



DOWN'S
HEART
GROUP

NEWSLETTER

Spring '89

Welcome

Yes, welcome to the very first newsletter of the Down's Heart Group.

We're aiming to produce the newsletter at least twice a year and thought it appropriate to start with a Spring one. It's been quite a rush putting it together, but I hope you'll think it worthwhile. In case you're wondering about the picture, it's of my daughter Katie, when about fifteen months old. (Unfortunately, she died in November '87 - aged three and a half - but we think the picture sums up how we feel about getting the group off the ground.)

This edition will go out to all those people Linda Walsh has had contact with over the past few years - all in all, over two hundred of you! Enclosed with the newsletter is a form to let us know whether you want to continue to receive future editions. There is no charge, just the cost of a postage stamp to return the form.

There are altogether about ten different sections in the newsletter, starting with a report on the group itself from Linda. Most of the sections are ones that will need contributions from you to keep going: Letters, Accounts, Ideas, etc. There's a section for you to ask for help from other parents, as well, and another where we can display children's drawings or other contributions. I'd also welcome suggestions for new sections to add. So, the newsletter will be as good as you help to make it! We've also some original cartoons from Lyn Gouck of Glasgow and a few drawings I've copied from my (second) daughter, Vicky's books.

That's enough from me. I do hope you enjoy the Newsletter and look forward to hearing your comments and getting your contributions. The next newsletter will be out for Autumn so the deadline for contributions is the beginning of July.

Tony Linde



Hooray!

Down's Heart Group

It took two years but we've done it! The Down's Heart Group is here to stay.

We've come a long way since I first started getting your letters and phone calls back in September 1986. Two hundred families have contacted me since then, all of them, with very few exceptions, prepared to offer support and a sympathetic ear to other families in time of need. The stories of twelve of their children have been used as the basis for a book on the AV Canal Defect, which affects so many of our children and this is ready to go to the printers just as soon as time and the funds are available. A factsheet, explaining how heart defects affect children with Down's Syndrome has been distributed to lots of interested professionals, members of the public and parents too, all helping to spread the word that our children are precious to us and full of potential.

Now that a few other parents have come forward to help with this work, we have formed a Steering Committee (new members welcomed) and we know that even more progress will be made. How much we do depends on how much help we get - both practical and financial. Here's what we have in mind:

- three more books of case histories on ASD, VSD and Fallot's Tetralogy
- a series of leaflets to help with common concerns, eg Feeding Problems, Coping in Hospital, Childhood Illnesses
- a regional network of Family Support Representatives, who can act as a local point of contact for families in need of support (in the meantime, I will continue to act as national point of contact)
- a team of hospital liaison representatives who can represent the Down's Heart Group in each of the cardiac units around the country, working to gain the confidence and respect of hospital staff from consultants to nursing staff and social workers

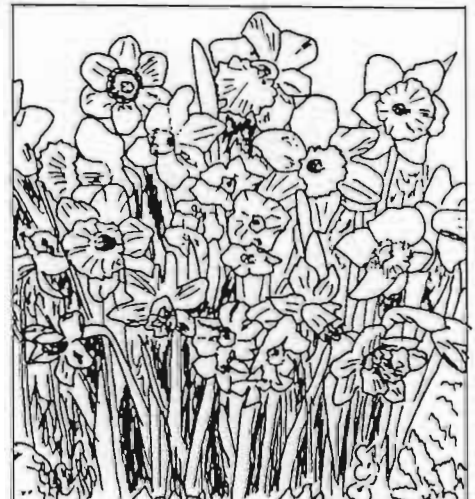
In the longer term our main aim is to ensure that a research project is set up to establish exactly how heart problems affect the quality and length of life of people with Down's Syndrome. Our resources are for the moment concentrated on giving support and information to families but, ultimately, it is only research that will save lives and this will always be ahead of us as a goal to work toward.

A lot has happened since September 1986 and I have shared with some of you the most painful experiences of our lives. Your support and the work involved in getting the Down's Heart Group off the ground have certainly helped me to cope and I can now take comfort from the knowledge that out of our loss, a strong and healthy group is growing. With help, it looks ready to grow into a caring, respected and active group which will benefit both the families of our children and, ultimately, the children themselves.

