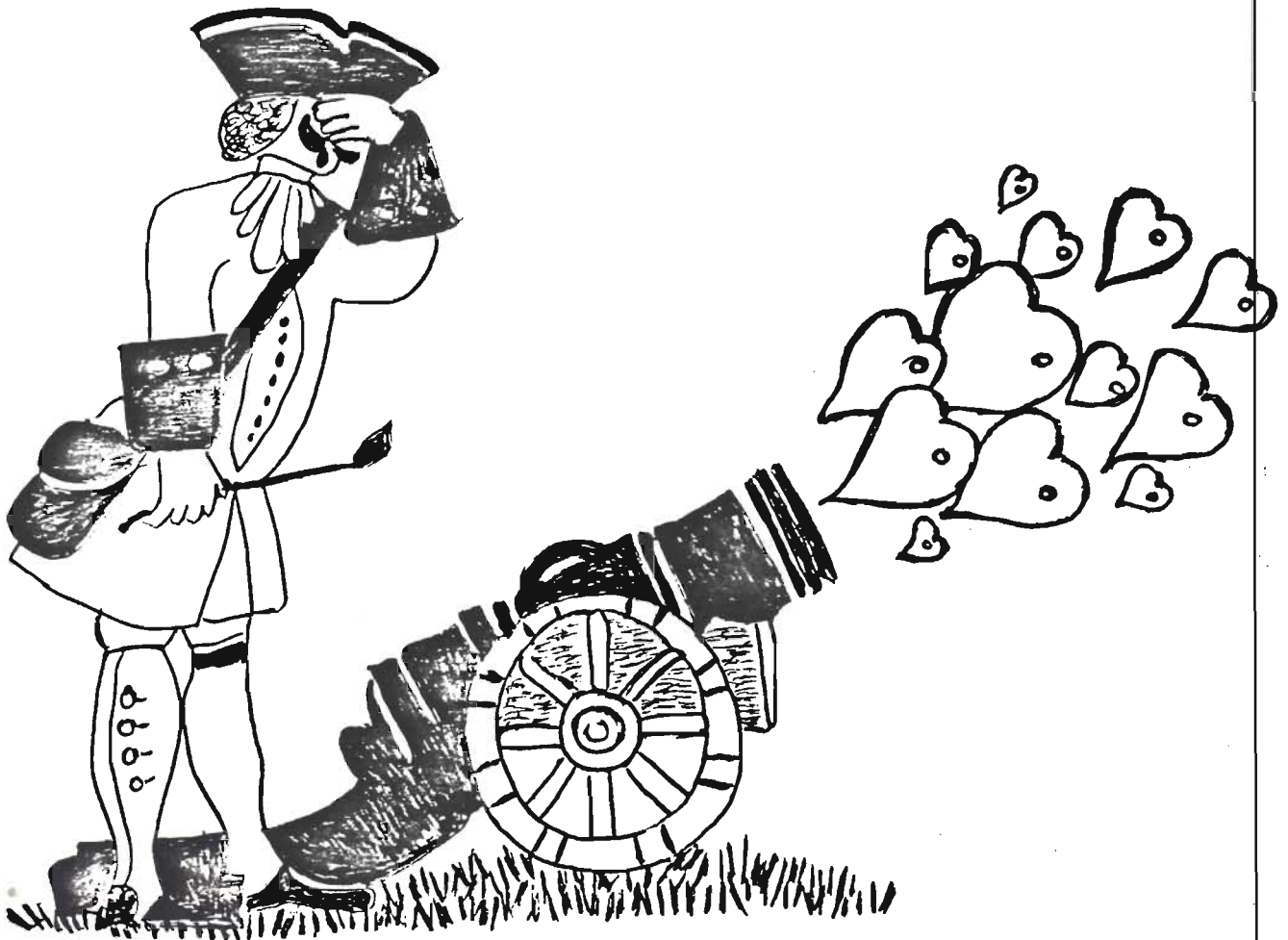




DOWN'S  
HEART  
GROUP

# NEWSLETTER

WINTER 1990/91



## STEERING COMMITTEE CONTACTS

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### Chairman

Euan Forsythe




### Vice Chairman

John King



### Treasurer

Sue Bamber




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### Secretary

Anna Danson




### Founder & Research

Linda Walsh



### Family Support Co-ord

Penny Green





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### Fundraiser

HELP

### Design

Wendy Tucker



### Newsletter

Denis Hopkins




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## EDITORIAL

Happy belated New Year to all our readers. Sorry folks but the new Committee voted that I continue to edit the Newsletter, I must impressed you with the Autumn 90 issue!!

My thanks have to go to Pam Cook for doing the computer work for me on this issue.

We held our Inaugural General Meeting in November 1990, so a Committee was elected to office. Linda Wash has taken on the task of research for the Group and we hope to be able to obtain a good computer for her to collect information and to work alongside Hospitals and Heart Specialists. Sue Bamber, our Treasurer is having to leave the Group to concentrate on having her second child, a brother or sister for Scott. Congratulations to Sue and husband. Simon Paul, our fundraiser, also has to give us his post because of business commitments. Both Sue and Simon are what we term as friends of the Down's Heart Group, they have committed themselves even though they don't have Down's children or their own.

Our expanding correspondence with you now means that we print 600 copies of our Newsletter. This is probably the Group's our most expensive yearly item. We had great sponsorship from Alf, our printer. Draft copies are usually produced by a friend but postage is expensive - it costs approx. 80p per copy to produce and post. We have tried for the cheap postage rate but unfortunately we do not comply as our mailing is under 4,000. Because of the high cost of producing the Newsletter, the Committee voted and it was agreed that we print only three editions per year instead of four. This was a hard decision to come to. The next edition will hopefully be available June 1991. I would like to thank everybody who sent in articles and please keep sending them.

