ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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The magazine for people with
Spina Bifida and/or Hydrocephalus

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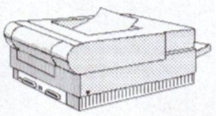

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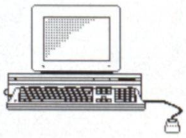

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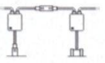

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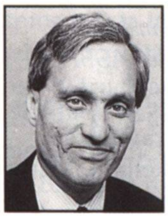
Towards simple justice

New Year message from Andrew Russell, Executive Director of ASBAH



IT IS of fundamental importance for all of us involved in providing services, whether professional or voluntary, on behalf of ASBAH, to uphold the **rights** of individuals with disabilities to a decent life, a good environment, an appropriate education, opportunities in employment, and special help to minimise disability. These things are due to simple justice; they should not be a special privilegein the Western world approaching the 21st Century. This is why we must not allow or collude with the increasing trend in social policy towards caring-where-possible, services-if-they-can-be-afforded-locally, provision-where-practicable.

This, of course, was at the heart of the recent débacle of the Civil Rights (Disabled Persons) Bill, talked out of Parliament by politicians who purported to back it. They knew that, if you give rights in law to people, services have to be made possible, provision has to be practicable. However, though that particular battle was lost back in the summer, disabled people will win in the end and the campaign continues. It will be very interesting to see how the Government's proposals to counter discrimination progress in 1995.

ASBAH must, as well as providing services, be an agent for change, and must involve the ideas and energy of disabled people in pressing for change.

As a voluntary organisation in the 1990s, ASBAH wants to involve more people with disabilities in our structure, our thinking and our staffing.

Partly, we want to make this statement to people with spina bifida and/or hydrocephalus: this is largely their organisation. But it is also an association of parents other family and friends, and professionals who take a deep interest and want to devote some free time to ASBAH. But too few disabled people have been and are involved and we need to change that, which means investing in that change, and encouraging and informing people.

Partly also, we want to make a statement to the outside world that ASBAH values the ideas, the work and the support that our members with disabilities give us. In doing so, we must think through some problems and try to avoid a clash of values. Opinions increasingly being articulated by disabled people - in particular, organisations of disabled people - emphasize rights not charity; empowerment not welfare; participation not oppression.

There is a great deal of justice in this viewpoint, because a great deal of injustice has been going on for a long time. However, ASBAH **is** 'A CHARITY', and we do provide 'services' including 'welfare grants'. We do not want ASBAH, and the enormous amount of commitment and intelligence that has gone into creating us, to be rejected by articulate and intelligent people who have spina bifida and/or hydrocephalus, because they may come to see ASBAH as part of an

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ASBAH is a registered charity

Cover: Jackie Doughton drives into the record books on board a 38-tonnes truck. Full story, see page 5. Photo: Volvo.

OBITUARIES: Mr C Moore OBE, Mr R Baker, Mr N Cook

TRIBUTES have been paid to the life and work of the late **Charles Moore OBE**, best remembered as executive director of the John Groom's Association for the Disabled for 23 years, who died in November. He was aged 67.

Charles, whose wife Shirley was ASBAH fieldworker in Essex for seven years until 1991, retired from the Christian-based John Grooms Association in 1992. He then spent two years with the Disabled Living Foundation (DLF).

He joined John Grooms in 1969 and was largely responsible for the growth of its work in the 70's and 80's. He founded the John Grooms Housing Association to meet the desperate shortage of wheelchair-friendly accommodation.

A spokeswoman for the DLF commented: "He would always listen and he was very much a father-figure."

ROY BAKER, chairman/secretary of the South Hants Association for Spina Bifida and Hydrocephalus, died on 26 November.

He was a founder member of the group over 30 years ago, and the members, families and children owe to him a great debt of gratitude, *writes trustee Tony Ellis.*

"Roy always had time for our problems - even when he had a more serious one of his own. If there was a solution, he would find it. His advice was sound, not necessarily the easy option - counselling, self-help, if appropriate - but always able to recognise the real need", wrote Mr Ellis.

NIGEL COOK, a former chairman of South Wales ASBAH and a prime mover in his local PHAB club, packed a considerable amount of living into his short life (he was 29), *writes John Lewis, chairman of South Wales ASBAH.*

"He had a wide range of interests including amateur dramatics, youth work and basketball. Many people still recall the match between Nigel's team and Barry Rugby Football Club, which proved that wheelchairs are far more manoeuvrable than legs any day!"