If you feel you could help in any way, large or small, or we could help you or your family, then please contact me or another Steering Committee member without delay; page 3 includes a list of which committee members to contact for information in specific areas.

Best wishes for a happy and healthy spring-time.

Linda Walsh
Founder



Steering Committee Contacts

Mrs S Bamber
(Sue)

*Treasurer
Local Fund Raising*

Mr J King
(John)

*Hospital Liaison
Fund Raising*

Mr & Mrs T Linde
(Tony & Maqie)

*Newsletter
Publications
Computerisation*

Mr & Mrs R Myatt
(Robert & Sarah)

*Family Support, West Midlands
Bereavement*

Mr P Stephenson
(Peter)

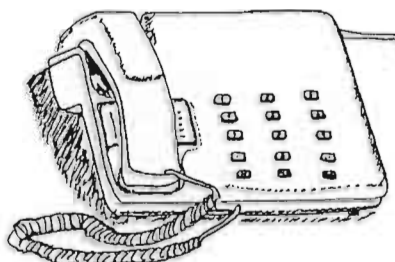
Family Support, South East

Mrs W Tucker
(Wendy)

*Design
Publications*

Mrs L Walsh
(Linda)

*Founder
Director
Family Support, National*



Letters

This is a section we hope to run permanently. But, of course, that depends on you. Any comments you might have on the group, its aims, what it should or should not do, etc - please drop us a line and I'll be happy to include your comments and ideas on this page. Linda has received one letter with comments relating to the group from Pat Lucy; I've reproduced that part of her letter here and her account of her son Vincent's progress later on.

Please also meet Sara, below left!



Lyn Gouck

Hello, my name is Sara. I am four years old and my mummy says that I have an AV septal defect and poor muscle tone - hence the walking frame. I'm a bit prone to chest infections but I never complain. My favourite things are biscuits, music, my teddy and 'Neighbours'. I don't like meat, medicine, getting my toenails cut and physiotherapists who always make me work too hard. My mummy calls me her 'little problem page' but I know she loves me really!

Hello, my name is Pat Lucy. I shall start by taking this opportunity to thank all involved in starting our unique Heart Group for our children with Down's Syndrome. It is such a relief to know that you can contact other parents who have shared the same or similar problems to yourself. I found it a great help talking to Linda and then through her getting in touch with other families. What you think is something only you are going through suddenly becomes almost common to all. Anyway, thanks again and I hope it continues to grow and expand to help those of us who have children of our own and others who are interested...

Continued on page 8



Fund Raising

First came all the ideas, then came the harsh realities. Everything your group wants to do costs money. Do you have any ideas for fund-raising? Are you able to hold an event, or perhaps your firm would help if we appealed to them?

If you have any ideas, please contact me on 0509 416033.

London Marathon

The Down's Heart Group has a runner in this year's London Marathon on 23rd April. Bill Adams is swapping his comfortable car seat in his Driving School to run an awesome 26 miles. All we have to do is ask our friends or work colleagues to sponsor Bill in his magnificent effort.

Bill will complete the course so get as many sponsors as possible. A sponsorship form is enclosed with this newsletter. Please get people to add their names to the form and collect their money after the event (if anyone wants evidence that Bill completed the run, please contact me or Linda Walsh and it will be sent to them). Then send the form and a cheque for the total amount to either me or Sue Bamber (Treasurer).

John King

Help

This section is for people who want help from other parents - it could be advice about some impending stage in their child's life (as with Wendy's request, below right), request for equipment or, indeed, any sort of help. In fact, we start with a general request for help for the group from Linda.

Help the DHG

The Down's Heart Group urgently needs help from individuals who are willing to help in the Group's work in the following areas:

- Public Relations co-ordinator
- Fundraising co-ordinator
- Research co-ordinator

It must be stressed that these are co-ordinating roles, eg the Fundraiser needn't get involved in organising events him/herself, but would co-ordinate the efforts of others.

Other people we need are:

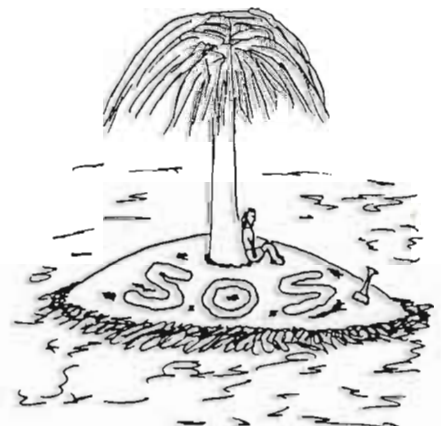
- Legal advisor for advice on charity registration
- Secretary to minute the Steering Committee meetings
- Administrative help, eg typing, filing, etc.

