Link

The magazine for people with
Spina Bifida and/or Hydrocephalus

February/March 1997
Issue No 168 Price 80p

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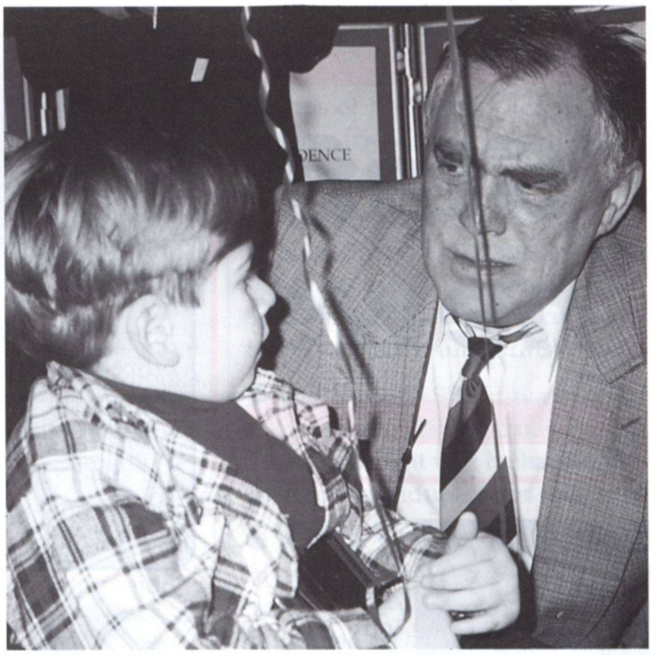
TV pigeon fancier meets Jamie



SIX-year-old Jamie Donaldson bumped into Britain's most famous pigeon fancier at a show which regularly makes generous donations to national ASBAH.

He met TV star Bill Tarmey, who plays Jack on *Coronation Street*. Jack runs the Rovers Return on the popular soap programme and is supposed to keep pigeons.

Bill was one of the star turns at at the British Homing World 'Show of the Year' at Blackpool – the pigeon racers' premier annual event.

The actor confessed to being terrified of pigeons in real life while he was posing with them for photographers.

Jamie, who has spina bifida and hydrocephalus, met Bill by accident at the show after going there with his dad from their home in Dromore, County Down, Northern Ireland.

Organisers of the show gave a generous £20,000 to ASBAH in January this year, bringing the grand total of donations over many years to £275,000.

Feedback to latex allergy survey

WE HAVE had only a small number of responses, so far, to our survey on people with latex allergy and spina bifida.

We included a questionnaire in the last issue of *Link* (Dec '96/Jan '97) in our centre-page spread on the subject.

As this issue of *Link* went to press (mid-January) we had only received four completed survey forms, including a letter from a mother which is published on page 26 of this issue.

The survey form will be re-printed with further reports on latex allergy and spina bifida in the next issue of *Link*.

Contents

ASBAH is a registered charity

Cover: Coronation Street star Bill Tarmey (Jack Duckworth) appeared at the pigeon 'Show of the Year' to receive a big cheque for ASBAH. Photo: Dave Nelson, Citizen Newspapers.

Staff news

● MARY White, founder of our continence service, left ASBAH after nine years to make her experience and skills more widely available.

She will continue to be available to people with spina bifida through the specialist clinics she attends and the assessments requested by health authorities, education departments and social services.

Mary said: "I feel the knowledge and experience I've gleaned working with people with spina bifida is of enormous value to other people with disabilities such as multiple sclerosis, spinal injuries, Parkinson's Disease, stroke and diabetes. My favourite group will always be people with spina bifida and my links with ASBAH will remain very strong."

She will be giving advice over the phone to professionals, and training professionals all over the country and in Europe.

With a nursing background, Mary started off as a part-time fieldworker with ASBAH covering Derbyshire, Nottinghamshire and Lincolnshire. She started ASBAH's continence service in 1990, becoming a full-time national adviser, specialising in continence. In 1995 she went half-time to do consultancy work.

● DONNA Treanor, who has worked for ASBAH for seven years, has been promoted to appeals manager.

Previously, Donna was liaison officer in appeals. She took up the new job from 1 December, following the departure of John Williams.

Donna now manages the on-going work in the appeals department such as obtaining grants from trusts, sponsorship from companies, deeds of covenant, gift aid, shops, legacies and sponsor forms.

She is the primary point of contact for any individual or organisation which undertakes sponsored events for us, and will develop new fundraising ideas and campaigns.

The appeals department deals with all ASBAH's charitable fundraising not within the remit of telesales or Computer Sense Ltd.

● LINDA Maxwell is the new specialist adviser (independence) in Northern Ireland. Over two years she will be assessing the training needs of service users in Northern Ireland and setting up courses on mobility and social skills for them.

A qualified teacher, Linda's first job was working at a day centre for people with severe learning difficulties. She then became assistant regional officer for MENCAP for four years.

After a break for her first daughter, Linda became part-time events co-ordinator for the Northern Ireland Association of Youth Clubs, working with able-bodied youngsters. At the same time she taught in the social work department of a local college – teaching courses in care – and was involved in provision for students with disabilities.

For the last six years she has worked at both ends of the spectrum – training the trainers in the form of classroom assistants and Btec students – as well as setting up and running a course for adults with learning difficulties. She has also organised the summer programme for the Northern Ireland Council for Orthopaedic Development for people with physical disabilities.

Linda started with ASBAH on 6 January and is based at her home, just outside Belfast.

The two-year post is being funded by a grant from the European Union Special Support Programme for Peace and Reconciliation.

● JACKY Hockey is the new adviser for Herts and Beds. Jacky has worked for social services for 30 years.

Her last two jobs were running family-based respite care schemes for children with disabilities – first in Hertfordshire and then in Bedfordshire.

Jacky feels she can make good use of her knowledge and skills as an ASBAH adviser. "I wanted to work more directly with families which isn't easy in the pressured environment of local authorities," she added.

She first came across spina bifida in Sheffield 24 years ago through the pioneering research work of a paediatrician, and has worked with people with spina bifida and hydrocephalus over the years.

Prescriptions delivered to your doorstep

ALPHAMED is a company which delivers continence equipment to your door in discreet plain packages and gives a donation to ASBAH for every one of your prescriptions which they dispense.

If you would like to try their service, all you have to do is to sign the back of your prescription (if you are exempt from charges) and send it to the FREEPOST address below. Please make sure you indicate that you are an ASBAH member the first time you use the service.

The arrangement was ethically approved by ASBAH's Executive Committee in 1994, and is explained more fully in the starter pack.

If you want to help ASBAH and benefit from the convenience of this service, send your prescription to: ***ISC Home Delivery Service, FREEPOST CN2763, Thornton Heath, Surrey CR7 7XT.*** If you have any questions about the service or product range, call ***Alphamed FREEPHONE on 0800 515317.***

Lottery success stories

● ASBAH Northern Ireland Region has won £74,635 from the National Lottery Charities Board. The grant – spread over three years – will pay for a specialist adviser for hydrocephalus and a user-group convener.

Northern Ireland Region has more than 700 service-users on its books. Many have hydrocephalus and spina bifida, but an increasing number have hydrocephalus by itself.

Northern Ireland Region co-ordinator Margaret Young said: "Once the new staff are in post, we shall be able to provide a much higher level of support to people with hydrocephalus alone."

The convener will set up a user-forum – ensuring that people with the disabilities are actually involved in running the organisation. "We're committed to the participation of people with spina bifida and hydrocephalus at all levels," said Mrs Young.

● Leeds and Bradford ASBAH won £44,391 over three years for three part-time activity co-ordinators for groups of young people in Leeds, Bradford and Harrogate.

The aim is that in three years the groups of 15-24-year-olds will become friends and have the confidence to go out together.

Fundraiser Ann Duffy said: "News that we'd won the grant came as a wonderful Christmas present. There were a lot of good causes but we struck it lucky this time."

● Mid-Wales ASBAH was awarded £13,000 for mobility aids. The equipment will be handed over to individuals later this year.

● ASBAH's Hon Consultant on Hydrocephalus, Dr Roger Bayston, won a three-year grant of £178,000, following an application made by the Wade Charitable Trust.

The money will go towards his salary and pay a PhD student and technician to work on a new project concerned with treating shunt infection while keeping the shunt in place.

This project is being run by Dr Bayston – a senior microbiologist at Nottingham University – in addition to the one National ASBAH is raising money for.

● Bids were rejected by the National Lotteries Board for money to set up an ASBAH Central Region and to give every area adviser a lap-top computer.

Officers & Staff

Making fundraising fun!

WHEN dog kennel and cattery owner Lorraine Davies heard that five wheelchairs were needed to get all the children with spina bifida mobile in North Cornwall, she set out to raise the necessary £6,000.

Donning a collecting tin, sponsor forms and a chatty frame of mind, Lorraine picked a pub a night over several months and persuaded regulars to part with their cash.

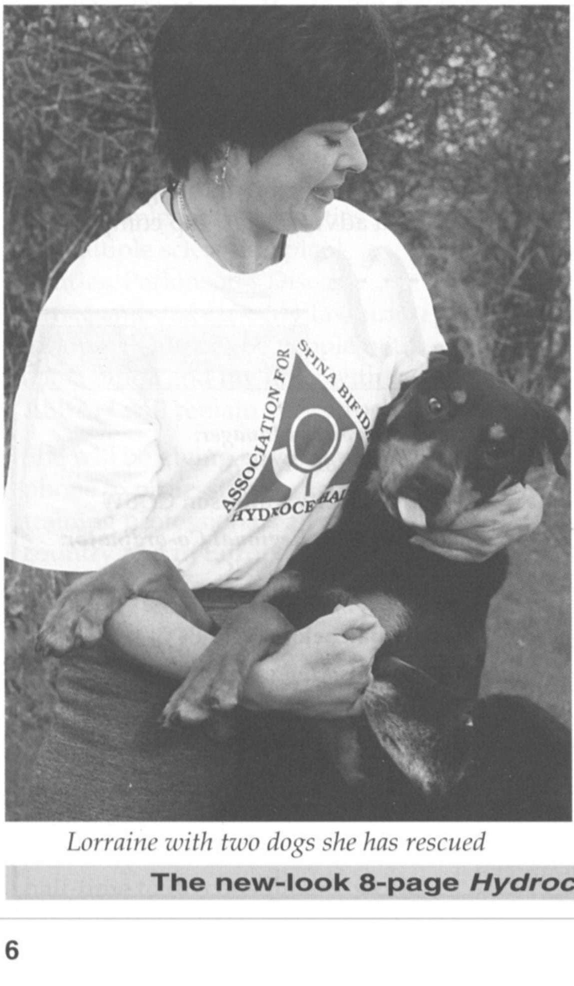
She told them about the five local children and young adults in North Cornwall who needed lightweight wheelchairs and said she was going to do a sponsored parachute jump for them.

