now sixteen has a complete AV Canal defect of his heart and although not autistic has always been a great problem when anything has needed doing in hospital or at the dentist.

It has taken years for a really child friendly dentist to even get him into the reclining chair. His baby teeth refuse to fall out when his second ones are growing causing gross overcrowding, so he had to go to Guys to have eight teeth removed under general anaesthetic. They couldn't get him to be x-rayed and couldn't get all the teeth out as his heart started to fail.

He had haemorrhagic chicken pox and was so ill that he had to go into hospital. Because they suspected septicaemia they needed blood samples and to administer intravenous antibiotics but the stress caused by these procedures was worse than the illness. Matthew also has a horror of plasters on himself or anyone else. When I tried to treat a verruca and apply plasters he was so miserable till I took them off each time that I gave up.

It took about twelve years to gain acceptance of hair washing but only at home. Strange toilets were also a problem. He still will not ask to go unless he is at home. Any new situation or anyone doing anything to him causes him great distress but I should say that he adores being hugged! Holidays are a real challenge. He has now developed irritable bowel syndrome and anything vaguely stressful or exciting can trigger it.

We have a lovely paediatrician but we haven't seen a heart specialist for years. Should we be doing so? Also for his general care where should he be looked after? He has many problems. What happens when children with serious conditions and complex needs reach adolescence? I don't want to lose my paediatrician who has a good understanding and overview of Matthew's needs. Also if it comes to hospitalisation where should he go? A children's ward is much more appropriate than an adult ward which Matthew finds very frightening even as a visitor because of the many older chronically sick patients. He saw my father of whom he was very fond, in the earlier stages of dying of cancer and he still has nightmares about it.

Do other parents of severely affected adolescents have a problem? I wonder what the views and experiences are of other parents in similar situations.

**Angela Weaver**  
**Cuxton**

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

Alex Boulton - Andover

Millicent Castel

Catherine Holmes - (Grandma to Catherine Aylward)

Ken Hymus - (Grandpa to Daniel Green)

Alec Mann - Sawbridgeworth

Liam Meston - St Leonards-on-Sea

# Fund-raising Update

Re: London Marathon 1998

Thanks to a rugby injury to my left thigh back in November, which required numerous visits to the Doctor, followed by twelve weeks of physiotherapy to get the leg working again, the training 'schedule' (if such a thing ever existed other than in my dreams) did not go well. Offers to go for training runs in February of seventeen miles or more with a group of friends were all politely turned down, and lunchtime jaunts from Tower Place in London out to Canary Wharf and back took their place - that way I thought that I could hide my incompetence from the gaze of the world, and kid myself that I was 'on track' for the big one, despite the fact that my longest run had been ten miles.

During the real thing, of course, there is nowhere to hide, in fact, life is worse than that - there is always the possibility that the dreaded Rhino will appear over your shoulder, or that the relentless advance of the 'Utterly Butterly Tub' and accompanying 'Pink Fairy with Wand' will eat you up and spit you out just as you stagger through the twenty two mile mark. 1998 was however, to be the year of the Telly Tubby Disguise, and thankfully for all those who had not put in the requisite training, Tinky Winky, Dipsy, LaLa and Po themselves would have posed more of a threat than their alter egos did on the day.

Just before the gun went off at 09.30hrs, for some reason I found myself thinking back to something I had read in some running magazine or other earlier in the year - the article was all to do with how to taper a training schedule leading up to a big event in order to optimise performance on the day - unfortunately, I came to the conclusion that the only way to have tapered my training was to have spent the last week in bed.....

Anyway, the gun went off, and seconds later 20,000 runners at the blue start on Blackheath set off like a mass of lemmings towards our communal goal - not, in this instance, over a distant cliff-top in the search for instant death as part of a population reduction plan, but nevertheless towards certain pain and suffering over the next twenty six miles three hundred and eighty five yards in the interests of our fellow man, and for some a degree of personal satisfaction.....

Miles one to five proved uneventful, as the runners jockeyed to establish their early positions on the route to make sure that they ran on the blue line (this follows the racing line of the race, and represents the measured Marathon distance) and I actually started to think that the 'several' ten mile runs that I had put in over the past weeks might actually have paid dividends - how easy it is to be lulled into a false sense of security!! After mile six and the Cutty Sark, still feeling fairly bullish, I actually started to look forward to seeing friends at the ten mile point. Unfortunately the cool weather had discouraged many from leaving their beds but I trudged on towards the twelve mile mark, where I knew that my wife Bibi would be waiting, full of praise no matter how pedestrian the pace.