If you can help in any way, please get in touch with me, Linda Walsh.

Vaccination Reactions

Wendy Tucker's little boy, Alex, is four and has only had his first triple vaccination so far, due to an adverse reaction to it at the time. He is now stronger and Wendy is afraid that measles and whooping cough are a greater threat to his life than the possible reactions to the vaccinations.

Could any parent whose child has had reactions to the normal vaccinations (triple, measles or MMR), please get in touch with Wendy, either in writing or by phone. Her address and phone number are on page 3.



Gallery

We'd like to demonstrate our childrens' artistic talents in this Newsletter, so please get the pencils and crayons out. At the moment, we're only photocopying pictures, so it would be best if the children would use white paper and dark colours. Please also include the child's name and age, and a description of what the picture represents. Thanks.

For now, we're proud to present the first national showing of Nicola Beattie's art work. Nicola is the daughter of Francoise Beattie, a member of the Steering Committee. Nicola is 9 years old and this is a self-portrait, as is quite obvious from the long hair!



Accounts

On this and the next couple of pages, we've accounts from parents of what has happened to their children. The first two were sent to Linda some time ago; the third is the continuation of Pat Lucy's letter (from page 4).

If you'd like to share your experiences with other parents, please write them down and send them to me. I can assure you: there will be other people out there who are helped by knowing that they are not alone in what they are going through. Or perhaps you've learned things through your experience that would help someone else about to tread the same path. Please let us know.

Francis Kenny

Copy of an account sent to Linda, January 1988.

Our son Francis is our only child, born when I was 46. I am a teacher, my husband a free-lance pianist; we now live in Sussex.

Francis was born on October 3rd, 1983 in University College Hospital, London. We immediately knew he had Down's Syndrome so his heart was checked at once. He was apparently bluish that first night, and went to the neo-natal unit, but was back with me in the morning. A great many different people seemed to come and see us, though most of the explaining was done by one paediatrician. Francis had a serious AV canal defect, and the gravity of his condition was made clear, but as, after the first night, he was so extremely healthy, it was difficult to take it in.

The symptoms he had were only that he didn't like lying on his front, and as he became active and mobile, he didn't like doing anything on his front. He never looked blue, or out of breath, and he always fed well. We attended out-patients at UCH for check-ups until we went to Great Ormond Street in the run-up to his operation, which was done in November 1984 when he was 13 months old.

We were told that if he didn't have it done, he probably would not live through his teens, but given every opportunity to refuse the operation if we wanted. Indeed there were one or two times when I almost felt they wanted us to refuse. They said they hadn't done all that many operations on Down's children, so didn't really know whether the pressure in the lungs would revert to normal after the operation as it would in another child. We were never in doubt that we wanted the operation. The risk was quoted as one in ten (UCH) then one in twenty (GOS) not surviving the operation - figures are for Down's children (so they must have done enough to be able to give such figures).

About the operation; he was in hospital first for catheterization to examine the defect, then post-operatively in intensive care for five days and out of hospital on the eighth day. He was kept on drugs for another three or four months with the doses diminishing all the time. There was a great improvement in strength when he came off the drugs at last.

Francis is now four. He shows no sign of heart trouble, walks about a mile, though not fast. Post-operative checks showed a 98 or 99 percent success. He has three times been in hospital - twice for one night, once for two nights, each time with croup. We do have to see the doctor five or six times a year, with chest infections or heavy colds. Unfortunately, these troubles run in our family anyway.

He attends playgroups and joins in everything, though often at a slower pace than many children. This is noticeable only on group walks or outings. He gets there in the end - just takes longer.

Caroline Kenny

Half and half... Charlie and Rose Cubitt

Letter from a mum, sent to Linda on 29th September, 1987.

Dear Linda,

My circumstances are not really what you are looking for - I have one child with Down's Syndrome and one with a heart defect!