"Nigel was an enthusiastic youth worker, socialiser and friend. We will all miss him. South Wales ASBAH intends creating a special fund to honour Nigel's memory and enthusiasm for life", added Mr Lewis.

Towards simple justice *by Andrew Russell*

from page 3

oppressive system rather than an agent for changes.

I believe we must say two things clearly:

Firstly, we are here to try to improve things for individuals, in ways they want, because we and they are in the middle of a system not of our making, which will not change overnight. Although legally and constitutionally we are a charity, the style of our work is not charity, but that of a professional, independent sector organisation advocating and providing specialised services.

Secondly, we are a 'single-disability' agency - if, for this purpose, spina bifida and/or hydrocephalus can be called a single disability - and this concentration on a named condition identifies us (for radical disabled people) firmly as part of the 'medical model'. The medical model is rejected by them as part of the mechanism of oppression. I believe this rejection of organisations like ASBAH is unnecessarily extreme, because there are particular aspects of these disabilities that are complex, hard to address, and not well-known. That was why ASBAH was set up nearly 30 years ago, and the need is still very much there, in spite of many changes in law, in medicine, in education and in every way for our members.

No one associated with ASBAH, least of all doctors, wants to see the return of a medical model of dealing with people, based on the power of doctors, on the mystification of the subject, and the colonisation of decisions by experts. The question remains: is there a need for experts? I believe there is, but that their role is to serve their clients or patients, not to control them.

This continuing role for ASBAH , as a specialist independent organisation, is quite compatible with support for a social model of disability, which stresses the right to inclusion and empowerment of individuals in all aspects of life.

ASBAH has called for full implementation of civil rights for people with disabilities, and has presented a united front with other national agencies in this campaign. Our response to the Government's consultation was written by members with disabilities, so it fully reflects their views.

Each year since I joined ASBAH, more individuals with spina bifida and/or hydrocephalus have been elected to our Executive Committee, and I am sure this will continue. The consultative forum 'Your Voice in ASBAH' is now playing an important part by contributing to the views and attitudes of our Association. These views are positive, assertive and challenging, in line with the services that ASBAH provides to people, to help them secure the best support, equipment, benefits and training to do the things that they want.

Jackie motors into history books!

DETERMINED Jackie Doughton has achieved a lifetime's ambition by becoming the first person with spina bifida to put aside her wheelchair, take the wheel of a heavy truck and pass the driving test for a 38-tonne artic - the biggest vehicle normally allowed on Britain's roads.

Jackie - who used to dream about taking the wheel when her dad John took her for trips in his cab when he was an HGV driver - qualified as a driver of these monster lorries at a test centre in Birmingham in November. No allowances were made for her disability.

"The worst thing was the reversing. It was my worst nightmare come true", said 35-year-old Jackie, who lives at Bilston, near Birmingham. She can now drive all goods vehicles with an automatic gearbox, appropriate hand-control conversion and operating at up to the UK legal maximum of 38 tonnes.

"And the first time they let me out on my own after passing the test, I had a TV crew in the cab filming my every mistake. It was hair-raising!."

To obtain her licence, Jackie took a rigorous test lasting two hours at the Garretts Green test centre in Birmingham, which she passed at third go. The test involved threading the truck and trailer combination through a series of tight manoeuvring exercises designed to stretch her driving skills to their limits.

This was followed by over an hour negotiating the truck through typically busy traffic on roads in and around south Birmingham.

Coventry-based companies Jim Doran Hand Controls and Heart of England LGV Training stepped in to provide the throttle-brake conversion and driving tuition respectively, with Long Marston Airport at Stratford-upon-Avon providing off-road familiarisation.


Jackie Doughton. Photo: Volvo

To reach her goal of becoming a trucker, Jackie roped in Lady Truckers Club president Ilona Richards whom she met at a trucking festival in the summer. Ilona - a heavy goods driver for 18 years - commented: "Getting the licence is usually hard enough work, if you are able-bodied. To want to do it, if you are in a wheelchair without the use of your legs, is something special.

"But Jackie is so full of life and determined that I knew nothing would put her off."

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Officers & Staff

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

A befriending service

ASBAH executive director ANDREW RUSSELL writes about a scheme which will be discussed at our next Council meeting on 4 March. The scheme hinges on the basis of partnership and co-operation between local and national ASBAHs, and he invited you to write in before the Council meeting to let us know what you and your own Association think. *Please write to Andrew Russell, ASBAH, 42 Park Road, Peterborough PE1 2UQ, as soon as possible.*

A PRIMARY concern of ASBAH, for many years, has been how to provide friendly, helpful and informative contact between ASBAH and local families who have a child, or an adult, with spina bifida and/or hydrocephalus.