Individual tactics differ from race to race, from runner to runner - mine on the day were to get to the halfway point as quickly as possible, with the intention of using any time

'gained' to take it easy in the second half. Thirteen miles gone, and encouraged by wifely cheers as well as the fact that the threatened downpour had yet to materialise, I just about managed to keep in touch with a group of runners heading for a three and a half hour finish. Any banter with the crowd had long since ceased, a far cry from the previous year when my suit and bowler hat outfit had kept me in the public eye, this year I was far more businesslike about the whole affair, and concentrated on sore feet and legs.

Canary Wharf, Mud Chute and the Isle of Dogs were about as attractive as they sound, only worsened by the fact that the heavens opened for the first time. Doubly depressing was the fact that a glance at the wristwatch confirmed that the winners would have their feet up, and be enjoying their second cup of cocoa by now, and we determined souls still had nine or ten miles to run.

Somehow, and despite having run twice as far as my longest training run, my legs were still holding out at twenty miles, although the occasional wave to the thinning crowd through the pouring rain was becoming more of an effort with each stride, and my hopes of even raising a smile for my wife at the next rendezvous (twenty five miles), were fading fast..... The cobbles leading up to the Tower of London were awash, and standing water an inch deep greeted us as we splashed past a sodden Capital Radio stand by the Tower Hotel. An extra helping of depression was served as I lurched past the office door in Tower Place, already 'happy' in the knowledge that I would have to be back there in eighteen hours or so.

I do not know how accurate the measuring device they use for the Marathon is, but I can tell you that the last four miles seem like the entire length of the M1. I read somewhere that the physical and mental effort to cover the last four miles represents 70% of the total required for the entire race, but I never believed that until last Sunday. I may as well have been asked to climb the North Face of the Eiger.

Thankfully, pride and self preservation took over, and my head came up off my chest momentarily as I passed my wife for the final time at twenty five miles (drier than most, she had managed somehow to procure a large umbrella) and headed for the final straight. The finish was a welcome sight, and somehow I had managed to turn in a respectable time of 3hrs 37 minutes - don't ask me how!

Despite the sore legs and 'never again' thoughts that inevitably follow the run, all being well I will be back next year for number seven in the series of ten London Marathons that is my goal.

**John Tyszkiewicz**

*John was one of our intrepid Marathon runners this year, who between them raised in the region of £5000 for the Group. If you or someone you know has a place in the 1999 London Marathon, please consider sponsorship for the Down's Heart Group. If you would like to run but don't get a place, please contact us, we do have some places available for runners who can guarantee a minimum sponsorship.*



# WEST END STARS HOST GALA EVENING

in aid of the Down's Syndrome Association  
and the Down's Heart Group

at Her Majesties Theatre, London (home of Phantom of The Opera)

**Sunday 1st November**

**7.00pm**

**Tickets £10 - £25**

**Sponsored by Future Integrated Telephony PLC**

## STAR PERFORMERS

(all giving freely of their time)

Phil Cavill of Les Miserables

Melvin Whitfield of Hotstuff

Battersea Dance Troop a newly formed group  
of dancers, all of whom have Down's Syndrome

Many of the cast of Beauty and the Beast

AND MANY OTHER WEST END STARS

## PRODUCTION TEAM

Producer Pam Haines

Musical Director Julian Kelly famed for  
Hotstuff seen at the  
Haymarket

Co Musical Director Jae Alexander famed for  
Beauty and the  
Beast on in the West  
End

Producer Pam Haines owns the Westcotes Day Nursery in Leicester, where she had the good fortune to look after a little boy with Down's Syndrome from the age of three months to five years. She and her staff found this such a rewarding experience that they decided to support the work of the Down's Syndrome Association.

Two years ago, Pam organised and hosted a Gala Evening at the Haymarket and had a great success, raising a good deal of money from her efforts. This year she has set her sights even higher to take the event to the West End, again raising money for the Down's Syndrome Association and this year also the Down's Heart Group.

**This promises to be a spectacular evening from the accounts of  
two years ago.**

**Please encourage people to go along and give their support.**

**Tickets can be obtained by contacting Pam Haines on  
01162 546413 (please mention DHG)  
or from Sarah Smith on [REDACTED]  
or National Office on [REDACTED]**

## MY ANGEL FROM ABOVE

I may not be the perfect child,  
In each and every way.  
I sometimes may look puzzled,  
With certain things you say.