Charlie has Down's Syndrome, he is now just 7, and his sister Rose was born with a heart defect: she will be 6 after Christmas. I have two older children who have no physical problems at all - only emotional ones to do with growing up!

Charlie is perfectly all right apart from Down's Syndrome. He is small but everything works fine including hearing and sight. The reason I thought to write to you is my experience with doctors: they thought that when Charlie was born it was a dreadful catastrophe; but I had known a Down's child when I was a child, my worry was that I would not know how to care for him and teach him. I soon learned that my experience with the older two WAS relevant, Charlie needs only what all children need, just a bit more. He is a delight, very independent - he himself causes no problems, the problems are the local education authority and the doctors! I believe now that the doctors believe Down's Syndrome to be a major catastrophe - the worst thing that could befall - because they know that it is in the nature of the condition that they will never be able to "cure" it.

Rose's heart is OK for them, because they can cure it. Not so for me, her mother. There was the worry for six months when she was a baby of not knowing what was wrong and being treated like a hysterical mother by health visitor and GP who believed nothing was wrong. Then she had major heart surgery at Great Ormond Street when she was 18 months old (the doctors having finally listened to me). The defect was not what they had believed (no fault of Great Ormond Street, where the medical team are completely different from any I have encountered locally, treating the mother as a part of the team working for the child, and admitting they are human) so instead of two days in intensive care it was four days, with the prospect of more operations in the future. I don't have words to describe what I went through in those ten days, other than "going through the wringer". Not only through worry about Rose, but also meeting other parents in the hospital whose children were in worse condition than Rose - she survived the operation and became so well that she seemed a different child! But I still dread the prospect of another operation.

I suppose that people will say that when they grow up I will appreciate that the doctors are right and Down's Syndrome is worse than a heart defect: but I don't think so. When children grow up they leave home and you can only hope that you did your best to help them fulfil their full potential: I will feel the same things about all my children; during their childhood they give you partly delight and partly heartache - the fact is that IF I could choose, as a mother and with my present knowledge, I would choose the Down's Syndrome rather than the heart defect. What the child would choose, who could say? But I believe that the heart defect is what causes problems for parents.

Yours,

Henrietta Cubitt

PS: Heart defects run in families, I discovered when Rose was diagnosed. Had I known that before, I would have known what was wrong with her earlier as I was born with a heart defect (minor compared with hers). But of course the medical profession had not seen fit to advise me of that either before or after I had children.

Who needs food and sleep? ... Vincent Lucy

Letter received, February 1989

continued from page 4

... Well, about ourselves now. I am a widow and have two children, a daughter, Jane, who is nearly fifteen, and a little rascal of a son, Vincent, who is nearly four.

Vincent has Down's Syndrome; he also has an inoperable AV Septal Defect, although to look at him, people don't think he has any problems. He is normally quite a good colour only going very blue when he has an infection of some kind. He is very active, spending a lot of time running, dancing, jumping, playing football etc, just as any of his friends. He is very small, though, both in height and weight, looking more like an average two-year old than a four-year old. He does take a lot more rests in between his active play than his friends but, again, no-one really notices it.

He has a hearing loss, which we think is quite severe in his left ear but not so bad in the right. He is under the ENT department at Great Ormond Street, and they are keeping a close eye on things. He also has some visual problems which, again, are being looked into at GOS.

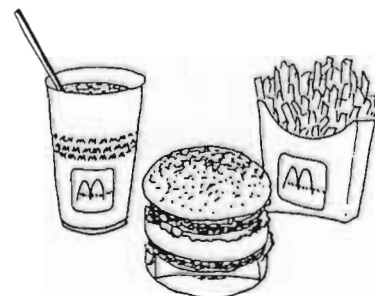
Vincent has a very poor appetite. I often wonder how he actually survives on what he eats. I cannot honestly think of one favourite food. He will eat an occasional Kit Kat bar but only at playgroup or nursery. He loves to go into McDonalds and I often get dragged in when we are out shopping, but he only enjoys it for the social atmosphere - he does not eat anything on their menu, only at very most a little bit of toasted bun. When we went to Lourdes last year, he survived totally on french bread and his fruit juices.