## INAUGURAL GENERAL MEETING

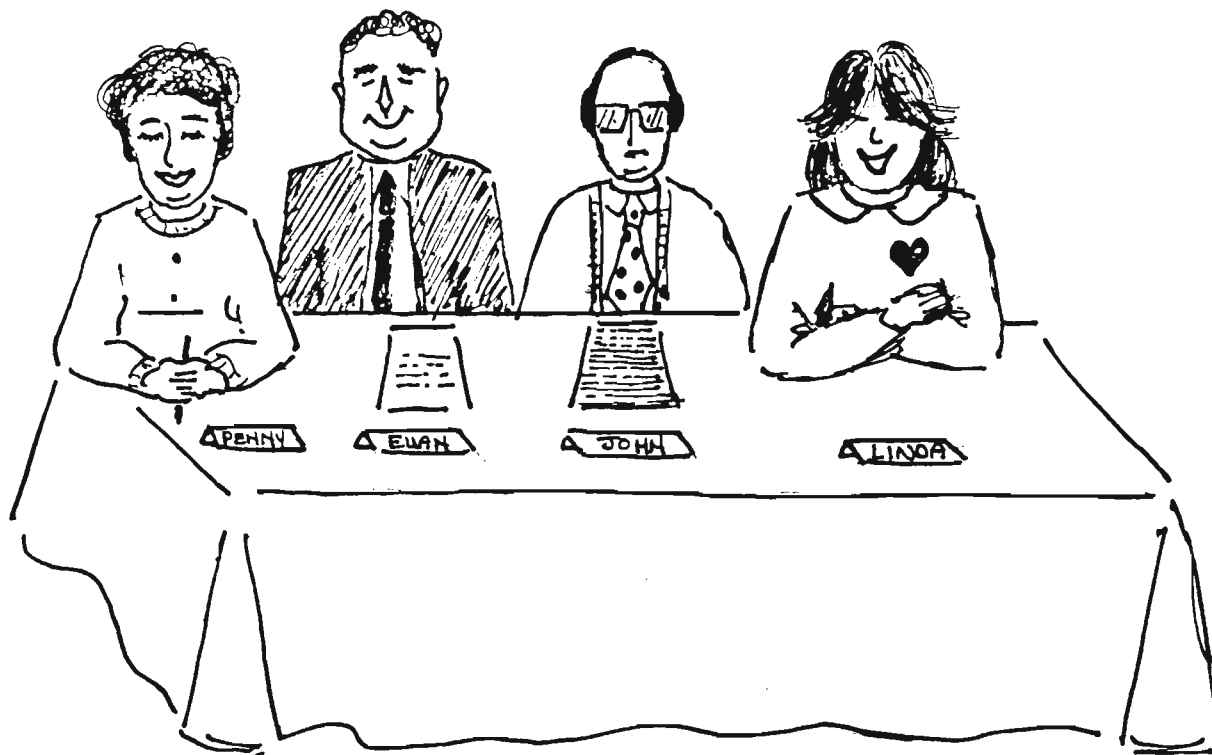
The Group held its IGM on 3.12.90. The day started with registration and then a welcome by the outgoing Director. Linda Walsh, the Group's founder, following with a talk on the first two years, which covered the time when she decided there was a need to start the Down's Heart Group right up to the present day. Our main speaker was Dr C.C.H. Newman MB., FRCP., DCH., Consultant Paediatric Cardiologist at Westminster Hospital who gave a very interesting talk lasting for 45 minutes, mainly referring to the needs for research into the problems of Down's Syndrome and Heart Defect. He wished us well for the future and also expressed the fact that the Down's Heart Group could well assist him with further research.

The IGM meant that we, as members, had to vote into office a General Committee to oversee the running of the Down's Heart Group. Euan Forsythe was voted Chairman, John King - Vice-Chairman, Penny Green - National Family Support Co-ordinator, Anna Danson - Secretary and Sue Bamber - Treasurer. Additional Committee Members were duly elected and their names can be found on page 4.

The afternoon saw a brilliant display by th Leicestershire Gymnastic Display Team made up mainly of Down's Syndrome children - not a dry eye in the audience! Carlene Keleman talked and showed a video on the 'Special Olympics'. After the video she introduced a young lady who had appeared as gymnast in the last 'Special Olympics'; she was a very capable young lady with Down's Syndrome who could show us able bodied a thing or two about keeping fit.

Phil Rowe, a Vice Chairman of the DSA gave a 15 minute talk of how the DSA and DHG could work well together and hoped that we would continue our association with them. The future of the Down's Heart Group was the topic for our now new Chairman, Euan Forsythe. We hope the future is rosy.

Many thanks go to all the people who made this a very successful day, not only to our speakers, but also to the kind people who gave their time for the catering, the creche facilities, the displays, and for all who turned up on the day.



Some of the v.i.p.'s at our recent A.G.M.!

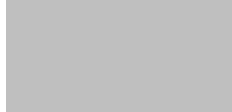
## REGIONAL REPORT

### LONDON & NORTHERN HOME COUNTIES

I attended a meeting at the Brompton Hospital on 9.11.90. This meeting was held by the Paediatric Surgeons Society and was attended by many top doctors and nurses. Voluntary groups were given display stands and were asked to attend for two hours during the delegates lunch break. I made contact with a number of other voluntary groups, handed out plenty of leaflets, and only wish that I had taken more Newsletters. Fran Cox, who organised this meeting, was our contact for the Brompton, but has now taken promotion within the hospital and Linda Partridge, who has taken over from Fran, showed a great deal of interest in our Group and I know she will help us as much as possible.

Lots of new names to add to our membership so I thank all of you for contacting me. I now have two contact names and addresses, so if you feel you would like to contact someone a little more local to you, then please do so:

Janet Drage



Sue Binns



Thanks to Nigel and Dina Woolmer for their kind donation, this will go towards the cost of Newsletter.

## REGIONAL CO-ORDINATORS

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### Wessex Area

Tel:

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### Kent & London South

Peter Stephenson



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### North East England

Sandra Welsh



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### London & Northern Home Counties

Denis Hopkins



---

### Northern Ireland & Eire

Rosina Brierly



---

### Bristol & South West

Sheila Forsythe



---

### Scotland


Lynn Gouck



---

### East Midlands

Gina Hojabri & Anna Danson



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### West Midlands

Pat Mitchell



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### North West England


Mike Halpin



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These are group members who have volunteered to take over a region to try and develop local family support. They live in their designated area and liaise with the National office, hospitals and new and existing local members. Any information received by the National office is passed on to these co-ordinators who in turn will make contact with the people in their region who may require that information. However, as you will see, the regions covered are very large and we still need more regional co-ordinators, and group contacts to cover smaller areas. If you think you can help in your area, please contact the National Office:

Penny Green



## PERSONAL PROFILE

### PENNY GREEN (FAMILY SUPPORT CO-ORDINATOR)

- FAMILY DETAILS** Husband is Malcolm (he knows a 'very nice man' who prints newsletters). We've just celebrated 10 years of marriage and have a son Andrew, who was born 22.4.88.
- DS CHILD** Our second son, Daniel, was born 3.8.89 on his Mum's birthday. He had an AV canal, and ASD and a Patent Ductus, also a bowel complaint called Hirschsprungs Disease. He died on 13.11.89 aged 14½ weeks. He had spent all of his life in GOS and our local hospital.
- OCCUPATION (Now/Prev)** I was a Bank Clerk for 10 years before having the children, and worked as a nanny for six months before having Daniel. I now work for a different Bank and do 3 evenings a week from 5.30-11.00, although I am often there later than that.
- WHY GET INVOLVED?** My reason for getting involved with DHG is obviously Daniel. I was helped by talking to others, and I feel that there is a great need for support and information for families with a Down's Syndrome child who has a heart defect. Having been through it myself, I hope that I can help other parents in some small way.
- WHY STAY INVOLVED?** I think there is a lot that the Down's Heart Group can achieve and I hope that I may be able to help. We still have a long way to go and are desperately short of bodies to get everything done.
- INTEREST/HOBBIES etc** Hobbies : stamp collecting, messing about with the DHG computer, being a MUM and moaning at John King.  
Ambitions : to do an Open University degree course and to fit 28 hours into a day.
- GROUPS FUTURE** I hope that we will be able to ensure that our Group is so well known, that all parents who need us will know straight away of our existence and how to reach us. I also hope that in the not too distant future, we will be in a position to get involved with some really productive research.
- COMMENTS** I hope that by Christmas I will be able to move all the DHG equipment, currently residing in our bedroom, out into the office that Malcolm is building at the back of the garage. (It is supposed to be his office, but by the time the computer, filing cabinet etc. are out there, he won't have a lot of room left.)