Pub goers, dog kennel and cattery customers, not to mention friends and passers-by, have signed her sponsor forms in droves.

Before Christmas Lorraine had raised more than two-thirds to the total. Now having successfully trained and completed one parachute jump, she plans a second this Easter.

Lorraine Davies prepares for her next parachute jump for ASBAH

She has persuaded people to part with their cash in other ways too – a guess the number of conkers competition and guess the puppy's name. She even donated £40 from the sale of her gas cooker!



Lorraine with two dogs she has rescued

Lorraine's fervour for fundraising has been caught by friends and acquaintances. A woman she met on a hypnotherapy course did a sponsored yoga day. Mo's 78-year-old friend Cherry then organised a circle dancing marathon. These two events together raised £100. Her friend Mav held a coffee morning raising £252.

Lorraine's mate Julie, a clairvoyant who has spina bifida, did charity readings to help boost funds for the children's wheelchairs. Now Julie plans to do a sponsored trike ride with a trike given to her by the local Lions Club.

Lorraine, from Blisland, near Bodmin, Cornwall, says: "The idea is to get as many as possible of the local community to contribute towards mobility and independence of all the children and young adults in the area who are in need. By just talking to people you get a wonderful response. People get enthusiastic and say they'll do something to help. They might offer to take round your sponsor forms or organise their own event."

But she adds this little piece of advice to other fledgling fundraisers: "It's much easier to do local fundraising because people will nearly always give to something for people in their area.

"It's amazing how much you can get if your push yourself. It's been hard work but fun. And we're still going strong!"

Donna Treanor, manager of ASBAH's appeals department, commented: "Lorraine works so hard. She's the keenest fundraiser I've known."

The new-look 8-page *Hydrocephalus Network News* starts on page 17

Wheelchair worries

A SUSSEX mum was left with the possibility of not being able to look after her three-year-old twins because her local NHS wheelchair provider said it no longer issued spare chairs.

It took Kathy Wheeldon and her ASBAH adviser six months to get through to the service that if her wheelchair broke down, and she didn't have a spare, she and her children would be stranded.

Worthing Wheelchair Service assured Kathy that repairs could be carried out so quickly that a spare chair was unnecessary.

But this did not prove the case when a wheel buckled on a Saturday afternoon in June 1995 while Kathy was at a wedding.

Repair and maintenance contractor Electric Motor Company (EMC) in Hove had failed to leave its answerphone switched on, leaving Kathy forced to borrow a friend's chair from the Saturday to Tuesday morning.

TWO stories on this page and page 8 of wheelchair users left stranded because of failures of provision by NHS wheelchair services

Kathy, who lives in Durrington, near Worthing, said: "If I was totally on my own with the boys and without a chair, I would be sitting on the floor not being able to do anything for them."

On 30 June 1995, Worthing Wheelchair Service told Kathy that a second chair was on order but they never got back to her.

Kathy's ASBAH adviser Jane Renshaw tried leaving messages every working day for a fortnight on Worthing Wheelchair Service answerphone but these messages were left unanswered.

Jane takes up the story: "Finally, on 10 August 1995, a clerk at the

continued on page 8

OBITUARY: ANTHONY BOOTH 1934-1996

RETIRED consultant neurosurgeon Tony Booth died after a long battle against cancer.

He worked at Walsgrave Hospital in Coventry for more than 20 years before retiring two years ago. Before that he was based at the Neurosurgical and Neurological Institute at Queen's Square, London.

Fellow consultant neurosurgeon Bill Whatmore described Mr Booth as a kind, understanding, gentle man who was much respected by his patients, their relatives and especially by children. "He had a great empathy and rapport with children who used to think of him as a big teddy bear," Mr Whatmore told the *Coventry Evening Telegraph*.

ASBAH adviser Jenny Green added: "We all missed Mr Booth since he retired. I received a lot of phone calls from our service users and their families who were saddened by his death."

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

London, Surrey, Kent, West and East Sussex

ASBAH South East, 123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (0181) 449 0475. Regional Co-ordinator: Jo Francis.

Lincolnshire, Cambridgeshire, Leicestershire, Nottinghamshire, Northamptonshire, Norfolk, Suffolk, Essex, Hertfordshire, Bedfordshire

ASBAH East, ASBAH House, 42 Park Road, Peterborough PE1 2UQ. Tel (01733) 555988. Regional Co-ordinator: Mary Malcolm.

Northern Ireland

ASBAH Northern Ireland, 73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (01265) 51522 Regional Co-ordinator: Margaret Young.

Northumberland, Durham, Cleveland, North Yorkshire, South Yorkshire, West Yorkshire, Tyne & Wear, Humberside

ASBAH North, Five Oaks, Ben Rhydding Drive, Ilkley, W Yorks LS29 8BD. Tel (01943) 609468. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (01733) 555988

ASBAH welcomes and appreciates the support of its commercial partners.

***Larkhall Natural Health** gives us 10p from the sale of each container of Cantassium Folic Acid tablets. These can be obtained in chemists and health food shops.*

***AlphaMed Ltd** makes a donation for every prescription order received, as a result of ASBAH's introduction, for continence and medical equipment supplies. Tel services floor, 01733-555988, for introductory Freepost envelope. Prescriptions for drugs or medicines should not be sent to AlphaMed.*

Wheelchair worries

THE PATTERSON family have had to enlist the help of a charity to get a suitable wheelchair for their daughter because she could not push the offered NHS chairs up a two-inch kerb.

Thirteen-year-old Melissa, from Blyth in Northumberland, walks small distances but needs to use a chair to go further distances like to the shops.

Five years ago the Association of Wheelchair Children stepped in to give her a lightweight chair she could handle. Now that same chair is wearing out and the family face exactly the same problem in getting a replacement.

Father Ron commented: "Melissa is not a child to let her disabilities get on top of her, but for some time now she has had a wheelchair that has been absolutely falling to bits."

The NHS chairs Melissa tried were so heavy and difficult to self-propel that she could not get them up a 2-inch kerb without help.

Melissa, like all teenagers, is very fashion-conscious and needs a chair which makes her feel confident going out by herself.

The 'starting price' for a new lightweight chair is £700 which the family cannot afford.

Owen McGhee, director of the Association of Wheelchair Children, who was consulted in Melissa's case, commented: "The wheelchair service won't say whether the chairs it has offered are suitable or not, only that Melissa doesn't fall into a criteria for another type of chair."

Mr McGhee's view that Melissa should have a Meteor or a Roller – both of which are available from the NHS – was rejected. He has recently submitted a new complaint to Northumberland Community Health Trust which runs the local wheelchair service.

Chris Humphris, chief executive of Northumberland Community Health Trust said: "We issue lightweight chairs only when the person's range of mobility is severely limited when using a self-propelled chair. Melissa is able to walk around her school and can handle a Bluebird on the flat. She also has access to other modes of transport – a family car and a trike.

He said the Wheelchair Voucher Scheme might help as the family would then have a choice, making up any cost differential between this and the offered NHS chair.

Kathy Wheeldon, from p 7

wheelchair service picked up the phone when I was leaving a message. She suggested I write to the head of OT. The clerk promised to contact Kathy and said she believed EMC was holding a spare chair for Kathy in case of breakage."

A meeting was then arranged at Kathy's home with Jane present. At first the head of OT told them it was not possible to have a spare chair. But after much discussion, she agreed to Kathy having a spare at home.

Kathy said: "I explained the difficulties I faced if my chair was out of action, even for two hours. I wouldn't be able to pick up the twins from nursery."

The spare chair was delivered promptly. However, Kathy cannot transport the spare chair in the passenger seat area of the car – which she needs to do if driving without another adult – as it does not have quick-release wheels.

Kathy said: "I don't think they appreciate that I've got two small children and that I need to be able to go in and out of the car at a moment's notice."

Kathy, aged 33, has always had a spare chair, even when she was able to get about with callipers. Eight years ago she was given two lightweight, folding Barratts which were easy to get in and out of the car. When these wore out, the wheelchair service refused to give her another Barratt because they said Kathy was too heavy for this type of chair.

Instead she was given a larger, heavier chair (an 8L) with quick-release wheels which hurts her back and arm when lifting it in and out of the car. Kathy said: "There must be other chairs more suitable."

Pamela Downey, director of OT at Southlands Hospital, Shoreham-by-Sea, said: "It's very hard to live up to clients' expectations all the time.

"We have had a lot of contact with Miss Wheeldon. She's got through an awful lot of chairs and we had to order special chairs for her because of her weight."

Cutbacks in continence supplies

CONCERNED parents have been phoning ASBAH continence advisers about cutbacks in the provision of continence products.

Many health authorities are reducing the number of products such as continence pads and absorbent sheets and are increasing the age of children to whom they will supply these products free of charge.

Parents are being forced to make supplies go further or purchase their own continence products, which are often very expensive from chemists and a different type to what they are used to.

If your family is experiencing hardship or problems because of the new cutbacks, we would like to hear from you.

Write to: Liz Cawthorne, Editor, Link, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

OBITUARY: AUDREY SHEPHERD 1932-1996

THE LIFE of a much-loved founder member and former secretary of a local association is being celebrated by having an award for great achievers of the group named after her.

Audrey Shepherd, aged 64, whose son Paul has spina bifida, set up the Newcastle & District Association 29 years ago, and was largely responsible for forming the Sunderland & District Association 26 years ago.