Sleep is a very precious thing in our home as Vincent does not need more than a few hours at night, going down to bed, if we are lucky, about 10.00 - 10.30 and usually up again by 1.30 - 2.00 am. I often feel like a night worker, but without being able to grab a few hours during the day. He used to have a regular sleep pattern but it became disturbed at about eighteen months after a spell in hospital when he had lost a great deal of weight due to the fact that he did not eat anything for about seven weeks, relying only on a small amount of fluids. Since that time, only when he is unwell do we ever get a night's sleep (I suppose I look upon that as my little luxury) but I would rather be up every night and have him well and into all his usual mischievous ways.

Vincent has quite a lot of single words and uses Makaton signs to communicate as well. His favourite TV show is "Give us a Clue"; he knows all the signs and thoroughly enjoys the programme.

All round he is a little fighter, he has had a number of nasty infections which left him very weak but he has always pulled through. We are very proud of him, he has come on such a lot since we first saw this little bundle at his short-stay foster parents. We adopted him in July '86 when he was fifteen months old but have had him with us since he was eleven weeks. His poor long-suffering sister, Jane, loves him dearly. He enjoys a good rough and tumble game with her. Even if she locks herself in her bedroom to do her homework, when she hears that "knock, knock, 'ane, 'ane" (he cannot say Jane), she has to relent, open up the door and have a quick cuddle, or game, or read one of his much loved books, then return to her own work. Life would seem quite dull now without him, he gives us so much and thoroughly enjoys his own life to his own abilities. He is always happy to play and learn through his play with his friends at home, Playgroup or Nursery even though we do have what is called a separation problem - he will not let me leave him at Playgroup, making himself forceably vomit, putting up his already high blood pressure, so we are just taking it a day at a time. Anyway, I will stop now as I could write a book about young Vincent.

Pat Lucy



Clippings

This is a section of the Newsletter where we'd like to be able to reproduce whole articles or even small snippets about children with Down's Syndrome and heart conditions. They could be from newspapers, magazines, journals etc. Just send them in and we'll slot them in here.

On that point, does anyone have links with a doctor or anyone else who regularly gets medical journals and who could keep an eye out for us for relevant articles? Also, anyone in the social professions? We'd be very grateful for any information passed on.

Moving on ... the following is an extract from an article that Verity Ridgman saw in the Guardian last year and thought might be of interest.

In the company of angels



Anna Philips

Reprinted from Guardian, October 4th, 1988.

Our daughter Dolphin was born in the International Catholic Hospital near Shinjuku. (Known as the *Seibo* - Holy Mother - and not to be confused with *Seibu* Department Store.) The paediatrician told us that she had Down's Syndrome and holes in her poor heart within half an hour of her birth.

A Franciscan missionary nun from Boston acted as interpreter but the doctor's gentle face and the sweet way in which he rocked our blue and crumpled little baby as he spoke were better than words. She was baptised immediately. I was allowed to hold her and Breadwinner held the oxygen mask while all the nurses in the baby unit gathered round and sang the Ave Maria in Japanese

because Dolphin's real name is Mary. The Japanese call Down's people *tenshi*, "angels", and it hadn't taken Dolphin very long to show us why.

Although the doctors in the Heart Institute speak English, it's very frustrating not being able to communicate with the nurses and the other mothers, especially when I want to say how grateful I am for all their kindness. Smiling and nodding vigorously are OK for a while but impossible to keep up without looking silly. I hope my face shows gratitude as effectively as it masks amazement at some of the goings-on in the ward!

Having worked in a London hospital, I'm used to Sister blenching at Ribena rings on the locker tops or at the mildest whiff of apple core from the bin, and exploding at visitors who dare to perch on the beds. In Japan, patients are looked after by their relatives, who provide food, laundry and basic nursing care during the day and sleep on camp beds in the ward at night. That's why the air is thick with the steam of damp washing and the fumes of curry noodles. The fathers of most of the children on Dolphin's ward only come on Sundays. Exhausted after their six-day week, they turf their children out of bed and

curl up for their customary Sunday sleep. Breadwinner pronounced this an excellent scheme but he's too big for Dolphin's cot.

The mums were quite wary of us at the beginning, especially the ones from outside Tokyo who hadn't seen many live foreigners before. But after a certain amount of bowing and admiring of babies, little presents began appearing on Dolphin's locker: huge shiny pears from Hokkaido, sugared beans, paper cups filled with *sushi*, mysterious cans of drink called *Pocari Sweat* and *Calpis*, even a knitted bonnet with matching bright pink handbag. (Breadwinner had to sneak the beans out in his briefcase because they give me terrible wind.) Even when Dolphin and I are at home with Jo and Epiphania, gifts occasionally arrive by post. Last week, dove-shaped biscuits came from Mrs Kuro In Nagasaki. ...