#### EDS NOTE

*Penny took over the Family Co-ordinator job when Linda Walsh left to have her baby. Penny has done a great job with updating the records etc. When a problem comes up she always says yes she'll do it. The Down's Heart Group is honoured to have such a committed Member - well done Penny.*



## STOP PRESS

## FUND RAISING

The National Housebuilders Federation raised £220.75 at their Annual Dinner Dance held at Leicestershire.

Mrs April Keeps held a Car Boot Sale and raised £70.11.

£9.10 was raised by a group of young people from Bristol with a Coffee Morning.

Edith Weston Village Stores, King Edward's Way, Rutland, Leics. - kind donation from customers of the Village Stores.

Archbishop Blanch School, Wirral, Cheshire - Staff and Pupils held a sponsored silence and raised £135. Thank you everyone concerned.

Thanks to the Northwick Arms Knitting Club, Ketton, for the kind donation raised at their Christmas Bazaar.

Bristol and SW Group raised £60. This was used to contribute towards the print cost of the Autumn Newsletter.

Jon Spall, aged 31, from Shirley, Croydon, Surrey, is to run in this years LONDON MARATHON on 21 April 1991 on behalf of the Down's Heart Group. Jon's stepsister Elizabeth, nicknamed 'Bloomsie', was a Down's Syndrome child with an AVSD. Bloomsie has inspired Jon to run in this Marathon. All the best Jon.

#### Bedford Prison - Sunday 27 January 1991

John King, Penny Green, plus a number of families, were invited along to Bedford Prison to accept a cheque for over £2,000. This was presented by the Governor of the Bedford Prison. The money was raised by a Charitable Auction of memorabilia and autographs donated by celebrities. The event was put together by the inmates and staff of the Prison and broadcast by BBC Radio Bedford.

After the presentation a buffet lunch was prepared by Officer Mick Reeve and Ex-inmate 'Maximum'. Our thanks go out to all who were involved in this project.

## Teeshirts and Sweatshirts

*These are now available bearing the Down's Heart Group logo.*

### TEESHIRTS

*White with pink heart and black script.*

Adults	S M L XL	£4.99
Children's	24" 28" 32"	£3.50

### SWEATSHIRTS

*Sky blue, grey or white with pink heart and black script.*

Adults	S M L XL	£9.99
Children's	24" 28" 32"	£6.99

*These prices are inclusive of VAT and postage & packing. Cheque or postal order with order please to:*

*Mara Young*

*Please phone to confirm size and colour before sending order, complete with an order in writing and payment. Thanks.*

## FOOD, GLORIOUS FOOD

One section of the Newsletter that I have missed in the last couple of editions is the 'Food Glorious Food' slot.

Having been through nearly 3 years of feeding problems with Katy, which on many occasions reduced me to tears, I was surprised to hear from many other parents that they had experienced almost identical problems, and yet each of us believed at the time that nobody else was in the same boat!! Lots of our children are very strong willed and having once decided that they don't like, want, or need food, it takes the patience of 'Job' to convince them otherwise.

So come on all you survivors out there - if you have fought the fight and won a round or two, let us know the secrets of your success. Remember that lots of readers of this Newsletter are facing these problems right now and it might just be YOUR FEEDING TIP that helps persuade that tightly closed little mouth to open! Just to start the ball rolling, I'm sending Dennis a few ideas, but it's YOUR IDEAS we need if we are to make this a regular feature.

*Footnote: I have to forgive Dennis if he wonders what the fuss is about! I first met young Jonathan Hopkins at the Group's Christmas Party, but he couldn't say hello because his mouth was full of food, and I can honestly say that his well proportioned figure belied the amount that child eats! He is apparently insatiable. Any tips Den???*

### Breast Feeding?

Yes, contrary to popular myths, Down's Heart babies can, and do, breast-feed. Lots of mums in our Group are willing to talk to new mothers who want to breast-feed. Some professionals have been known to frighten new mothers into giving up because their baby is not gaining sufficient weight. Only when it is too late do they realise that the baby doesn't necessarily do any better on bottle-feeds. which suggests that the mother's milk supply was more than adequate in the first place.

My advice would be that it's worth persevering if you want to breast-feed, just so long as your baby doesn't continue to lose weight after the first week or so. Dozen of parents will confirm that whether on breast, bottle or solids, there are some babies who just do not gain enough weight to be measured over a few days - it may take weeks for a tiny increase to be shown. But keep calm, so long as the trend, however slow, is upwards and not downwards.

If you have breast-fed a child with Down's Syndrome and a heart problem, please let us know how you fared. Written accounts would be welcomed for inclusion in a future Information Sheet on Feeding Problems.

### Bottle Feeding?

Although my daughter would not even tolerate the teat of a bottle in her mouth, lots of other mothers have told me about their more successful, but often exhausting, experiences of bottle-feeding.

The majority of Down's Heart babies are bottle-fed - usually because anxious parents or professionals want to actually measure how much milk they are taking, or in most cases not taking. My advice here would be to try not to get too hung up on how many 'mls' your child takes at each feed. Do your best to relax while feeding and just keep trying different shaped teats and bottles and different types of milk (don't forget to try Soya milk or even diluted Carnation milk if your desperate).

*EDS NOTE: On this same subject read on - see articles pages 9 and 16 'Haberman Feeders' and details from 'Cow and Gate' on Soya formulas and standard baby milks.*

### Weight Gain

For both breast and bottle-fed babies who are not gaining weight as the charts say, they should remember:

1. The charts make no allowances either for Down's Syndrome or heart problems, so it is highly unlikely that your child's weight will even register (never mind shown as 'normal') on the standard clinic charts.
2. If your child seems to get tired while feeding, and you are really worried about their level of nourishment, then bend a few rules when it comes to introducing solids. Even very young babies may be better off for a spoonful or two of runny baby rice, which is not so tiring to swallow as all that milk which needs sucking!
3. 'Little but often' is a tried and tested method of increasing food intake - all too often feeds take so long that one 3-hour feed runs into the next. So try to accept the fact that your baby may only be able to accept tiny quantities of feed at each feed. It may be less tiring for both of you if you try very frequent but very short feeds rather than sitting for hours on end trying to get the prescribed number of 'mls' down before its time for the next feed.