To ensure she is not forgotten, Sunderland, South Tyneside, Durham & District Spina Bifida and Hydrocephalus Association is now also planning to start a project for independent living – one of Mrs Shepherd's greatest concerns.

Current secretary Jeff Pounder, commented: "Audrey was the mother of this association. She was the drive, enthusiasm and heart of the group."

Sandra Wheatley, a former ASBAH adviser whose area included Sunderland, added: "Audrey had a knack of making everybody feel special and was one of the kindest people I have ever known.

"Nothing was a bother to her. She was always doing something for other people and this took precedence."

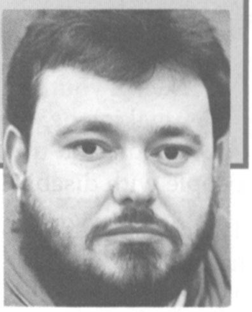
Mrs Shepherd was secretary for 22 years but even when she had relinquished the job, she was still very active at committee level.

Mrs Shepherd was also appreciated for her talent for fundraising – particularly in aid of the association's biannual trip to Disneyland. She was the energy behind fundraising events like the Boxing Day Dip, Great North Run, fun runs and fetes.

The first recipient of the Audrey Shepherd Award will be local association member Nicola Jarvis, an athlete who represented Britain in last year's Paralympics.

Darke at the cinema

by Paul Darke



I saw *CRASH* this week, and I hope you will get to see it soon, and it is as explicit and depraved as those who wish it banned say. But, and it is a big 'but,' I would argue that it is a seminal film of great quality and integrity.

The issues it deals with – the alienation of the individual in post-modern society; the quest for sexual and physical gratification in increasingly momentary ways; and the misogynistic attitudes that are pervasive in our society – are dealt with in such a way as to be almost all of the things it is being critical of if viewed un-critically.

The constant, varied and explicit sex scenes throughout the film verge on the tedious after a while; yet that is the point: the desire and exploitative quality of modern sexual experience has made copulation seem so ordinary that the search for the ultimate sexual high has replaced true intimacy between individuals.

David Cronenberg, who has taken a lot of stick for his direction of *CRASH* and most of his other films, intentionally makes the film characters mere mannequins of human activity in order to critique the way modern life has turned human beings into human machines who merely consume consumerist fantasies at the expense of their own and others inner spiritual humanity.

The disability connection is that one of the most controversial scenes in the film (and the number one reason Westminster Council wanted it banned) is when a sexual act takes place between the film's leading able-bodied and beautiful man (James Spader), and a woman in callipers (Rosanna Arquette).

Significantly, the disabled woman's callipers are specifically designed in retro-bondage style to make the fetishisation of the character complete; here the deformed and maimed become a sexual turn-on for their difference and signification of an alternative thrill.

It is not a 'positive' representation of seeing the difference of disability as an element of sexual attractiveness (the disabled have known that as a reality for centuries), and it is negative in that the sexual thrill and excitement of difference is in its not being normal. The attractiveness of this character is her disability not in her, which, in a different film, would be highly dubious.

Primarily, in *CRASH,* the objectification of the individual, be that able or disabled, is the theme of the film; it is the objectification of the disabled and abled that the film is challenging by showing in its absolute explicit and nihilistic bleakness.

If you are easily offended, or even capable of being offended, I would not recommend you see this film – its relentless exploration of the resulting inevitability of modern life leading to the living and actual death of the individual and their community is hard to stomach.

If you want to be outraged into challenging the way you think about your own life and the way in which society is headed, it is a must. Equally, beware though, the sex scenes, which are numerous and make up most of the film, are often intentionally violent, misogynistic and disturbing in order to jolt you out of your warm sense of security.

Youth clubs which are encouraging young people with disabilities to join

Clubability Challenge

Awareness is the key

SOME youth clubs are making headway in opening doors and minds to young people with disabilities.

The vital ingredient for making integration work is enthusiasm and awareness from both the youth leader and the club members themselves.

In the last issue of *Link,* we introduced ASBAH's *Clubability Challenge* by finding out what two boys with spina bifida wanted from a youth club, and what was stopping them attending.

We found that it wasn't just an inaccessible building that was a deterrent, but the attitudes and unfriendliness of the other members.

This issue we hear from the youth club leaders who have had some success in welcoming people with disabilities.

● **The Center in Southport** changed from a club used mainly by young men who did relatively little to a lively place where both women and disabled people have their say and make things happen.

Worker in charge, Jean Blanchard, believed the development of an equal opportunities policy and philosophy was the starting point for change.

The setting up of separate nights for young women and disabled young people was the key part of the strategy for change.

Jean explained: "Integration is a process, not a type of provision. Often separate provision for disabled young people is seen negatively. We see it as an essential element in the process of integration."

Workers at The Centre found that, to involve young people with disabilities, they had to build the trust of parents. Parents had to feel The Center was a safe place, with purposeful activity. The Center offers sport and arts and crafts activities for young people, and has open sessions as well as the separate nights.

● **The Playplus integrated youth programme in Stirling, Scotland** was developed at three levels. The first level was the development of integration of individuals into mainstream clubs. Its success depended on the attitude of the youthworkers, club leaders and the young people themselves, including the maturity and social skills of the young people with disabilities and special needs.

The second level was the development of special 'design' mixed ability projects in which groups of people with disabilities and other clubs came together for time-limited project work.

The third level saw youth groups set up for existing groups of young people or school friends with special needs. This was aimed at young people with special needs who attended a school some distance from home. These young people had been isolated in their own community for several years. Many had friendships within the school yet could not develop friendships within their own leisure time because of the geographical boundaries.

A girls group and a seniors and school leavers group, run by the members themselves, were established as stepping stones to integrated projects.

● **Farcet Youth Club, housed in a village hall on the outskirts of Peterborough,** has an equal access policy which goes beyond physical access issues.

Rachel Lee, patch co-ordinator for SE Peterborough, explained: "We hope that even if the building isn't suitable there are some opportunities for people with physical disabilities."

The front entrance of Farcet Village Hall is not wheelchair accessible but there is a ramp to the back door of the building.

Rachel continued: "You have to go up some steps to get into the front of the building, but the youth workers make every effort to ensure everyone gets an equal deal at the club."

Although there are, at present, no members with physical disabilities at Farcet Youth Club, some have learning difficulties.

Youth workers at another club, in Whittlesey near Peterborough, run a separate club for young people with special needs which is proving very successful.

Rachel said: "The success of integrating people with disabilities depends on the way it's handled by the leaders. It's important that they don't make a big deal out of some members, for example, using the back entrance if they use a wheelchair.

"What's needed is awareness. It's no good putting money into something without it. If the right attitudes are there, then things like building access tend to come."

A Cambridgeshire youth project called *Change It,* backed by Lottery money, gives young people the opportunity to change some aspect of their lives which could include access to their club.

Next issue:* Clubability Challenge *includes a report on SHOUT! an awareness-raising youth group in Lancashire which has been so successful it has done itself out of a job!

From the autobiography of Jon Wilson, a Scottish ASBAH member

Tuppence for me

PART 2

THE ATTITUDES and opinions of non-disabled people in the community are often the ones determining decisions for disabled people. This means that disabled people are often disregarded in situations which might require leadership or giving a viewpoint. Things are changing but it is taking a very long time for the able-bodied to believe in the trustworthy common sense of disabled people.

Then there are the silly attitudes which are surely not meant to hurt. It seems that standing more or less at eye-level height, using crutches, gets me a more positive response that when in my wheelchair. In the wheelchair there is a tendency for people to talk over my head, then use an altered tone when addressing me. At a sports day, when in my teens, an organiser asked dad, standing alongside me, 'Would he like to mark the score cards?' to which dad replied, 'Ask him.'

One day when out on a school project to survey wheelchair access to shops, a kindly elderly lady came up to me and said, 'Have you had a stroke, son?' My reply of 'No' went unheard. 'Never mind, I hope you'll soon be better.'

But the yob who shouted at me in the street one evening, 'go for it, ya spastic,' as I propelled myself to the pub with friends, got a bit of a surprise when my friends stopped in their tracks to confront the lad and told him, in words he would understand, that his behaviour wasn't acceptable.

Some attitudes will be hard to change. For example, those able-bodied people who use parking bays which have been set aside for disabled drivers. I don't believe it is worth challenging such actions. We cannot police the thoughtless behaviour of those who have no experience or imagination concerning disability. That is the down-side, but real efforts are made in other circumstances as I found one summer when I went to the air display at Leuchars in Scotland, where disabled parking had been set aside and monitored.

There are subjects on which I would welcome having a voice, for example, discussion on the pros and cons of abortion; the caring for the disabled in a society where resources are limited; to help raise the understanding of how costly it is to give 'quality of life' to the disabled person who will never work and has to rely on low benefits; to find out if lighter materials for the making of crutches, callipers, surgical boots and wheelchairs could be developed in the same way as hi-tech sports equipment for the able-bodied.

Those of us with hip, leg and feet difficulties are assessed in our early years as to the possibility of us being able to stay upright at least part of the time. There are various ways of getting ambulant, so improving muscle tone in limbs. Using crutches, callipers and surgical boots may enable some to make forward 'steps'. Everyone is different in what can be achieved. Some may feel the effort is just too much and will prefer or need to use a wheelchair. Staying upright means attention to diet as surplus weight slows you down.

At one stage the hospital services issued me with a three-wheeler bike with special foot-rests to which my feet were strapped. It was a good feeling to be able to ride a bike but with lack of feeling in my buttocks it proved difficult to avoid pressure sores. I tried a two-wheeler but lack of balance required a wall to lean against when I wanted to stop as putting on the brakes was not enough. But I did get the freedom to try.

Jon (pictured left), aged 23, on his first skiing holiday with his able-bodied twin brother Donald

A neck problem, perhaps as a result of constant use of crutches, made the ordinary wheelchair cause my neck to ache if used for long periods of time. Then, when on a 'school afloat' experience, I was in Germany when I saw a man in a different type of wheelchair coming towards me. This was propelled by levers and made in Germany. On my return home, enquiries were made through the hospital about the availability of such a wheelchair for my problem. I was able to obtain one through the NHS. It is bigger and is not easy to fold up but I can put it in my trailer when I want to go further afield.