In many areas, voluntary workers from local associations have provided helpful contact with families, to good effect. Fieldworkers employed by national ASBAH, and sometimes by local associations, have provided a more professional and systematic service, and this too continues to be of great help to thousands of families.

However, local associations do not always have the time available, or people available, who feel they can take on the task of contacting and visiting families who need support. National ASBAH cannot afford to employ enough fieldworkers to give sufficient cover to all areas of the country.

So, if a local network of voluntary befrienders or visitors could be recruited and trained, they could be a valuable source of friendly and informal contact with clients and families, working closely with local associations, and in regular contact with fieldworkers who could provide back-up and involvement when necessary.

Good training would be essential, and would help the voluntary befriender to understand important facts about our disabilities, and who the main helping agencies are. They could be given essential skills in listening, and the knowledge of the basic rights of disabled people, as well as the importance of such things as confidentiality when dealing with people and their problems.

National ASBAH could design and provide such training, in close collaboration with local associations.

National ASBAH would also expect to help with the recruitment of local voluntary befrienders, whose voluntary post could be seen as an appointment within the local association. Local associations which agreed to take part would be asked to pay the out-of-pocket expenses of voluntary befrienders, eg travel, postage and telephone costs, as part of the local association's supportive role within its area.

Through the work of the befriender, the local association could be in closer touch with the issues and problems facing clients and families in their area, and be in a better position to take these up with health, social services, education authorities etc.

For clients with particular difficulties, the services of the ASBAH fieldworker, or disabled living adviser, could be brought in to provide more expert advocacy in obtaining the right benefits or services.

We would like to invite local associations and members to comment on this suggested scheme, which will be a subject for discussion at the Council Meeting on Saturday, 4 March 1995, at ASBAH House in Peterborough.

If there is support for the proposal, the Executive Committee will consider how it can be developed and be put into operation. Please let us know your views.

Jackie motors into history books! from page 5

Volvo, the only UK manufacturer to have a top-of-the-range artic with automatic gear shift and no clutch pedal, quickly responded to the challenge - lending Jackie their 320bhp FL1 Geartronic trick, which lends itself to conversion to hand control.

A self-confessed truck fanatic who already has the certificate needed to practise as a transport manager, Jackie is currently studying up the regulations affecting the movement of hazardous materials.

Jackie, the latest member of 170-strong Lady Truckers Club, knows her physical limitations prevent her from becoming a professional truck driver, but she's well qualified and just enjoys trucks.

Staff changes

JOHN WILLIAMS, has become ASBAH's senior appeals manager to bring together the fundraising activities of covenants, company donations, trust applications, mailings and shop outlets.

His appointment follows the departure of Paul Wootton, fundraising/business liaison manager, who left at Christmas to direct a young group of publishing companies based in Peterborough.

John, 51, comes to ASBAH from a banking background and hopes build on the charity's past fundraising achievements.

TWO fieldworker vacancies in Northern Ireland will be filled. One post is empty after the promotion of Margaret Young to regional co-ordinator; the other was caused by the departure of Alison McArthur.

FAMILY commitments have forced **Pat Waller**, fieldworker for Northants and Leics, to leave ASBAH after 16 months. This vacancy will be filled.

ASBAH'S NORTHERN REGION: The regional team covering Tyne & Wear, Durham, Cleveland, Northumberland, North Yorkshire, West Yorkshire, South Yorkshire and Humberside is now up and running. It is the fourth region to be formed by ASBAH - the others being Northern Ireland, South-East and Eastern England.

The Northern Region team *(pictured below)* is made up Joan Pheasant (co-ordinator), Rose Hinchcliffe (disabled living adviser), Mark Best (housing support worker at Wharfedale), Bernadette Baldwin (fieldworker for West Yorkshire), Anne Walton (fieldworker for Northumberland and Tyneside) and Julie Turnbull (fieldworker for South Yorkshire). A full-time secretary is also being appointed.

Joan Pheasant, Rose Hinchcliffe and the secretary will divide their time between Northern Region and START - ASBAH's service team for assessment, rehabilitation and training. *For details about START contact: Joan Pheasant, ASBAH Five Oaks, Ben Rydding Drive, Ilkley, West Yorkshire, tel: 01943-603013.*

Help & Advice

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

London, Surrey, Kent, Sussex

123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (0181) 449 0475
Regional Co-ordinator: Gina Broughton, BA (Hons).