4. If you are a first time mum (as I was), its easy to think that everyone else knows best. I would dispute that very strongly now that I have had four babies. Every one of them has been different, and only 'mum' knows here baby well enough to be tuned to its needs.

### The Obvious

Lots of things that we tend to think of as 'junk food' do in fact have a little, and in some cases a lot, of nutritional value. So, if your child has feeding problems, but will tolerate some of the foods on this list, don't despair ..... it's doing them some good! - peanut butter, jam (high fruit)/low sugar if possible), milk shakes, jelly (make it with fruit juice or evaporated milk), baked beans, ice cream.

### The Not So Obvious

Little taste buds act in mysterious ways. Don't be too conservative in what you offer - strong or acquired tastes can go down quite well.

*Linda Walsh*

### ARE YOU HAVING FEEDING PROBLEMS WITH YOUR BABY HAVE YOU HEARD OF THE HABERMAN FEEDER?

This is a revolutionary feeder designed for infants with sucking problems. Babies with poor sucking action are commonly fed with conventional teats in which the hole has been enlarged or extra holes added, these frequently cause 'flooding' and inevitably result in panic and choking, the *Haberman Feeder* is a new approach to the problem.

The Feeder consists of four components for attachment to a conventional wide-necked bottle. The teat, formed from tear resistant food-grade silicone, has a mouthpiece which is soft and malleable and has a slit-valve opening.

Activated by tongue pressure rather than suction, it delivers feed in quantities controlled by the baby. If the baby need help, gentle finger pressure on the reservoir delivers a small quantity of feed at a time.

Alternatively, simple rotation of the teat in the mouth can reduce or stop the flow altogether, enabling a previously frightened baby to get used to the feel of the teat before feeding starts.

The *Haberman Feeder* can be used to give expressed breast milk. Not only is the Feeder easier and much more pleasant to use than spoon or tube feeding, but for babies with sucking difficulties, it is also far quicker than other oral methods. In hospital tests, it delivered on average nearly five times as much feed as conventional oral methods over a 15-minute period.

As a bonus the Feeder helps to reduce wind. Air must be taken in to replace the feed, but the unique design of the Feeder ensure that the air is taken into the body of the bottle at the same rate as the feed taken out. No Vacuum is created and the baby need not let go of the teat. Air swallowing is avoided, as in breast feeding.

This Feeder was designed by a mother - Mandy Haberman - who had first hand experience of feeding problems, and it has since been used successfully for many babies.

If you are experiencing problems and would like to obtain more information about the *Haberman Feeder*, you can get in touch at the following address:

*Haberman Feeders*  
44 Watford Road, Radlett, Hertfordshire WD7 8LR  
Telephone: (0923 853544)

### BEREAVEMENT QUESTIONNAIRE

I would like to thank everyone who completed the Bereavement Questionnaire. It was lengthy and difficult to complete, and I very much appreciate the thought and honesty everyone put into it. The experiences were upsetting to read, and I know they must have been even more upsetting and painful to write.

As painful as it was, I am confident that the results of the Questionnaires will offer some degree of hope and comfort to families in the future who sadly need information, and who may wish to know how others felt and coped. As we are all painfully aware, no-one understands how a bereaved parent feels better than another bereaved parent.

Finally, I would like to thank all of you who expressed your sympathy and best wishes following the death of our precious baby Kate.

Thank you.

*Lynn Stallwood*

## REPORT BY PENNY GREEN NATIONAL FAMILY SUPPORT CO-ORDINATOR

It seems strange now to be referring to Christmas, but as this is the first Newsletter after that busy period, it is my first opportunity to say "Thank You" to all those of you who sent us Christmas cards and orders for Down's Heart Group cards, and for the many donations and stamps I received. I wanted to write to everyone personally, but felt sure that most of you would think it a waste in that part of your generosity was spent on posting a letter. Please be assured, however, of our gratitude for every single gift sent, no matter the size. They will all be put into good use in our efforts to offer support and information to all our Members.

Things are going from strength to strength within our regions and we now have at least moderate representation in all areas, but there are still a few places where additional help would be gladly received. At present we have no Regional Co-ordinator in our Wessex Region covering Dorset, Hampshire, South West Wiltshire, Isle of Wight & Channel Islands; East of England covering Lincolnshire, Norfolk, Suffolk & Cambridgeshire; and Yorkshire and Humberside covering North, South & West Yorkshire and Humberside. Also our Scottish, Irish and North East Regions are represented by one person each, and I am sure that all three of them would welcome an extra pair of hands to assist them at times. If you feel that you could be of help in any way, please give me a ring for a 'no obligation' chat. It maybe that you have an important role to play in the Group, even if your time is limited.

Gradually, the DHG is becoming known to people in all areas and it is my personal hope that one day every family who have a child with Down's Syndrome and a heart defect will be made aware of our existence from the moment of diagnosis so that they know where to come for support and information without having to look. All of our Members have a valuable part to play in this. Even those who are presently in need of support and friendship will probably feel at sometime in the future, that they can share their experiences with a family who are newly faced with the problems and help them not to feel so alone.

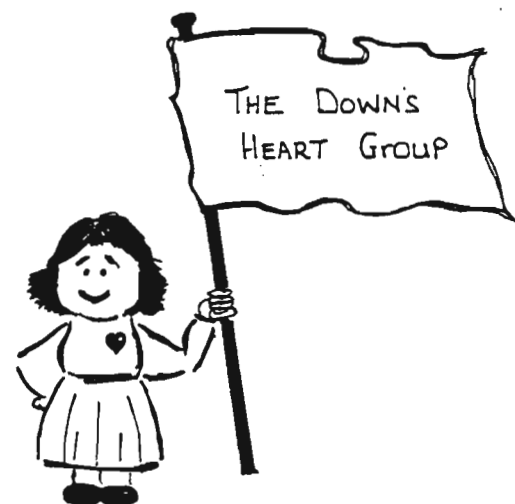
Finally, in our Summer '90 Newsletter I asked for your experiences with regard to claiming 'Attendance Allowance'. The response was very disappointing, with only a few families sending information, so it has been impossible to assess the situation accurately. From those replies I did receive (many thanks) there are a few helpful suggestions:

- When detailing your child's problems, leave Down's Syndrome until the last.
- Keep a diary for 7 days prior to your assessment, including every little thing that you do for your child in detail.
- Ask your paediatrician, family doctor, health visitors, social worker etc. if they would write you a letter supporting your claim.