Keeping myself mobile requires regular chiropody visits where the congenital foot deformities are checked out. Healing is poor in my feet. Even a nail sticking into a toe and causing bleeding is to be avoided.

Reaching car driving age was an exciting date. It coincided with the introduction of the Motability Scheme which offered me a leased car. In return, I handed over my Mobility Allowance towards a major part of my costs.

continued on page 12

Tuppence for me, from p 11

I got my first car, an automatic Mini, in 1981 – The Year of the Disabled. That December, I was invited to Buckingham Palace for the launching of the Motability Scheme. I had just passed my test and the prospect of driving in London was frightening. We went by train, with the car on board, to Euston, then we made our way to a very exclusive-looking hotel. We had a laugh on arrival as there was a commissionaire on duty to drive my Mini to its overnight parking.

The situation was even funnier in the morning when we were leaving for the Palace and there was my Mini dwarfed by luxury cars of overwhelming size and opulence. To add to our fun the organiser asked if we knew the way to the Royal Mews and, as we had gone out the previous evening to suss out the area I assured him that we knew our way. 'Fine then,' he said. 'Will you just lead the way for the other cars?' It still makes us chuckle to think of my wee Mini leading the small convoy of Motability leased vehicles down the Mall and round in front of the Palace to the Royal Mews where, thank goodness, a policeman was there to stop the traffic and direct us into the Mews.

The lease for the Mini, with hand controls, lasted the four years I worked at East Kilbride. I had a parking space in front of the office. At my present Revenue office in Motherwell, parking is close by. I moved on from a Mini to a modified Escort 1.6. Soon after leasing the Escort, I worked towards taking the Institute of Advanced Motorists driving test. This was partly for my own satisfaction and to show that disabled people can be as reliable drivers as anyone else.

We all have some kind of relationship with everyone we meet. How I differ from others is the development of such meetings. With male friends, there is an easy friendship with no apparent concessions required or given. With women there is also an easy camaraderie and I enjoy their banter and the give and take of comments. They will mention their dream partner as tall, dark and handsome, and I immediately fail in the height category! I am aware that to other men I am in no sense a threat to them for romantic attachments with women.

Because of my condition, it is unlikely that there could be children in a long-term partnership and this, and other considerations, could mean that a friendship deepening into a joint decision to live together would be a very special one indeed. While such a relationship would be welcome its absence so far is not one that causes me anxiety.

In recent years the relationship with my parents has changed. They would give of their utmost in a variety of ways; no matter what my difficulties I could speak to them openly and receive help. Today the relationship is still very strong but no longer one way. I now have my own responsibilities. We have a very warm and enjoyable relationship; three people each with different needs and interests.

The relationship with siblings is one that gives opportunities of hearing alternative ways of living. Such information is good to have. We are all free to respond to each other as each wishes.

Writing my thoughts, I have come to recognise that eventually there is a converging of needs by disabled people, accident victims and the aging population.

All of us are different, not only in temperament and the circumstances in which we live, but also in our abilities, or, to put it another way, in our degree of handicap. Like everyone else we face problems and hurdles that can often be diminished by forethought, planning and persevering practice in learning and developing appropriate skills.

TUPPENCE for me? the title of Jon Wilson's autobiography, is taken from a poem written by his mother in 1971 when Jon was seven years old:

How would I describe our son?
dark-eyed
smooth cheeked
seven years of living reached
broad of shoulder
straight of back
buoyant of nature and
full of laughter
his childhood happy
his future I fear.

How do others describe our son?
poor little cripple
it's a miracle he lives but
then God is good.
These children are happiest
with others like them.
Why does that little boy have
crutches and walk funny –
shhhh.

How does our son describe
himself?
I'll be a policeman
I'll have a motor-bike
when I grow up;
come and play football
school outings are fun
the paddle-boat's best and
tuppence for all
but not for me
perhaps the man doesn't charge
the handicapped.

Jon is a revenue assistant for Inland Revenue – a job he started from leaving school. He fulfils all the demands of the job except filing. "When I first went in, they had a closed mind about what I could do. I've had to slowly educate them and work things through with them," he says.

Jon enjoys golf, sailing, flying model aircraft build by his father, collecting model cars, skiing, driving and motorsport.

In 1995 he won the Winter League at Comrie Golf Course – quite an achievement as the only disabled club member. "I hold the crutch in one hand and swing the club in the other. Golf is a good game to test yourself against."

Football heroes tee off for ASBAH

SPORTS celebrities, golfing professionals and business people teed off together and raised thousands of pounds for ASBAH.

Eighteen teams each made up of a sports celebrity, a professional golfer and two businessmen entered the Glen Hoddle Charity Golf Classic in June.

England manager Glen Hoddle, Chelsea manager Ruud Gullit and world famous players Gary Lineker and Liam Brady were among those taking part.

The day was organised by Glen Hoddle's solicitor, James Devane, who is also golf captain at Mill Ride Golf Club, Ascot, Berkshire.

Andrew Russell, ASBAH executive director (second from left) receives a cheque from left to right: Chelsea manager Ruud Gullit, England manager Glen Hoddle and ex-England international footballer Gary Lineker

ASBAH was selected to benefit from the fundraising event because Mr Devane's son has spina bifida. Thirteen-year-old Gregory is a golf club member.

Mr Devane said: "We were very pleased to do what little we can for other children with spina bifida."

An entry fee and an auction in the evening raised around £11,500.

ASBAH executive director, Andrew Russell, visited the club to receive the cheque and say a big thank you on ASBAH's behalf.

BT backs *Challenge*

AFTER its future looked decidedly wobbly in the autumn, Britain's disability sports magazine *Challenge* has been given a reprieve – thanks to support from BT, which provided generous aid to disability sport in Paralympic year.

After a gap of eight weeks, issue number 12 of the monthly appeared in November, complete with pages of coverage of the achievements of Britain's athletes at the Atlanta Paralympics.

Editor, Marshall Thomas, asked readers to convert their free copies to paid-for subscriptions in order to secure the future of *Challenge*. Mr Thomas told *Link* he had BT support for four issues, which would be combined with a subscriptions drive and push for more advertising.

A year's subscription costs £15. Cheques to: ***Challenge Subs, Knightswood Publishing Ltd, 115-117 Caversham Road, Reading, Berks RG1 8AS.***

Making more of employees with disabilities

BT is attempting to stay ahead of discrimination law by publishing a glossy brochure on how its managers should make the most of employees and potential employees with disabilities.

Entitled ***Valuing Ability***, the brochure has pages devoted to some thought-provoking topics such as *Why employ people with disabilities?*, *Exploding the myths about employing disabled people* and *Disabled etiquette*.

It gives BT's policy on the recruitment, employment, training and promotion of people with all kinds of disabilities as a member of the Employment Service 'Two Ticks' scheme. It also tells managers where to obtain practical help (financial or otherwise) from within BT and from outside organisations such as the Placement Assessment and Counselling Team (PACT).

On each page BT illustrates its positive attitude to people with disabilities by including a photograph and write-up of a famous person who has a disability or a BT employee who has a disability.

Peter Bonfield, BT group managing director, introduces the ***Valuing Ability*** brochure with: "Many of the barriers faced by disabled people are caused by other people's misconceptions of what they are capable of achieving. The ***Valuing Ability*** booklet provides information on working with disabled people and outlines the role that managers can play in providing equal opportunity for disabled people in their team. It also contains more general information on BT's equal opportunity policy and examines the legal requirements that are placed on the company."

Home adaptions

PAYING for adaptions in the homes of people with disabilities is addressed in a new book by Frances Heywood and Gavin Smart.

Funding Adaptions guides the reader through the adaptions maze, bringing together information on all the funding sources for adaptions – from housing, social services and health budgets.

The report is particularly relevant with the introduction of the 1989 Local Government and Housing Act and the 1990 National Health Service and Community Care Act, which established people's rights to adaptions.

The book, published in July 1996 by the Joseph Rowntree Foundation, is priced £14.95. ISBN: 1 86134 010 9.

Share Music dates

DATES for the popular Share Music Courses, which aim to provide facilities and encouragement to enable young people with physical disabilities to take part in a variety of musical activities, have been finalised for 1997.

They are:

26 July - 2 August at Crabhill House, Redhill, Surrey.

26 July - 2 August at Calvert Trust Centre, Keswick.

9 - 16 August at Stackpole Centre, Pembroke, Wales.

9 - 16 August at Calvert Trust Centre, Keswick.

16 - 23 August at Calvert Trust Centre, Exmoor.

Brochures giving full details are available in February. Early booking is advisable. ***Contact: Dr Michael Swallow OBE, 15 Deramore Drive, Belfast, BT9 5JQ. Tel/fax: 01232-669042.***

Tanni Grey –

WHAT a year 1996 was for wheelchair athelete Tanni Grey MBE – gold and sliver medals in the Paralympics; the publication of her book *Tanni*; a new job developing competitive sport for people with disabilities; then to top it all, in December, a TV celebration of her life.

TOP wheelchair racer Tanni Grey, who won a gold and three silver medals at the Atlanta Paralympics, was left speechless when she was caught by *This Is Your Life!* presenter and ASBAH vice-president Michael Aspel.

At the time, she was at the end of filming at the BBC studios in London's Wood Lane for the popular TV quiz show *A Question of Sport.*

The MBE-holder spotted Michael Aspel waiting in the wings but was convinced he was going to spring the big red book on another quiz panelist.

She said: "It happened right at the end of the filming – they were doing re-takes for lighting.

"I saw Michael Aspel but he was looking at John Parrott *(a snooker player on the opposing quiz team).*

"When he came over to me, I looked pretty vacant and didn't say anything, I was so surprised."

The 27-year-old Cardiff athlete and a friend were whisked away to another part of the BBC building and treated like VIPs to fill in the hour before they started filming *This Is Your Life!*

Then the cameras rolled again and the story unfolded of Tanni's hard climb to athletic excellence in wheelchair racing.