I may act inappropriate,  
At situations that arise.  
Then there's days, I'll do something,  
And take you by surprise.

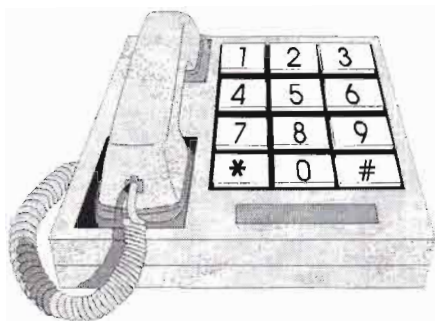
It takes more time, for me to do,  
Things, that others can.  
Sometimes I need encouragement,  
Sometimes I need a hand.

My mother sat with me for years,  
To teach me how to read.  
Now I'm very good at this,  
But your help, I sometimes need.

I smile at the smallest thing,  
I enjoy each new place.  
And everytime I accomplish something,  
Puts a smile on my Mom's face.

She says I have Down Syndrome,  
I am an angel from above.  
She says everyone that touches me,  
Now has a piece of, MY LOVE.

Brenda Robitaille, USA



## Have you changed your phone number - perhaps to cable?

Please let us have your new number  
just in case we need to contact you

## Research project on encouraging good sleep habits in young children with Down's Syndrome

Are you interested in learning how to establish better sleeping habits in your child or reducing the likelihood of sleep problems developing in the future?

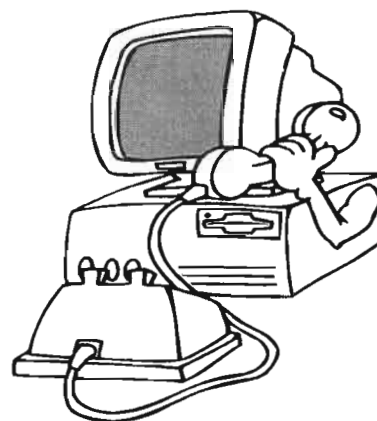
If your child with Down's Syndrome is aged between six months and five years and you would be willing to take part in a research project on this topic, please contact:

Dr Rebecca Stores  
University Section  
Park Hospital for Children  
Old Road  
Headington  
Oxford  
OX3 7LQ

Telephone : 01705 755083  
E-mail address: RStores@aol.com

Dr Stores and her team hope you will be willing to take part.

**THANK YOU VERY MUCH**



## Do you have e-mail?

Then please note our e-mail address  
on page 2, and perhaps you'd like to  
let us know your e-mail address too

# Change of Address?

*It's sad when we lose contact with a family because they forgot to tell us they were moving house. Often the redirection of mail has finished before we send the next copy of the newsletter, so if you are moving, please cut out the slip below and use it as a reminder to tell the Down's Heart Group your new address.*

Please note that with effect from ...../...../.....the new address for the .....family will be:

.....  
.....  
.....  
.....  
Postcode: .....  
Telephone : .....

Child's Name : .....

Child's Date of Birth : ...../...../.....

Send to: Down's Heart Group, [redacted] [redacted] [redacted] [redacted] [redacted]



## Order Form for Christmas Cards and other goods

**PLEASE COMPLETE USING BLOCK CAPITALS - THANK YOU**

Please send :

To :

..... packs of 10 cards BEARS @ £2.15p = £ ..... - ..... p .....

..... packs of 50 cards BEARS @ £9.50p = £ ..... - ..... p .....

..... packs of 10 cards MIXED @ £2.15p = £ ..... - ..... p .....

..... packs of 50 cards MIXED @ £9.50p = £ ..... - ..... p .....

..... books of 10 2nd class stamps @ £2.00p = £ ..... - ..... p .....

..... books of 10 1st class stamps @ £2.60p = £ ..... - ..... p .....

..... ceramic mugs @ £4.00p = £ ..... - ..... p Telephone No : .....

(useful if we need to contact you)

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

TOTAL of cheque or postal order enclosed = £ ..... - ..... p N.B. Postage and packing are included.  
Payable to "Down's Heart Group"

PLEASE ALLOW 14 DAYS FOR DELIVERY

**PLEASE SEND YOUR ORDER TO THE ADDRESS BELOW NOT NATIONAL OFFICE**

To : Down's Heart Group C/O [redacted] [redacted] [redacted] [redacted] [redacted]