*Penny Green*

### FROM A BIG BOTHER (who's only small)

At eighteen months it was hard to know  
The reasons why you had to go  
One year later, I still can't see  
Why you won't come back to me  
They say when I'm older I'll understand  
But I won't remember when I held you hand



Our little unplanned accident  
Another baby boy  
Born on his Mummy's birthday  
Oh great delight and joy

I had a few complications  
What a fuss and to do  
But whilst I was asleep  
You started going blue

The Doctor came to see us  
Explained as gently as he could  
They had to wait for confirmation  
But it really wasn't good

A Down's Syndrome baby  
How could he be? not mine  
I thought it happened to older mothers  
and I'm only twenty-nine

The tear and the rejection  
The trying to understand  
The thing that made it better  
Was touching your little hand

Before we could begin to recover  
They tore our world apart  
As well as a bowel problem  
There were problems with your heart

Then followed weeks of worry  
Filled with longing to bring you home  
Hours of hospital visiting  
You in your plastic dome

You had your first heart operation  
and made it through the night  
Finally we began to believe  
That things would be alright

Then it happened all so suddenly  
The phone call at midnight  
You had gone so quickly  
They just could not be right

Your tiny heart was broken  
When you left mine snapped in two  
And although life has to carry on  
I'll never forget you

I thought of you this birthday  
I'll do it every year  
The day we share together  
Oh little man so dear

Now I'm having another baby  
It took some courage to do  
But of one thing I'm certain  
It will never replace you

## Ward skills 'could save many babies'

HUNDREDS of babies could be saved from brain damage and death by improving the resuscitation skills of doctors and midwives, it was claimed yesterday, writes Liz Hunt.

A working party of the Royal College of Obstetricians and Gynaecologists said that all labour ward staff should be capable of reviving babies who fail to breathe in the first minutes after birth.

The college said that while improved facilities for neonatal intensive care are widely acknowledged, less attention is given to the first minutes of life when expert care without expensive technology can minimise long-term health problems.

Dr Harold Gamsu, chairman of the British Paediatric Association, said: "We have all seen examples which we have been dismayed about, where better management could have resulted in a healthy life rather than a tragic one."

About 600,000 babies are born every year in Britain. Of these, 100,000 are at risk in the first few minutes after birth. Between 20-30,000 babies are at "serious risk" if they do not receive help in breathing immediately. The working party estimated about 600 die or suffer permanent damage as a result of events in the first minutes after birth.

The working party has produced a video and information pack intended for anyone concerned with the care of the newborn. Dr Gamsu said the aim was to ensure that everyone in the labour ward would be capable of resuscitating babies.

*Article from 'Independent' 19.12.90*

*Article from  
'Independent'  
3.1.91*

## Deafness risk from untreated 'glue ear'

By Liz Hunt  
Medical Correspondent

A QUARTER of young children are at risk of permanent deafness from a hearing problem which often goes untreated, it was claimed yesterday.

The National Deaf Children's Society said that up to 80 per cent of cases of "glue ear" or otitis media in children under 10 went undiagnosed. It was the commonest cause of fluctuating deafness in the under-fives.

Robert Ashby, the society's public services officer, said glue ear could also impair learning ability.

At the launch of a campaign to alert parents, teachers, and doctors to the problem, Mr Ashby said: "The message is simple: diagnose and treat glue ear early and you avoid major traumas at school and at home." He said the condition was "like having your head enveloped in sponge." If untreated, it could permanently damage hearing.

Glue ear, which often follows a cold or flu, is the result of a build-up of mucus in the middle ear, the cavity behind the ear drum. If the tube linking the cavity to the back of the nose is also blocked, it cannot drain away and becomes compacted, stopping the eardrum from vibrating. The child will have deafness equivalent to "sticking a finger in each year".

The first symptom is some degree of deafness. The child may be unaware of this and unless parents or teachers notice unresponsiveness, the problem will go undetected. Other symptoms may include painful earache, while younger children will often tug repeatedly at their ears.

In many cases glue ear will clear up of its own accord but usually treatment with decongestants or antibiotics is necessary. If the problem is more severe, doctors will make a small hole in the eardrum to drain out the fluid.

## YOUR EXPERIENCES

### When a Child is Dying Katy's Storey

My baby daughter, Kate, was born with Down's Syndrome and a severe heart defect. At that time I knew no-one who had a child with either Down's Syndrome or a heart defect. Kate was not expected to live very long, and we were told we could possibly have her with us for a year. Our first shock had been news of the Down's, the second was the heart defect. To then be told she was going to die within a year felt like we were being machine gunned.

When we brought Kate home from hospital, we were told to expect a number of months with her, certainly not days or weeks. Kate was having cyanotic attacks and we were controlling her pain and distress with morphine. Then when Kate was just 3 weeks old she stopped breathing in the early hours of one morning. It was during the Ambulance Drivers dispute and we waited 40mins before the Army landrover arrived to take us to hospital, I thought Kate would die before I got her there. She was clearly very, very, poorly and I knew without being told that she was dying. Later that day I said to the Consultant that I knew Kate would die in the next two days, and he replied that medically he could not comment on that, but sometimes Mum knew best! He said Kate could be cared for in hospital and this simply confirmed what I already knew.

We decided that if Kate had to die, then she would die at home when I was with her and her family were around her. We brought Kate home that same day and she died in my arms two days later on 23 December 1989. Throughout all of this we felt very much alone. It was as though it had never happened to anyone else. When we were told initially that Kate would die, we were devastated. but once she was home her death was 'sometime in the future, it wasn't imminent, wasn't now, and we simply got on with giving her all the love we had and all the care we could. But after that rush to hospital that Thursday morning, her death was 'imminent', she was dying now. What we had always known had never left our minds, but now it was very, very, real and very painful and frightening.

It is one thing to know that your child is dying; it is another to know that it is happening now and that in a few hours or day, she or he will no longer be with you. We had had to make decisions that before Kate's birth we never would have believed we would have to face - should we have Kate cared for in hospital? should we allow her to die? These decisions we had to make and many others, and we had to make them alone for we

knew of no-one else who had been in this position. Even if we had known someone the decision would still have been ours, but it would have been comforting and helpful had we known someone who could have listened to us, who could have told us how they had coped, what decisions they had made and how they had made them, and whether they would have done anything differently. We felt so alone!

I wonder then whether we feel, within the Group, that we could establish a group of parents who have been through this and who would support other families facing it. It may be that we could support each other via the telephone, or by being with the parents either at hospital or home if this is what the parents wish for. Not all families would want to talk to someone at this point. When faced with the imminent death of your child, it takes all your resources to simply stay in one piece. But for those families who want to talk and what to know how other families coped, and what options they may be able to consider, perhaps it is worth thinking about setting up some sort of network.

I appreciate fully just how hard it would be to support families facing what we have already faced. Memories that will never leave us would be brought to the fore and we would once again relive our own heartbreak. But maybe we can at least consider the possibility and see if we think it feasible. I would like to know what you think. So please, if you have any views, write them for the next Newsletter or contact me at home.