Mum Sulwen, dad Peter and sister Sian – who had successfully kept the surprise from Tanni for over two months – were among the guests.

Tanni's boyfriend, Ian Thompson, a track and road racer who became a wheelchair user after breaking his back in a cycling accident, was also there.

Friends from school and university recounted their own special memories of Tanni.

Other wheelchair athletes from the Paralympics team – Chris Hallam, John Harris and Dave Holding – also helped make the 30-minute show extra special.

But the biggest surprise of all for Tanni was the appearance of her coach, Jenny Banks, who arrived all the way from Australia.

"They showed footage from the competitions I've entered – the Paralympics in Barcelona and Atlanta – and there were some dreadful pictures of when I was little," Tanni recalls.

Another highlight was a taped interview with good friend and former fierce track competitor, retired Danish athlete Ingrid Lauridson.

Tanni successfully defended her Paralympic 800m title in last year's Atlanta competition, and added three more silver medals in the shorter sprints to the four golds she won in Barcelona.

"It was great to see so many friends together at the same time. That was the best bit. We had a party afterwards at the BBC which was great fun."

WITHIN a week
from the Atlanta
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people going on throughout the country.

She will be looking at the coaching structure and trying to make it easier for non-disabled coaches to train athletes with disabilities. This will include running coaching development days.

More competitions at a regional level are also planned for athletes with disabilities.

Tanni said: "There's a lot going on at the moment. The idea is to bring it all together under one banner."

She will be responsible for administering the £500,000 plus funding pledged from BT to benefit disabled athletes throughout England, Scotland, Northern Ireland and Wales.

The scheme is being run in partnership with the British Paralympic Association, the British Sports Association for the Disabled and the UK Sports Association for People with Learning Disability.

How the surprise was sprung

TANNI'S parents and sister Sian were first approached back in August by the *This Is Your Life!* production team.

During much of that month Tanni was in America for the demonstration race, staying on for the Paralympics until the end of August.

So it was September and most of October when the family were hardest pressed to keep tight-lipped about the programme.

Mrs Grey said: "There were a couple of scary moments at Ian's *(Tanni's boyfriend)*. Somebody rang up to speak to him and couldn't leave her name in case Tanni was around.

"On another occasion, the girl researcher wanted to speak to Ian's sister Faith and guessed Tanni was around. Faith picked up the phone and replied: 'Yes. I don't want any more until after Christmas,' then hung up."

"If Tanni was staying with us in Cardiff, we told the researcher 'don't ring this weekend, Tanni's here.'

"It was very exciting not letting on. Because Tanni was on *A Question of Sport* beforehand, we had to be very careful when talking about the filming that *This Is Your Life!* didn't slip out as well. You always had to think before you said anything."

Although the family helped fill in the details of Tanni's life, they had no idea of the format of the programme until they went to the first rehearsal.

Mrs Grey said: "We said at the beginning that we didn't want it to be patronising as some programmes on disabled people are. They assured us that it would be a celebration of Tanni's life, and it was.

"The way they do it is extremely professional and quite clever. We were made to feel quite special."

When the filming of the 'red book day' finally arrived, the family had to make sure Tanni knew no one was in the house in case she phoned home.

"We had to tell a few white lies," admitted Mrs Grey. "Sian and I went to the first half of the second rehearsal of *This Is Your Life!* and then on to *A Question of Sport.*

"Tanni's father was needed for the whole of the second rehearsal so we told Tanni that he would be out dealing with a recent collection for the Royal National Lifeboat Institute – he is chairman of the Cardiff branch.

"Nobody contacted us and we contacted no one beforehand, so it was funny meeting people at Cardiff Station all on their way to the show. We said: 'We know where you're going!'"

As the cameras rolled for *A Question of Sport*, Mrs Grey and Sian waited on tenterhooks for the end of programme.

Mrs Grey said: "The quiz show seemed to go on and on. I don't suppose we took as much notice of the programme as we would have if *This Is Your Life!* wasn't coming afterwards."

Mind the gap!

REACHING out across the divide between able bodied people and people with disabilities, thinking about each other and doing something about it, is the aim of training consultancy *Mind the Gap!*

Director John Richards promotes the Christian belief that all people should value each other through mutual understanding and respect.

John, aged 46, has spina bifida and is visually impaired due to developing hydrocephalus following corrective spinal surgery when he was four.

"My wife thought of the name 'Mind the Gap!' on a train in London," said John *(pictured above)*. "I'm asking both sets of people to think about disability and do something about it."

He is developing the consultancy through his role as part-time development officer for the Centre of Integrated Living in Milton Keynes – a regular venue for the local ASBAH support group – and through seminars and workshops.

"Being visually impaired, I've grown up as a disabled person so I am aware of the issues from the point of view of the consumer or user," he says. "But having a diploma in Social Work, I have a professional view as well, so can take a broader perspective.

Part of the development officer job is to run a voluntary befriending scheme called 'Two's Company' for those with a newly acquired disability or someone new to the city. The idea is to have 'a friend' to accompany you to the cinema, share a hobby or change a light bulb.

With an honours degree in Social Policy and the diploma, John worked for six years in hospitals with patients suffering from terminal illness, amputations and various traumatic situations including coping with the efffect of the diagnosis of disabling and often degenerative conditions.

Being used to working with people with various backgrounds and beliefs, he says he is not out to convert people in his job.

"As a hospital social worker, working with many faiths, I had to work with the philosophies of the group so I could get alongside people," he said. "From this point of view, I'm divorced from my faith. I don't believe God would want anyone who is trapped to make a decision. All I can do is offer God's love through myself by giving support."

John has also worked as a senior policy officer at RADAR and for seven years in Buckinghamshire Social Services.

He has held several posts in a variety of voluntary organisations and has served as a trustee of Shenley Christian Fellowship and leader of Milton Keynes Torch Fellowship for blind and partially sighted people.

Of the Church's attitude to disability, he says: "I believe churches have to look at disability as well as anyone else. Disability can be viewed by them as an accident – that things have gone wrong. But this is not necessarily the case. Disabled people can make a contribution to their church."

In his consultancy role, John is planning a 10-week course for SCOPE to help people who have been in residential care find a place in society. "Sometimes disabled people themselves have got to look beyond the disability and understand that the world doesn't revolve around them," he said.

Contact details for Mind the Gap! are: John Richards, 44 Marjoram Place, Conniburrow, Milton Keynes, MK14 7AQ. Tel: 01908-676089.

More about the Milton Keynes Centre for Integrated Living

MILTON Keynes Centre for Integrated Living (CIL) is a resource and information service for disabled people, their families, carers and those working in the field of disability. Located in the centre of Milton Keynes, opposite Marks & Spencer, at 330 Saxon Gate West, it is run by disabled and non-disabled, paid and unpaid workers. It offers:

- ● Local and national information covering topics such as equipment, transport, social support groups, leisure and sport, accessible pubs!
- ● Appointments with specialist services on employment and disability benefits.
- ● Meeting room hire for groups, business meetings, training and leisure activities.

CIL's telephone, minicom and fax lines are open Monday to Friday 10am-4pm.

It is open for visitors on Tuesday, Wednesday and Thursday, 10am-4pm. An answering machine is available at all other times (voice only).

Voice 01908-231344; minicom 01908-231505; fax 01908-231335.

HYDROCEPHALUS NETWORK NEWS

ASBAH, 42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
Internet Web Site: http://www.asbah.demon.co.uk/
Reg Charity Number 249338

Spring '97

New Alert card available

WE ARE issuing a revised shunt Alert card which takes account of our experience of working with the first card over the last two years.

The new card – which people with hydrocephalus shunts should carry at all times – will ask for more detail about the type, manufacture and serial number of the implanted shunt, and which surgeon did the operation.

It will provide greater assistance to medical staff who are having to make quick decisions in the event of shunt failure.

The first card was taken up by 1,459 people. It was devised by ASBAH – along with a GP Information Sheet – because we found that many family doctors and hospital staff are unfamiliar with the symptoms of a blocked shunt. These symptoms can be life-threatening left undetected over even quite short periods of time.

If you would like the new Alert card – even if you already have the old one – please send your name, address, telephone number and your GP's name and address, plus a stamped addressed envelope to: ***Lyn Rylance, Services Dept, ASBAH, 42 Park Road, Peterborough PE1 2UQ.***

Please mark the top left-hand corner of the envelope 'H.'

Eating problems and children with hydrocephalus

I AM trying to gather information on children with hydrocephalus and associated eating disorders.

I would be grateful to hear from any parents of children with hydrocephalus who have had problems, or who are experiencing problems, with eating, no matter how small or large.

Please contact Paula Thompson at ASBAH's national centre.

Subs charge for HNN

WE REGRET that increased print and postage costs mean that we shall have to charge a subscription to people who receive *Hydrocephalus Network News (HNN)* in the future. But we hope you like the new format – eight pages means double the amount of reading from now on.

We will have more space for articles from the experts, a letters page, plus readers' personal stories.

The new charge will apply from the next issue of *HNN*, which will appear in July.

Subscription rates will be:

- ▲ £2 a year (four issues) for readers living in the UK,
- ▲ £5 a year for European and overseas surface mail subscriptions,
- ▲ £10 to receive *H N News* by airmail.

Thanks to everyone for their generous donations in the past.

To receive HNN in future, please fill in and return the coupon on the back page of HNN.

£8,558 raised in our Dr Bayston research appeal

LOCAL associations and individuals have sent in £8,558 for an appeal to fund important research into the diagnosis and treatment of hydrocephalus shunt infections.

The £10,000 appeal is for a research project led by Dr Roger Bayston, a senior microbiologist at Nottingham University and ASBAH's honorary consultant on hydrocephalus.

National ASBAH launched the appeal last summer. Full details of the project to benefit from the appeal appeared on page 6 of the June/July '96 issue of our *Link* magazine. We asked local associations and individuals to help, pledging to make up the balance.

Local associations, plus Irish ASBAH, had donated a total of £5,450 as this issue of *H N News* went to press. Gifts from individuals had totalled £3,108.

ASBAH executive director Andrew Russell thanked all those who had contributed.

See opposite page for news of another research project being conducted by Dr Bayston.