Ideas

This is a feature we hope to be able to run regularly - with your help! We thought it would be useful to pass on to each other experiences which had been helpful in bringing up our children: pieces of equipment that we'd found worked well, unusual toys or hints on overcoming any of the difficulties we'd been faced with. Sometimes the simplest item of equipment or piece of advice can be a godsend.

When our daughter Katie was born in 1984, we were very fortunate to have an extremely helpful Toy Library close by and a very sympathetic physiotherapist who was attached to the local special school. Without them, I know helping Katie make the best progress would have been much more difficult.

When Katie arrived, we were determined to get her all the latest equipment - thinking it would do her the most good - but we soon learnt that wasn't the case.

We had a super baby bouncer but the ones available then were not very substantial - stuffing it with rolled-up nappies to stop her slipping through the straps meant her movements, tiny though they were, were restricted. She didn't have the strength to bounce the chair but she obviously liked being able to see things and we were keen to "stimulate" her. It wasn't until my first visit to the Toy Library that the perfect solution was found.

I arrived very apprehensive of what I'd find, was welcomed with open arms - literally. The ladies in charge were all anxious to give Katie a cuddle. Then a cup of tea arrived and Katie was promptly popped onto a bean bag. I was horrified. I needn't have been. She loved it. She was supported comfortably, could watch what was happening and was able to move her arms and legs. We bought her one. She was happy to lie on it when she was tiny before she could hold her head up and afterwards she liked squirming in it; it even helped her in learning to walk! By holding her a step away and 'throwing' her gently towards it, it became a favourite game. She had so much fun 'diving' into it she was soon actually taking steps as we inched further and further away from it.

There followed a wonderful corner seat and table which I'm sure gave her the extra confidence, just as she was trying to sit unaided. We've enclosed a sketch to show her busily at work with her toys.

Our local physiotherapist had it all worked out. After this came a small table and chair. Unfortunately, Katie was so small that the chair was too high, her feet didn't touch the floor so she needed help to get on and off and didn't feel very secure. We hit upon a very useful alternative - a piece of ordinary pallet, topped with foam and covered with a soft material. She used this little "bench" for over a year. Friends could sit beside her and help her with her games but it was also the perfect place for lessons from Chris, her teacher/counsellor - just like being at school. It seemed to help her concentrate as when Chris arrived Katie went straight to her table and bench and was ready to begin. It also worked the other way - when she'd had enough, she upped and left.

I'm sure lots of you have useful ideas that would be helpful to others - do drop us a line so we can spread the word. Maybe talented parents have designed special toys or pieces of equipment - if so please share your ideas with us - it may make all the difference to someone you've never even met.

Maggie Linde



Tony Linde

Research

In this section, we'd like to report on any research of particular importance to our children. So, once again, any of you with close links to professionals receiving research journals - please ask your friends to pass on copies of any relevant research.

The following report relates to the education of children with Down's Syndrome and, though it does not touch on heart conditions in any way, still I thought it would be of interest. I've not tried to produce a precis of the study, but have merely extracted relevant and representative bits.

Let me know if this is the sort of thing you want to see in your Newsletter. If anyone wants a complete copy of the report (with full list of references), please write to me enclosing a stamped addressed envelope.

Br. J. Psychol., 58, 279-286, 1988

INTEGRATION OF DOWN'S SYNDROME CHILDREN IN THE PRIMARY SCHOOL: A LONGITUDINAL STUDY OF COGNITIVE DEVELOPMENT AND ACADEMIC ATTAINMENTS

By Wendy Casey, David Jones, Barbara Kugler and Brian Watkins

Summary

Thirty-six Down's Syndrome children, half of whom attended mainstream primary or nursery schools and half schools for children with moderate learning difficulties, were assessed over a two-year period. Baseline and six-monthly measurements were taken of their progress in expressive language, comprehension, numeracy, verbal fluency, drawing ability and reading. Mental age was estimated at baseline and at the end of the two years. The mainstream children made significantly greater progress in numeracy, comprehension and mental age and compared favourably on all other measures. The results are discussed in terms of their implications for integrated education.