*Lyn Stallwood*



### Michael's Story

I have come by a copy of the first edition of the 'Down's Heart Group Newsletter'. I found myself unable to put it down until I had read every word because it was all too close to my experience with our son Michael.

Almost a year old now, Michael is a healthy, though little, chap thanks to successful surgery to repair an AVSD when he was a month old. I hold in awe the team at Birmingham Children's Hospital who looked after him. Words cannot express the debt of gratitude I feel to those people who, it seems, gave Michael a real chance to live. There are so many aspects of the experience which occurs to me that I feel I could write pages, but I shall try to restrict myself,



for the moment, to one or two objectives.

I am not sure whether many parents, like myself, hesitate to agree to early surgery. I was as reluctant to put Michael through an operation, to risk his little life. He was so fragile, so trusting, so dependent, that the idea of his tiny body and tiny heart being cut really shocked me at first. However, now I see so many reasons why a skillful surgeon should be allowed to operate as early as possible.

1. A young babies heart is a strong muscle if heart failure has not affected it for a long enough time to weaken its functioning. As a result it is able to better withstand the trauma of surgery.
2. I think everyone is aware that the younger the tissue, the quicker it heals. A child's cuts and grazes heal so much sooner than adults, so a young baby undergoing surgery will heal up much more quickly and, therefore, be less at risk of post operative infections in the wounds.
3. Since our Down's Syndrome children are more susceptible to chest infections and the like, there is a greater risk that an older child may have suffered some damage to his lungs which could complicate the operation or the child's recovery from it.

These are some of the factors which I believe helped Michael to a speedy recovery. One other thing which I feel strongly about is the positive benefits which he gained from being exclusively breast-fed. It is well documented that breast milk contains antibodies which give the baby resistance to many infections. At no time is this more vital than when recovering from a major operation. Additionally, since it is such a natural food, the stomach finds it easier to digest than formula milk, so resuming milk feeding after surgery is easier too.

I do feel that we should do more to encourage mothers of all babies to breast-feed, but more especially to do so for Down's Syndrome babies and particularly Down's Syndrome 'heart' babies. Of course it can be difficult, but couldn't we do more to support those who might be willing to try in the early days to give our babies a little extra help?

*Mary Solomon  
Tettenhall, Wolverhampton 2.10.89*

## Lucy's Story

Lucy was born on 28.11.84 in Torbay Hospital, her heart defect was not diagnosed immediately. Lucy was being placed with us as Foster Parents prior to her being Adopted. When Lucy was almost 3 weeks old, she was due to come home with us when it was discovered she had a heart murmur. It was decided, however, that she could come home, but would have to have her heart monitored regularly.

Lucy had her regular heart check-ups. We were always assured it was a small hole and there was every possibility it could heal itself over. If it didn't, it should not cause her any problem. However, her clinic doctor had always maintained it would need surgery and she was ultimately proved correct. In August, when Lucy was about 9 months old, I took her to the Children's Hospital attached to the Bristol Royal Infirmary, for a catheter test. It was discovered that there was also a blockage between the heart and the lungs. This blockage, in fact, was of benefit to Lucy, as it prevented a lot of the blood returning to the lungs through the hole. Lucy did need to have an operation sometime during the next 3-6 months. If she didn't, her life expectancy would only be to her teens and if the operation wasn't performed during the next 6 months too much damage would be done to the lungs and she would not be operable.

We were asked in view of Lucy having Down's Syndrome, how did we feel Lucy's quality of life rated, in other words, did she warrant having the operation when there were other children needing the operation who were not mentally handicapped. This was not done in a nasty way at all, in fact we felt quite sorry that doctors had to take such awful decisions - deciding which child they could afford to operate on and which they couldn't. We felt complete and utter relief that he decided Lucy did warrant the op. In actual fact, as Lucy was only Fostered by us, we had no decision to make as to whether or not she had surgery. The decision was made by the Local Authority, but we knew they would agree to it. The element of risk was around 75%. Lucy didn't appear to have any symptoms of a heart problem prior to surgery, although afterwards she improved so tremendously and looked so much better - pinker - that we realised how severe her heart condition had been.

Before Lucy's operation, she had been in hospital for the catheter test in the August and in the December immediately prior to her operation. On this occasion it was for a chest infection, but she soon recovered sufficiently to return home after 5 days.

Lucy was 14 months old when she had the operation to close the hole in her heart etc. She was in theatre for almost 5 hours and in the Intensive Therapy Unit for 24 hours. Ten days after the operation Lucy was allowed home, much to everyone's relief. Her 'convalescence period' at home lasted for about 6 weeks, although at Lucy's age it was hardly convalescence. After 6 weeks we returned for her check-up and everyone was quite happy. We were told, before we left hospital, that the hole had been a lot larger than they had originally thought and were unable to stitch it, but had to patch it instead. She still had a slight heart murmur, which could be caused either by a small seepage through the patch, or more likely from where the blockage had been treated. Either way it was nothing to worry about and further surgery was highly unlikely.

The hospital stay was, for all of us, quite a traumatic experience. My husband was ill with flu whilst we were away, and my daughter missed us terribly and wanted to come and stay with us. They visited us for a couple of days during the stay - that's when David had the flu - Elizabeth, although 12 at the time, cried when she had to return home.

Prior to going into hospital for her operation. Lucy had been very friendly and happy with anyone and everyone. However, as soon as she had had her operation and she had to have blood tests. X rays, heart monitors regularly, she changed completely. She cried everytime someone came into the room, especially if they wore a uniform - even the tea ladies upset her. She would scream and cry if I left her and this continued for months. In fact, at the time, the change in her character upset me more than anything else. It took months and months before she returned to anything like normal. Because of this emotional upset, which lasted for such a long time, I feel it hindered her physical progress and I think it took a good 6 months before she started to improve in an 'all round' way. The heart specialists were pleased with her heart, but looking back, there was a lot more to it than that.

Lucy is now 3 years 2 months old - two years this week since we were in Bristol Hospital and she shows no sign of any heart problem now. She is very small for her age - about 18 months to 2 years in size and still takes a 2 hour nap a day, which I feel is quite a lot for a 3 year old, but this past month she seems to be able to get through each morning and lunch time without a sleep, so she is improving. Since her operation, Lucy hasn't been in hospital and only sees the family doctor if she is poorly, usually with a cold or needs antibiotics. I know myself now when she needs them and when she is coping, but as soon as she goes down with a cold, I get a prescription just in case.

After Lucy's operation we returned to Bristol Royal Infirmary after 6 weeks, then 3 months, a further 3 months, then two 6 monthly visits. Now we are reduced to a 12 month visit and all appears to be going well. During these visits Lucy is weighed, has a chest Xray and the specialist listens to her heart. Sometimes she goes on a monitoring machine, but that hasn't happened for a while.