DO you struggle to intervene when others make prejudicial remarks or jokes? Would you like to learn skills which assist you to be more effective in such a situation?

The National Coalition Building Institute, Leicester, is running Welcoming Diversity and Prejudice Reduction *workshops on 13 March and 8 May. Tel: 0116-260 3232 for details.*

New year, new you?

THINKING of taking up a new hobby or sport? Then *Sport and Leisure* could be the book for you.

It has information on equipment for activities ranging from card games to angling; water-skiing to hang-gliding. It tells you who to ask for further information and advice; where to go to meet like-minded people and find support.

Sport & Leisure ***is available from: The Disability Information Trust, Mary Marlborough Centre, Nuffield Orthopaedic Centre, Headington, Oxford OX3 7LD, price £10.***

Independent living exhibitions in the regions

A SERIES of regional independent living events, designed to reach consumers and busy professionals, will be staged during 1997.

The shows, endorsed by Naidex Care Management, will give information and have displays on mobility products, household adaptions, personal care, public access, communication equipment, adapted transport and education.

They will be held at:
- Bristol – 20-21 March.
- Glasgow – 25-26 April.
- Esher, Surrey – 7-8 August
- Doncaster – 25-26 Sept.

In addition to their good transport links, the venues have been selected for easy access and excellent parking facilities.

Admission is free providing you have a ticket in advance. To order your free ticket for the show call the ticket hotline on **01275-836465.**

Parents want to talk

A LONDON couple who have a two-year-old son with hydrocephalus would like to talk to parents in a similar situation, perhaps with a slightly older child.

John and Jacqui Bowmer, from Earls Court, hope to hear from parents of a child aged up to seven or eight years old. Their son, Alexander, has a first-time shunt for hydrocephalus.

"I know it's a bit selfish, but we would like to speak to people who have trodden the path before. They will have experience we can benefit from," said Mr Bowmer.

Please contact Mr and Mrs Bowmer on 0171-373 6384.

A report on Dr Roger Bayston's study of the immune response in shunt infections, and development of a diagnostic test. Dr Bayston is ASBAH's honorary consultant on hydrocephalus.

SOME readers will recall that, some years ago, a blood test was available for diagnosis of shunt infections. This proved invaluable in sorting out difficult or puzzling cases, and when used as a screening test it was instrumental in getting rid of the risk of shunt nephritis, a cause of kidney failure.

When Dr Bayston developed this test, most shunts drained into the heart (VA shunts). Over the years the situation has changed, with most shunts now draining into the abdomen. Unfortunately, the original blood test is not helpful in such cases, and Dr Bayston has conducted preliminary research to explain why this is so.

The work has been severely hampered by lack of funds, as such research is not attractive to funding councils, and it has had to be carried out piece-meal over several years.

Dr Bayston has been concerned that during this period no testing or reference service has been available, but he has now, with Mr Jonathan Punt, appointed a PhD student, Miss Helen Wood, to develop this research further with a view to re-establishing a diagnostic/screening test for use nationally.

Helen's core support comes from the European Commission, but the bulk of the research costs will be provided from money raised in response to ASBAH's campaign to raise funds to support Dr Bayston's research into aspects of hydrocephalus.

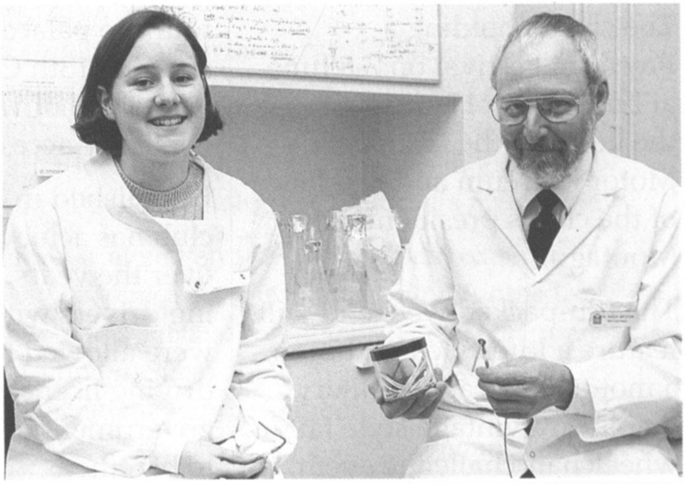
Helen is a graduate of the University of Nottingham, where Dr Bayston's research laboratory is situated.

The intention is to be able to provide information from the blood tests which will help to make a diagnosis in cases where there is a problem, such as recurrent blockage of the lower catheter, but where other tests are unhelpful or inconclusive.

A great deal of clinical information and experience has also been accumulated over many years which will be invaluable in interpreting the data. Quite a lot more basic research is necessary before a full service can again be offered, but the original blood test has already been returned to service to help with diagnosis of problems in cases of VA shunts.

Dr Bayston will be contacting consultants throughout the country to ask them to supply blood samples for the research, and if you are unlucky enough to have to visit hospital for investigation or for shunting you may be asked to participate. We will need a sample before operation, and another at about six months after operation. If a problem arises after surgery, we will need another sample.

Dr Bayston can be contacted through ASBAH for further information, and progress reports will appear from time to time.



Dr Roger Bayston with PhD student Helen Wood, who has been appointed to help re-establish a blood test for the diagnosis of shunt infections.

What's in the Feb/Mar Link

Link is ASBAH's main magazine. Subscription details from National Centre.

The Written Driving Test

by Tim Leech, ASBAH national mobility adviser

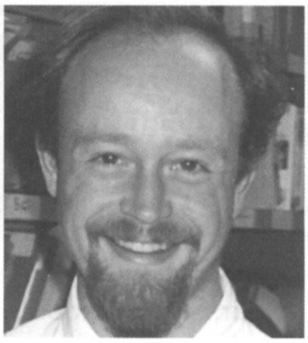
THE written section of the driving test was introduced in April 1996. Thankfully, individual arrangements have been made for people who have problems with written language.

The test is multiple choice and examples of the type of question are available in two books or on CD-Rom. (*Theory Test Sample Question Papers, The Complete Theory Test for Cars and Motorcycles* and *The Theory Test and Beyond*).

Problematic areas may be the language in which questions are couched, picking the right letter of the multiple choice because of short-term memory and structural sequencing can be difficult.

However, arrangements can be made to take the test on a one-to-one basis with questions read out and more difficult language being explained, or more time given. To arrange this, complete the portion of the application about 'Special Needs' and provide medical and educational information.

Alternatively, contact the Special Needs Department of the Driving Assessment Centre in Coventry on 064-5000555. To book a test contact the **Special Needs Department of the Driving Assessment Centre in Coventry on 064-5000666.** This will also allow you to find wheelchair and general accessible testing centres. Other useful contact points could be: **The Road Safety Department of the Department of Transport on 0171-2714733** and **the Driving Standard Agency on 0115-9557600.**



Tim Leech

Problems may also occur due to examiners' lack of knowledge over how to assess a person with hydrocephalus and spina bifida and making sure that people spot the section that needs to be filled in on the form.

Books mentioned are available from WH Smith, HMSO and The Theory Test Unit of the Department of Transport. Other recommended publications are *The Driving Manual* and *The Highway Code*.

Freedom Festival to celebrate a 75th anniversary

PEOPLE with disabilities can gain free entry to the National Motor Museum on two days in June to celebrate the 75th anniversary of the Disabled Drivers' Motor Club.

The club is holding a Freedom Festival on 7-8 June at Beaulieu in Hampshire – the home of the National Motor Museum and residence of the club's president, Lord Montagu.

The fun-packed weekend will feature a Lifestyle Exhibition, a motor cavalcade, military displays, a vintage style fair, a wheelchair challenge event, test drive facilities for adapted cars, falconry, strolling players and a Big Bash Barbecue in the evening.

Visitors can also enter the National Motor Museum, tour the palace gardens and visit the 13th Century Abbey, all of which are generally accessible.

Established in 1922, the club has achieved many goals over the years, notably ensuring drivers with disabilities were allowed to hold full driving licences when the government of the day sought to ban them.

The club has also kept a close watch on government policies and campaigned for the rights of disabled people and will continue to do so.

People with disabilities can register for their free entry by calling 01275-836465.

For those without a disability, the discounted entry fee is £7.50 for adults, £5.80 for teenagers and £5.00 for children. Tel: 01832-735989 for details of how to buy a discounted ticket (24-hour answerphone).

Re-inventing The Wheel

or Third Ventriculostomy

by Michael Vloeberghs MD

WHY re-invent the wheel? There was nothing wrong with the old ones. This may be true for wheels but not when it comes to the treatment of hydrocephalus. It wasn't until the 1960s, with the development of implants, that the treatment of hydrocephalus became possible and shunts (the diversion of fluid from brain to chest, the heart, or usually the belly with silicone tubing) became a routine procedure for neurosurgeons and others. Apart from technical advances in structure and shape, the concept has remained the same. The problems associated with shunts haven't changed either. Shunts still fail mechanically, block, overdrain and infect. Very little can be done on this front and if shunts were kitchen appliances, the manufacturers would recall them.

There is an alternative which is endoscopic third ventriculostomy. This very old procedure (dating back to the 1900s) was abandoned because of outrageous complications due to poor anaesthetics and inappropriate equipment. Technical progress in optics, electronics and image processing have made endoscopy (which means looking inside something) accessible to all medical disciplines. In the 1980s endoscopic instruments were purpose-built for neurosurgery and an increasing number of applications were found. Currently in our department two to three neuroendoscopies are performed per week for a variety of indications, mostly for the treatment of hydrocephalus but also in tumour surgery.

Endoscopic ventriculostomy, which means opening the floor of the brain using a miniaturised telescope, was one of the first applications. Because of the position of the cavities of the brain, specifically in hydrocephalus, you can navigate from the top of the skull through the brain to the floor of the brain. The floor is very thin and can be opened using a laser fibre or another cutting device. This allows the fluid to flow out of the brain via a natural bypass. The risk of this procedure is very low and there are no side effects, there is no overdrainage, no blockage, the risk of infection is very small and, most important of all, there is no foreign material left behind that can cause difficulties at a later date.