...

Sample

Thirty-six Down's Syndrome children, half of whom attended mainstream schools and half attended schools for children with moderate learning difficulties (MLD), were identified by approaches to Local Education Authorities (LEAs) in Greater London and the Home Counties. ...*(The final sample had nine girls and nine boys in both the mainstream and MLD schools.)*

In all, 12 MLD and 17 mainstream schools across 11 LEAs took part in the study. In four LEAs the general policy was to place MLD Down's children in MLD schools and only one child in these LEAs was attending a mainstream school; this was at the parents' specific request. In six LEAs the general policy was to place MLD Down's children in mainstream schools and all children from these LEAs in our sample were thus placed. In the remaining LEA parents had the option of mainstream/MLD placement for their Down's children. Three children from this LEA were included in the present sample. By parental preference, two children were in mainstream education and one was in MLD education.

...

Discussion

It is apparent that there is an overall trend within the results which would suggest that Down's Syndrome children in mainstream schools do at least as well as, and frequently better than, their peers in MLD schools. ... in general the children in mainstream education perform better on all the variables measured over the two-year period.

The progress made by the mainstream children is not attributable to differences between the groups at

continued

or before baseline ... The main differences then between the mainstream and MLD children in terms of the effects of schooling are in higher numeracy and comprehension scores and a significantly greater gain in MA (mental age) in the former group at the end of the two-year period.

It is outside the remit of this study to attempt to make causal statements regarding the nature of the influence of mainstream education on the progress made by Down's Syndrome children. It would indeed be difficult to determine which aspects of the mainstream placements contributed to the improvements made by the children in just two years study. However, the results, indicating as they do specific academic advantages in numeracy and comprehension in these mainstream children, as well as significant improvements in general cognitive ability and a trend in their favour on other measures, go some way to providing the sort of efficacy data for mainstreaming demanded by Zigler and Hall (1986). A wider ranging study is called for which would control more educational and social variables, ... The evidence from this study is that Down's Syndrome children whose ability levels are congruent with those of children with moderate learning difficulties are capable of having their special educational needs met within the mainstream curriculum and the environment of the mainstream primary school.

References

...

Zigler, E., and Hall, N. (1986). Mainstreaming and the philosophy of normalisation. In Meisel, C. J. (Ed.), *Mainstreaming Handicapped Children: Outcomes, Controversies and New Directions*. Hillsdale, N. J.: Lawrence Erlbaum.



Other Groups

In this section, we'll let you know about any other groups that come to our attention that would be of interest to parents. We'll just include a short piece on the reasons for the group's existence and the name, address and phone number of a contact.

Any other suggestions?

The 1PF Specials

Or, rather, the One Parent Family Specials.

I've extracted this information from a copy of the group's second Newsletter (dated December 1988), which was given to me by Linda.

The group is a national one aiming to put single parents of *special needs* children in touch with each other. There seems to be a wide variation in both 'marital status' of members and the type of handicap being dealt with.

To find out any information about the group, contact:

Bryony Glass,
102 The Butts,
Westbury,
Wilts BA13 3EZ

Phone: 0373-865019

The Family Fund

The Newsletter from the 1PF Specials contained a note about the Family Fund which can give help to families of severely handicapped children under 16. This help can be in the form of a washing machine (if the child's disability, for example, means an inordinate amount of clothes washing has to be done), money for holidays or family outings, bedding and clothing grants.

The fund is financed by the government and independently administered by the Joseph Rowntree Memorial Trust. Contact:

The Family Fund,
PO Box 50,
York YO1 1UY

Network '81

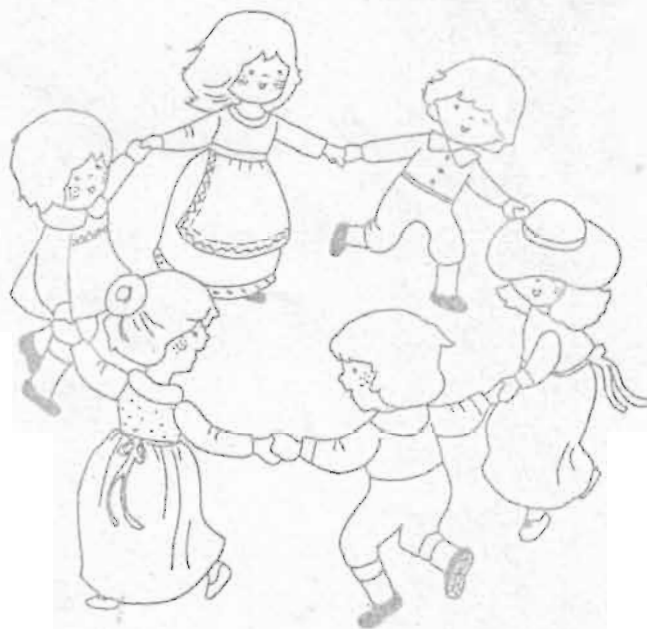
Formerly known as *'81 Action*.

Network '81 is a network of parents who offer support and advice on special educational needs. It therefore caters for other than children with Down's Syndrome but, obviously, they figure prominently in the network's membership.

The group is generally pro-integration but not at all costs - and it should be proper integration. The group provides information and can put parents in touch with people who can help. Local groups are very important as education policy differs from area to area.

For more information, ring Liz and David Arondelle on 0279-503244.

(Incidentally, Liz and David have a lovely daughter, Kirstie, who has Down's Syndrome but no heart defect, and who entered a mainstream secondary school last September).



Reviews

In this section, I'd like to invite readers to review books, TV and radio programmes, etc that they found interesting and which are of relevance to the group. (Eg, would someone like to comment on the recent series of programmes on TV on Birmingham Children's Hospital.)

We start with a couple of book reviews, one by Linda of her own booklet on the AV Canal Defect and then one by Peter Stephenson on a general 'heart' book.

TITLE: Heart Problems in Children with Down's Syndrome: The AV Canal Defect
 EDITOR: Linda Walsh,
 PUBLISHER: The Down's Heart Group, PRICE: £1 (draft copies only)

A unique source of detailed information on this complex heart defect which affects over half of our children, but only occurs very rarely in the non-Down's population. It is written by the parents of twelve children who have AV Canal Defect (sometimes known as AVSD or Endocardial Cushion Defect) and gives an overview of the experiences and quality of life of these and other children.

The main purpose of the booklet is to share these experiences with parents who are facing a decision with regard to corrective surgery. There are many arguments put forward, both for and against the operation and, in order to be as objective as possible, the cases have been selected, not for their optimistic tone or happy endings, but to reflect the patterns which emerged from the DHG sample of 88 cases of AV Canal Defect.

For this reason, the booklet does not make light reading. Some readers may find it distressing as it is designed to offer a personal and often emotional insight into the problems faced by these families and their ways of coming to terms with or resolving their problems.

The booklet also includes simple diagrams, a consultant's description of the defect, a question and answer section, glossary of terms and lists of further reading and useful addresses.

This is recommended reading for parents who need to know what might lie ahead for their child and for professionals who could benefit from the parents' perspective on this complex issue.

The first (unbound) draft copies of this 80-page booklet are now available. For those whose need is less than urgent, we are taking orders for the final bound edition which will be available soon, price about £1.50.

Linda Walsh (editor)

TITLE: Your Healthy Heart
 AUTHOR: Christian Barnard with Peter Evans
 PUBLISHER: McDonald & Co. Ltd
 ISBN: 0 356 10524 5
 YEAR: 1985 PRICE: £12.95

I obtained my copy of this book from my library. It is divided into two sections.

The first section deals with "The Heart" - how it works and what goes wrong. This section contains chapters on: Heart Surgery - the Early Years; Accidents of Birth; Acquired Heart Disease; Treatment of Heart Problems; and Cardiac Research / Technology. Obviously "Accidents of Birth" dealing with the various congenital heart defects would be of interest to parents. All common defects are explained with easy to understand diagrams and text.

Section two is entitled: "Keeping Healthy". As its title suggests, this section contains chapters with practical advice on health care for the heart. Chapters include: Controlling Stress; How to Stop Smoking; and Diet / Keeping Fit. Whilst this section is interesting, the advice given has probably been heard by most of us before.

In conclusion, I would thoroughly recommend reading this book - even if only the chapter on "Accidents of Birth" is of immediate interest.

Peter Stephenson