Lucy goes to Playgroup twice a week and Opportunity Playgroup once a week. She swims once a week, is due to start Tumble Tots and has been waiting for some time to go horse riding. She is on the go all the time and joins in everything that all the other children do. Apart from her scar, no-one would realise what she has gone through.

We still use a buggy because although Lucy can walk quite well, she never wants to walk in the same direction as the rest of us. She was 2½ before she walked properly, on her own. It had taken 6 months from taking her first 2 steps to walking all the time. As far as her heart condition is concerned, I foresee no further problems for which we consider ourselves extremely lucky.

It was immediately after Lucy's heart surgery that we all decided that we couldn't bear to part with her, and applied to adopt her. Thirteen months later we finally went to Court and she became legally a member of the Cox family.

*Diana Cox, Chelston, Torquay - 1988*

*EDS word:*

*Diana, please give us an update and some photos.*

### **Lauren's Story**

This is the story of my darling little granddaughter - Lauren. Lauren was born to my daughter, aged 16, on the 8 April 1989. Lauren has Down's Syndrome with a ventricular septal heart defect. In the early days of Lauren's life the staff on the Special Care Baby Unit worked very hard, and with the care and love they gave Lauren we were able to bring her home in June. We were told that Lauren would need a big operation around the age of 1 year.

Lauren had to go to Pendlebury Children's Hospital in Manchester for catheter operation and to have her ducts tied. She used to surprise the staff on how soon she recovered.

All through the summer Lauren was very well and came on in progress, rolling over both ways and splashing

everyone when having her bath, which she loved. Then winter came and Lauren got a lot of chest problems. In November she was rushed to Pendlebury Hospital with Bronchial Pneumonia, but again with the staffs care on Holden Ward she was back home in 2 weeks.

Christmas came and we made a big fuss of Lauren with it being her first Christmas (I don't think she knew what on earth was going on). All through winter Lauren struggled with chest infections, one after another. Then in February she was admitted back in the Royal Oldham with Bronchialites, but once again our brave little Lauren was back home two weeks after. The staff grew to know Lauren and all seemed to shower her with love. Lauren's family doctor came to see Lauren every week, making sure when the big operation came she would have her well enough for it. She was marvelous with Lauren.

Well Lauren's first birthday came and I am sure Lauren knew from waking up in the morning - she just smiled and smiled. She went to bed that night one very happy and tired baby.

Then the letter came from Liverpool's Alder Hey Hospital for us to take Lauren to the hospital on 29 April for the operation on the 1 May. Lauren went to theatre at 8.30am and taking Lauren to the theatre was so hard - leaving this tiny baby there knowing what a big fight was in front of her. Quite a few tears and prayers said, and 5 hours later Mr Franks came and said everything was fine, although Lauren's right lung had collapsed. Lauren was ventilated for 15 days. She never moaned once and when she came off the vent and was more awake, she watched every move the nurses made. Those nurses were great and never left Lauren's side.

Lauren came down to the Children's Ward, on the 19 May and was sent home on the 21 May. She seemed very floppy but the operation had been a success, which was great news. Anyway, home we came and everything seemed fine.

Lauren then started having feeding and breathing problems, so on the advice from my health visitor, I took Lauren to the doctor. Unfortunately her normal doctor was on holiday so I had to see another doctor at the practice. He checked Lauren and said she seemed fine, although this sometimes happens after major surgery as she could be attention seeking - he said nothing was wrong. I came out thinking 'attention seeking' this was rubbish, but with him saying nothing being wrong, I thought am I fussing?

A few days later Lauren was still not feeding as she used to, so I phoned my health visitor again who said she would take us to the hospital to get Lauren looked at. Once again the doctor at casualty said he could find nothing wrong, but that he would admit Lauren to the children's Ward for observation. Lauren was kept in for 3 days and was then sent home with oxygen in case her breathing caused problems. The doctor thought it might be asthma.

We struggled with Lauren for a day and night, then she had a bad blue attack, so I rushed her back to the Children's Ward and said to the Staff Nurse 'I just don't know what to do'. The Staff Nurse said 'you have done the right thing, she is ill'.

Lauren had a very high temperature and late on Sunday she had her first convulsion and was very distressed, so I sat nursing her with the oxygen mask over her face and she was sleeping on and off. Monday came and her temperature was still very high. We were told that they didn't think Lauren would make it through the night. When the doctor let us back to Lauren I was begging her, please don't die. She put her hand out to be stroked (this was all she needed to be comforted) and whined as though to say bye - I love you. I will never forget her little eyes pleading.

Lauren was rushed to Special Care where the nurses who had previously saved her life when she was born worked for 1½ hours to try and save her. But after another convulsion and 5 more heart attacks, her little body could take no more. Lauren had passed away. A nurse wrote on Lauren's notes 'Lauren is at peace now in God's care'. We were all in a flood of tears, even the staff.

But as the poem says 'Heavens Special Child' and Lauren sure was. The joy she brought to us will never be forgotten. There is a record which we said was Lauren's song - Eternal Flame, which when we hear it we always get a lump in our throats and think of our special angel who is always in our thoughts.

The doctor at the hospital said he should have listened more in the first week of admittance. All I can say is if only he had. But we are very grateful for the 14 months we had Lauren, also for the hard work the nurses and doctors gave to Lauren.

*From a very proud grandma.  
Pat Ridings*

*EDS word:  
What can I say to this story*



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JB/AD/J18

5th December 1990

Dear Mr Hopkins,

Please find attached the copy for the editorial explaining the differences between soya formulas and standard baby milks.

If you feel there are any points that you would like me to explain further, or if I have missed anything that you would like included, please telephone me and I will be very happy to discuss these areas with you.

Kind regards.

Yours sincerely,

Jane.