The success of this treatment is determined by what caused the hydrocephalus in the first place. If the natural outflow of fluid is blocked by a tumour or from birth (obstructive hydrocephalus) the success rate is 85%, when there has been an infection (meningitis) or a bleed in the brain the success rate is about

continued on page 6

MICHAEL VLOEBERGHS MD is full-time paediatric neurosurgeon and senior lecturer at the University of Nottingham in the Department of Child Health. Having originally trained in Belgium, he spent one year of final training in the UK. He then returned to the Vrije Universiteit in Brussels where he held a consultant post for two years in a mixed adult and children's practice.

The attraction to children's neurosurgery and Britain, he says, proved too strong to resist, so he returned to practice alongside Mr Jonathan Punt at the Queen's Medical Centre, University Hospital in Nottingham. Mr Vloeberghs' main interest lies in technology and the application of new technology in children's neurosurgery.

"This does not imply trial and error at the patients' expense," he says. "It does mean keeping your ear to the ground for the latest developments in domains such as computer science, electronics, robotics etc, and to find medical applications of this technology that benefit both the patient and the surgeon. There is a surprising

continued on page 6

Re-inventing The Wheel – or Third Ventriculostomy, *from page 5*

50%. The overall success rate for endoscopic ventriculostomy in hydrocephalus is two-thirds. The advantage is that once a ventriculostomy functions and the hydrocephalus is relieved there is no need for further surgery. Ventriculostomy, when successful, is a one-off procedure with permanent result. We now treat an increasing number of patients with shunt complications with the same overall success rate. Having a shunt in place does not preclude endoscopic treatment.

This compares favourably with the 'classic' treatment of hydrocephalus, ie shunts, since 70% will fail within a 10-year period and a child needs a mean of five to six shunts before reaching adult age. We have come to the point that we offer endoscopic treatment for every new case of hydrocephalus and for every shunt blockage.

But what if the endoscopic treatment does not work? Overall there remain one-third of the patients in whom the procedure will not relieve the hydrocephalus. In those patients the only option is to divert the fluid with a shunt. A prior ventriculostomy does not influence the procedure. Up to now there is no way of predicting which patient will benefit from the procedure so we must remain honest about the results and it is only after a lengthy and informative talk with the parents that we proceed.

Unfortunately, we can't take any credit for either the operation or the equipment, but we may have re-invented the wheel in the sense that we are rediscovering an old procedure using the latest technology and improving the results.

MICHAEL VLOEBERGHS, from page 5

amount of ideas and applications in aerospace and defence technology no one has looked at from a medical viewpoint."

To this effect several research projects have been launched in co-operation with the mechanical engineering and intelligent machines departments of the University of Nottingham.

His main interest lies in hydrocephalus and in the promotion of neuroendoscopy as an alternative to shunts in the treatment of hydrocephalus. "All this high tech, high profile stuff is very nice," he says, "but only worthwhile if there is a real application which will make life easier for your patients or their parents. Whichever research angle or application of technology you examine, you must ask yourself if what you are doing really makes any difference in the treatment you are offering and whether there is a genuine improvement in outcome or in quality of life for the child you are treating. This is the reason I pursued a career in children's neurosurgery, in this speciality you can really make a difference."

My experience of Third Ventriculostomy

By Nina-Louise Poole, Great Barford, Bedford

I HAVE had hydrocephalus since I was eight months old due to having meningitis. At eight months old I had a VA shunt put in at Walton Hospital, Liverpool and at four years old I had a VP shunt fitted at Booth Hall Children's Hospital, Manchester.

After five years of having no problems, my shunt blocked five times, one after another.

Then finally they realised it was time to do a ventriculostomy.

I had a third ventriculostomy. They drill a hole in your skull, then make a hole in your brain with a laser which makes a natural channel for the fluid to run through.

This technique requires training and skill and is still fairly new.

I feel better after my operation thanks to Queens Medical Centre, Nottingham, and Mr J A Punt and all the staff on E39.

The best thing about having a third ventriculostomy is that, after having a shunt all my life, I have now been stitched up and had the tube removed from my neck to my stomach.

So now I haven't got a shunt which is the best thing in the world because I thought I'd have a shunt for life.

It's as if I'm a normal child.

HYDROCEPHALUS NETWORK NEWS

Contacts

Network Co-ordinator: Rosemary Batchelor 01733-555988.

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Medical Adviser (National): Paula Thompson 01733-555988.

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Education Adviser (Northern Ireland): Lorna Johnston 012477-72191

Medical/Continence Adviser (Northern Ireland): Marie McGonnell 016487-64748.

ASBAH's Honorary Consultant on Hydrocephalus: Dr Roger Bayston M Med Sci MRC Path, contact through ASBAH's Services Dept at ASBAH House.

HN NEWS letters

MY OWN situation was very stressful from a very young age because I suffered without any diagnosis from doctors. In school I was often off sick because the headaches would make me feel sick and dizzy. The doctor at the time always prescribed pills for migraine.

At 19 I was seen by a specialist in Birmingham. I went for a scan which showed there was a blockage in my head – that was a relief. Surgery followed and my shunt was fitted at the age of 19. Since then I have had no major problems but the headaches are still a part of my daily life.

The highlight of my life came on 7 August 1996 when I had my first baby boy. After years of worry and uncertainty my view of life changed. I know people may think very little of having a baby but for me it was a major hurdle.

I am writing this to give other readers hope that all can be achieved if you believe in yourself.

Throughout my pregnancy I was in such good health that even I couldn't believe it. I did have to have a Caesarean delivery because my baby was lying breech.

After my son was born, I recovered very quickly. He is now six months old and I am looking forward to having another baby in the future.

My only thought throughout my life has been that there is nothing in the world I cannot do even if I have a shunt.

Baljeet Ghavri
London N9

TO continue with the objection to the term 'water on the brain' being incorrectly used (*Link*, Dec '96), a certain Sunday newspaper upset me by using this phrase in an insulting way.

When I wrote to them with my objection, they agreed to donate £25 to my eight-year-old niece Kylie Pratten's sponsored tricycle ride in aid of ASBAH. Perhaps we should object more often!

Mrs Susan Dagama
Barton, Torquay

PARENTABILITY is a national network of disabled people who are parents or who hope to become parents.

It is part of the National Childbirth Trust, giving support for pregnancy, childbirth and early parenting.

ParentAbility offers a contact register to put parents in touch with each other, a newsletter, helpline, and a professional contact register.

Contact: National Childbirth Trust, Alexandra House, Oldham Terrace, London W3 6NH, tel: 0181-992 8637, and you will be put in touch with a member of ParentAbility.

True story

by Mandy Tindal from Gosport in Hants

AFTER receiving your letter of support, I decided to give Darren's doctors one more opportunity to sort things out.

Darren had an appointment and as soon as we sat down I told the doctor not to bother telling us that Darren was having migraines. I just couldn't believe that line of thought anymore. I knew deep down, like most mothers I suppose, that Darren had a problem with his shunt. I became upset, but it did the trick as Darren was admitted to hospital two weeks later for tests.

As luck would have it, Darren didn't have one headache for five days but the consultant still agreed to fit a device so the pressure inside Darren's head could be monitored.

Darren was hooked up most of the day and the doctors were considering taking him off the monitor as everything seemed OK.

Then, while we were talking, Darren started to get a headache and within seconds Darren's reading had gone right off the scale.

I felt terrible to think it, but this is what we had been waiting so long for – the proof that the doctors needed as they just didn't believe what Darren had been going through all this time, four years or more.

A doctor removed some fluid with a syringe and Darren couldn't believe how quickly his headache disappeared. It was 'like magic' he said. He soon had the headache back but was fitted with a drain soon after, and was taken to theatre that evening to have a new shunt fitted.

Darren Tindal

The consultant said the old shunt was stuck and couldn't be removed – it had become blocked up and useless – and just a line to my son, which was 'Oh Darren you weren't lying, were you?' These words were not what we had expected to hear and conjured up a lot of bad feelings.

To look at Darren is to look at any normal healthy, happy nine-year-old, but when he was ill he suffered so much.

The times I had wished I could have filmed Darren when he was bad to prove to his doctors what was happening. As the comment from the consultant shows, they just didn't believe.

I am happy to say that Darren is doing extremely well and not one headache since. I have learned a very big lesson through all of this – to follow my instincts and not give up, no matter what. The doctors are not gods and don't know it all. How could they?

YES! I would like to take out an annual subscription – four issues a year – of 'HN News.' Annual subscription rates: £2 (UK); £5 European and overseas surface mail; £10 by airmail.

Service user's name ______________________

Parent's name (IF APPLICABLE) ______________________

Address ______________________

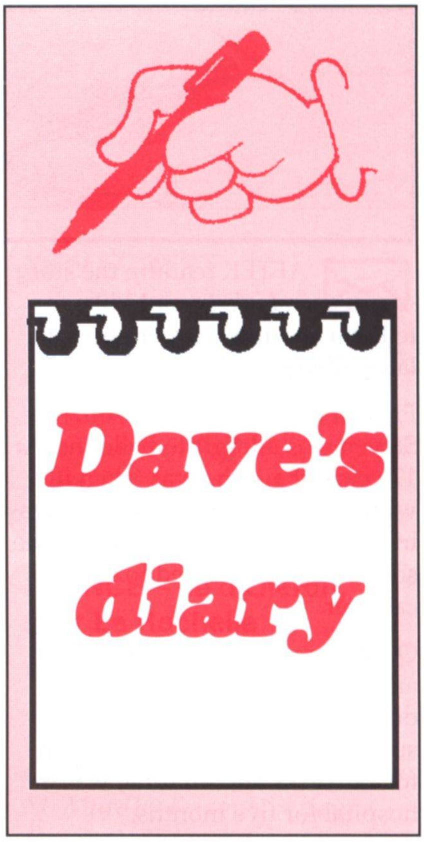
____

Postcode ______________ **Tel:** ______________

I enclose a cheque/postal order payable to 'ASBAH.' All payments should be made in Sterling.

Please cut out or photocopy completed forms and send to: Lynn Thomas, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

If you have a true story you would like to tell other members of the Hydrocephalus Network, send it to: Rosemary Batchelor, Co-ordinator, Specialist Advisers, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.



Dave's diary

Forget operations, going to school, etc – moving house is *the* most exhausting thing I've ever done! Only now can I summon the energy to write of the ordeal! It's not just Moving Day that knackers you, it's all the time before. Moving occupies so much time that recovering from a major op seems a mere eye-blink in time. There's months of looking at houses, considering paints, planning and finally packing.

My name is Dave and I am a hoarder. If there's a help group for hoarders I will willingly go. Along with a thousand other precious items which others dismiss as 'junk,' I found school reports from 15 years ago (which I'd not seen since then) and proclaimed that I must take them with me, I simply couldn't live without them and they'd just have to make room in the van – and they weren't even *good* reports! I don't know if it's having spina-bifida, hydrocephalus, or just being me, but I get terribly attached to objects and the memories I associate with them. It was stressful to see my stuff go into the van, knowing not everything would make it out intact!

It helps to keep the stress down if dear Mother Nature doesn't make the week you're shifting heavy boxes the hottest this century. My body responded to this brilliant bit of luck in its usual fashion – I got ill. I also got careless. With the move I'd been too busy to check the backs of my legs, where I have little sensation, until one day when I felt two hot lumps. As I'd packed my mirror and don't know any yoga, I had to ask mum if she'd have a look. She almost fainted with shock and rushed me off to the doctor's straight away.

The doctor's initial diagnosis was "Yuk, I don't like the look of that," which was not greatly reassuring! It turned out I had a plague of boils and I was swiftly on antibiotics and off the booze. I returned later for more pills and the lady doctor told me that Americans call my condition 'Trucker's Butt.' Lovely! This transatlantic herald of Global Warming is so called because truckers sit on their rears for long periods in the heat, wearing thick trousers. This results in chaffing, which in sensation-free me developed into boils. Fortunately it soon cleared up and I've hopefully seen the back of the surgery for a while.

Doctors' surgeries warp the mind. Typically, if you aren't staring at other patients, the two things that occupy your mind are the music/intercom system or the magazines. I don't know which is worse. The ancient intercom buzzes like bees on steroids so you can't hear who's being called. But that is far better than the dreadful 'music' – Elton John hits re-written for the penny whistle or organ.

The alternative is to dig into the pile of Reader's Digests and women's mags that festoon every surgery. After years of reading women's magazines I now know more about women's problems than *any* so-called 'New Man!' In an attempt to shift the hormonal balance and get 'male reading matter' into waiting rooms, I have begun sending my old magazines to the doctors. I invite male readers to do the same!

David Fulford-Brown

One-stop continence service

A ONE-STOP service for a wide range of continence products has been set up at Disabled Living in Manchester.

The exhibition, known as PromoCon, is open Monday-Friday 9am-4.30pm but it is best to ring first (see below for address and telephone details). All the products on display are featured in the Continence Foundation's catalogue.

Smaller displays of continence products are being set up at disabled living centres throughout the country.

PromoCon, a three-year project funded partly by the Department of Health, is a national initiative between the Continence Foundation and the Disabled Living Centres Council. It is led by Continence 2001 in Manchester.

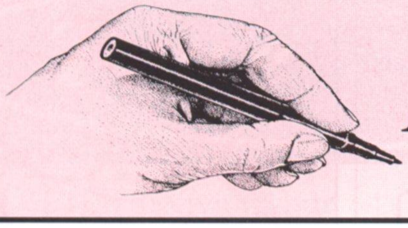
For further information contact: Helen White or Debra Evans at Disabled Living, 4 St Chad's Street, Cheetham, Manchester M8 8QA. Tel: 0161-832 3678.

Mums, we need your help

CALLING all mothers with spina bifida. We need your help to compile an information sheet with ParentAbility on pregnancy and child birth.

What would you have liked to have known when you were pregnant or during child birth? We would welcome a note of your thoughts, ideas and experiences.

Please write to: Gill Winfield, Information Officer, ASBAH, 42 Park Road, Peterborough PE1 2UQ as soon as possible.



Letters

We invite letters for publication. Send them to: *Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.* We reserve the right to edit letters for publication, so keep them as short as possible.

AFTER reading the story in *Link*, I would like to tell you about my experience of latex allergy.

From the age of five, my son Steven was allergic to balloons. At 17 years of age, he was taken ill with food poisoning. While he was in hospital he could not pass urine, so the doctors decided to insert a catheter.

On doing so, Steven went into anaphylactic shock which the doctors did not think he would survive. He was in intensive care for 12 weeks and, in total, was in hospital for five months.

The point I am trying to make is that it should be recognised that there is a link between spina bifida and latex allergy.

Is there something Steven could carry with him – a bracelet or badge – which would inform people of his allergy?

Steven is now 21 and we would never like to go through anything like that again. I do hope that this allergy will be recognised in this country, like it is in America.

Please carry on your good work.

Mrs V Lynch
Bridgend, Mid Glam

Editor's note: The Medic Alert bracelet or neck pendant is a very useful device. It is engraved with the wearer's medical condition, personal identification number and a 24-hour emergency phone number. Medical staff can obtain vital additional information by phoning the emergency number, from anywhere in the world.

Medic Alert, 12 Bridge Wharf, Caledonian Road, London N1 9UU. Tel: 0171-833 3034.

Bonjour! My name is Diane. I am the mother of Catherine who is six years old and has spina bifida and hydrocephalus.

I would like to write to other mothers of children with spina bifida. We can share experiences, happy or sad – hospital, school, family, siblings, etc.

I eagerly await your letters.

Diane Mercier
1700 Galt
Montreal, Quebec
H4E 1JZ, Canada

I WOULD like to amend a statement in the article on latex allergy in Dec/Jan '97 *Link*.

The section entitled 'Foods with a Cross-Reactivity to Latex' states: 'if your mouth itches when you eat any of the foods listed below, you could be allergic to latex as well.' It then goes on to identify certain foods.

Mouth itching is not the only sign of allergy to food. Other common signs of food allergy are bronchial congestion, swelling of the tongue, skin rash and vomiting. Severe allergic reactions may cause anaphylactic shock – a severe and sometimes fatal reaction.

Caroline Berkley
ASBAH specialist adviser (medical & continence)

DATES FOR YOUR DIARY

Monday 14 April

Spina bifida/hydrocephalus support group meeting, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, tel: 01582-605749.*

Monday 12 May

Spina bifida/hydrocephalus support group meeting, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, tel: 01582-605749.*

Monday 12 May

ASBAH conference for medical and health professionals, 'Current Approaches to Spina Bifida and Hydrocephalus,' National Motorcycle Museum, Birmingham, 9.30 for 10am-4.30pm. Speakers include Mr A E MacKinnon, Mr M Vloeberghs, Mr J H Patrick, Miss J Iddon, Mr K Parashar. *Details: Geraldine Long, ASBAH, 12 Priory Road, Alcester, Warwickshire B49 5DY.*

Saturday 17 May

Spina Bifida & Hydrocephalus – an holistic approach, study day organised by ASBAH Eastern Region, The Lincoln Suite, The Lawn, Union Road, Lincoln, 9.30am-4.05pm. Speakers: Professor Kypros Nicolaides, consultant paediatric neurosurgeon Jonathon Punt, consultant paediatric surgeon and urologist Christopher Rance, ASBAH specialist adviser (medical) Julie Llewelyn. £15 service-users and family members, £60 professionals. *Booking forms (returnable by 18 April) from Rebecca Sewell, ASBAH East Region, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988.*

HOLIDAY ACCOMMODATION

When booking, check to make sure the accommodation suits your particular needs

WEYMOUTH BAY

Fully-equipped, wheelchair accessible caravan – sleeps five; on Haven Holiday Park, full use of all facilities – heated indoor & outdoor pools, bars, children's club & full entertainment programme, Three miles from Weymouth. *Details from Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).*

ISLE OF WIGHT ASBAH

Fully-equipped two-bedroom holiday bungalow, sleeps six plus cot. Clubhouse, indoor heated pool, shop etc. Site overlooks sea. Own transport advisable. *Details: Mrs P Burden, 36 Sherbourne Avenue, Binstead, Ryde, IOW, PO33 3PX, tel: 01983-564604.*

SELSEY, WEST SUSSEX (SASBAH)

Fully equipped purpose-designed for wheelchair access mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. *Details from Mrs B Nunn, tel: 01903-763473.*

MOLD, NORTH WALES

Luxury, wheelchair-accessible bungalow. Sleeps 4/5. All mod cons. Two bathrooms, private south-facing garden. Ideal base. £280 weekly. *Brochure: Mrs Dowling, 23 Gleneagles Road, Great Sutton, South Wirral L66 4NF. (Tel: 0151-339 5316).*

NEW FOREST

Fully equipped caravan designed for wheelchair access throughout. Sleeps 5-6. Club house, indoor swimming pool, shop, sited at Bashley Park, New Milton, Hants. *Contact Joan Searle, tel: 01705-376816.*

FRANCE – Ile d'Oleron, near La Rochelle

Mobile home for wheelchair users. Fully adapted (shower etc), sleeps six, near beach, disabled owner. *Brochure from M Mardle, Fricourt, Filey Road, Old Heath Road, Southminster, Essex CM0 7BS. Tel: 01621-785899.*

FOR SALE

FOR SALE – Puma Booster de-luxe chair with electric seat-tilt, backrest and leg rests. Batteries, charger, lights and indicators. Used one week only. Cost £5,500 new. Offers, please ring 01372-458195. High-edge ramp also available.

LINK Rates

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Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of *LINK* (April) should be submitted by Friday, 14 March. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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Highfield
Hemel Hempstead
Herts HP2 5PA

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Tel: 01484-424479

HULL & DISTRICT
Mr Philip Brown
233 Cranbook Avenue
Hull HU6 7TX
Tel: 01482 857 165

KENT
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Tel: 01732 822985

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37 Milton Road
Hanwell, London W7 1LQ
Tel: 0181 579 4685

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15 Woodvale Walk
Elder Road
W Norwood
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