Jane Beaven  
Product Manager - Specialised Formula Foods

c.c. Cheryl Honig



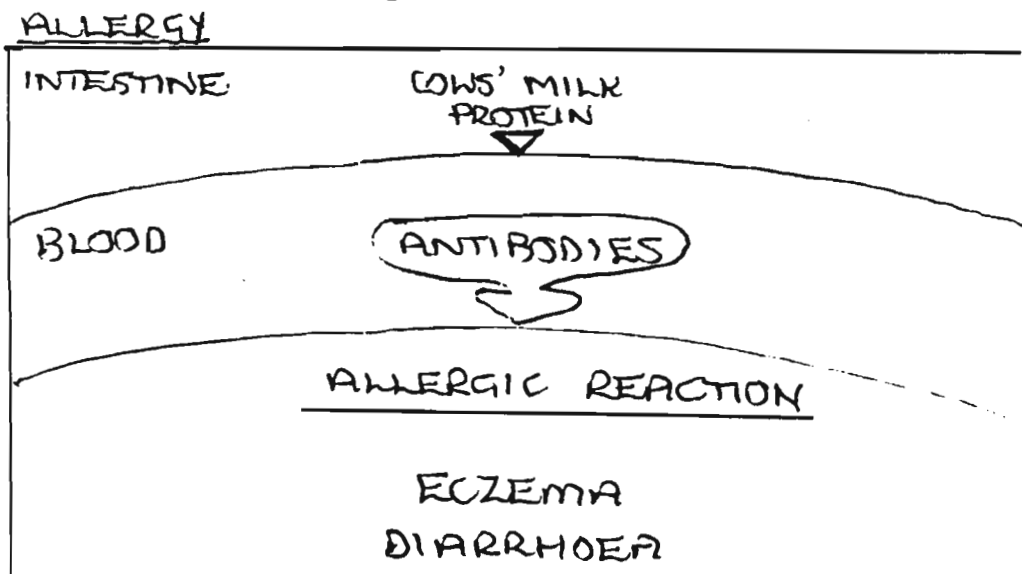
## MILK INTOLERANCE

While it is generally accepted that breast milk is the ideal food for a young baby, not all mothers are able to breast feed or choose to do so. For those mothers it is important that an approved infant milk formula is available. There are four manufacturers of standard infant formulas who make their products available in this country. This type of formula is based on cows' milk which is modified to provide nutrient levels in line with government recommendations, which in turn are based on average breastmilk values.

The vast majority of bottlefed babies never have a problem with a standard infant formula and grow and thrive quite satisfactorily. However, there is a minority of babies who are milk intolerant for one of two reasons:

### 1. Cows Milk Protein Allergy

Conservative estimates place the true incidence of milk protein allergy at less than 1% of babies. However, many babies are presumed to have the condition because they exhibit one or more non-specific symptoms, such as sickness and diarrhoea or a skin rash. It is very difficult to obtain a firm diagnosis of allergy and therefore many more babies may be treated than actually have the condition. But what exactly is Cows' Milk Allergy? In allergic babies when they receive an infant formula the body's defense mechanisms are alerted. The 'defense cells', or antibodies, react with the cows' milk protein and this interaction causes symptoms such as vomiting, diarrhoea, eczema and so on. Normally when babies take in infant formulas they digest and absorb it without involvement of the defense system.



Treatment involves removal of cows' milk formula from the diet and replacement with another feed which is free of cows' milk protein eg. a soya formula specially prepared for infants and young children. However, these products should only be used under medical supervision as other foods in the diet may need to be considered if the baby is on a mixed diet.

## 2. Lactose Intolerance

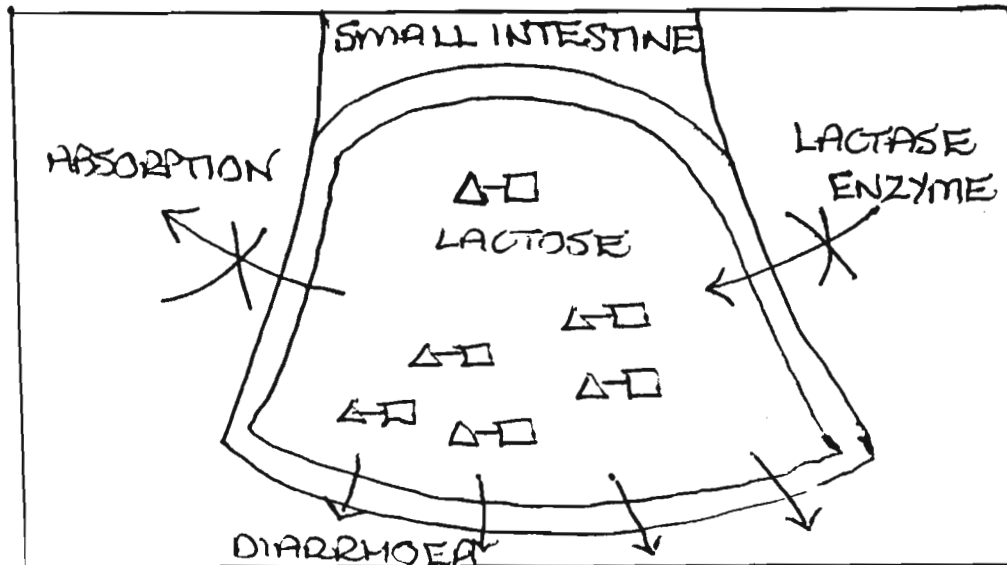
The other fairly common problem associated with milk feeding during infancy is lactose intolerance. Lactose is the carbohydrate found in milk. It is made up of two components which need to be separated so that the body can absorb them to provide energy. This separation involves a substance called lactase which is produced as part of the process of digestion. If lactase is not produced by the body in the required amounts then lactose cannot be separated and hence cannot be absorbed by the body. When this happens the lactose is excreted from the body resulting in watery diarrhoea.

In very rare cases babies may be born without the ability to produce enough lactase. More commonly, babies are born with enough lactase but the ability to produce it is reduced due to another disorder eg. gastroenteritis, or following surgery of the intestine. Once the initial disorder improves then the lactose intolerance subsides and baby can go onto a normal infant formula again.

The treatment of lactose intolerance will obviously require the removal of lactose from the diet until the situation improves. As infant formulas contain lactose they will need to be replaced with a lactose free alternative. Soya formulas for infants are lactose free. The carbohydrate source is a glucose polymer (you may have come across the term glucose syrup or maltodextrin - these are all glucose polymer). Because the glucose molecules are joined in chains they do not taste sweet and are less likely to upset baby's tummy than if free glucose particles were used.

The enzyme required to break down the glucose polymer is produced in large amounts even when there is a problem such as gastroenteritis.

Lactose Intolerance



So in Summary - why are soya formulas used in the dietary management of milk intolerance?

INFANT FORMULAS	SOYA FORMULAS	
<u>Protein</u>	<u>Soya Protein</u>	
Cows' Milk Protein	Soya Protein	Soya protein can help prevent symptoms of cows milk allergy.
<u>Carbohydrate</u>	<u>Carbohydrate</u>	
Lactose	Glucose Polymer	Glucose polymers are used when there is lactose intolerance.
<u>Fat</u>	<u>Fat</u>	
<u>Vitamins &amp; Minerals</u>	<u>Vitamins &amp; Minerals</u>	
For normal, healthy babies.	Prescribable by the doctor for cows' milk allergy and lactose intolerance.	

Both types of formulas comply with the nutrient level guide - lines set by the government, and therefore whether your baby is receiving a standard infant formula or a soya formula for infants you can be assured he is receiving all the nutrients he needs for a healthy start in life.

### ROGUES GALLERY



*Eddie Sowter - 1989*



*Stefanie Lawrance - July 1988*



*Danielle Atkins - July 1986*