Lincs, Cambs, Leics, Notts, Northants, Norfolk, Sussex, Essex, Herts, Beds

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

Northern Ireland

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

Northumberland, Durham, N Yorks, S Yorks, W Yorks, Tyne & Wear

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

Rest of England and Wales

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. Prescriptions for drugs or medicines should not be sent to AlphaMed.*

Hi-tech village hall!

FORMER Your Voice in ASBAH chair Jon Burke *(seated in photo)* took on new responsibilities just before Christmas when the Disabled People's Electronic Village Hall (DP-EVH) at Dewsbury, West Yorkshire, marked its imminent independence from the local council with a management handover ceremony to a steering committee consisting of people with disabilities.

Jon, DP-EVH steering committee chair, is pictured taking on the mantle of leadership watched by *(left to right)* Kirklees mayor Harold Sheldon, Euro-MP Tom Megahay and Westminster MPs Barry Sheerman and Ann Taylor.

DP-EVH aims to give disabled people a good grounding in modern office practice so they can compete at an equal level for white-collar jobs. Fifty people have enrolled so far for courses in word-processing, desktop publishing, spread-sheeting, computer literacy and electronic mail systems. They pay £5 a term towards their first-choice course, and £2.50 towards extra courses.

Students wanting to work at their own pace can do so on Friday when 'open access' is provided, so long as work-stations are booked in advance.

For details, tel: 01924-453502.
E-mail: GEO2:DP-EVH.

Wanted: holiday insurance experiences

INFORMATION officer Gill Winfield, at ASBAH's national centre in Peterborough, wants to hear from readers about their experiences of holiday insurance.

Gill is especially interested in hearing from people who have travelled abroad after taking out insurance to cover any problems with hydrocephalus shunts.

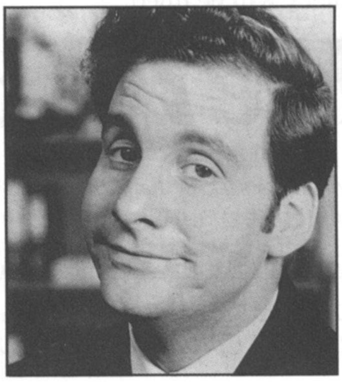
She would also like to hear from those who have used standard holiday insurance and whether it caused any problems. ***You can write to Gill Winfield at ASBAH House, 42 Park Road, Peterborough, PE1 2UQ or telephone 01733-555988.***

What kind of motor vehicle do you need?

WHEELCHAIR users are being asked to help find out the need for a small car or van which could be driven from a wheelchair. Researchers at Cranfield University want to know which features wheelchair users would require from such a small vehicle and to estimate the market for it.

They would like to hear from people who have, or expect to have, difficulty transferring from a wheelchair in order to drive.

If you would like to help with the survey contact: Kathryn Harney, Cranfield Centre for Logistics and Transportation, Cranfield University, Cranfield, Bedford, MK43 0AL. Tel: 01234 - 751122.



Oh, Mr Brittas!

TV sit-com star Chris Barrie is backing a campaign to persuade more people to run for ASBAH.

The man who plays leisure centre manager, Gordon Brittas, in *The Brittas Empire* has written to newspapers all over the country asking runners to raise money for ASBAH. And with every sponsor form and running vest applied for from ASBAH's national centre, Chris will be sending his own personal message of support.

Chailey Heritage

All-round service

SASBAH

A CLINIC which gives all-round attention to adults with spina bifida and/or hydrocephalus has just celebrated its 10th birthday.

As well as being able to see a consultant doctor and specialist nurse, there is a physiotherapist and occupational therapist on hand, and an ASBAH fieldworker.

Most of the 225 or so adults who have used the service, attend the clinic once a year although appointments can be more or less frequent depending on individual requirements.

The service is run at Chailey Heritage Rehabilitation and Development Centre near Lewes, East Sussex on alternate Friday mornings and has been a great success since the idea was first mooted by Sussex ASBAH (SASBAH) more than a decade ago.

Margaret White, SASBAH county organiser, explained why the group felt it so necessary to start the clinic.

"So many young people were leaving the school at Chailey Heritage and getting lost in the community.

"SASBAH got in touch with Dr Gillian McCarthy, consultant neuropaediatrician, who set up a pilot project for which SASBAH paid £2,000 per annum for two years.

"The clinic now funds itself. People are referred there by their GPs and are funded by the ECR system."

The clinic team pictured from left to right are: Mary Jones (occupational therapist), Ruth Cartwright (physiotherapist), Val Hall (medical secretary), Sister Deidre Browning and Dr Gillian McCarthy (seated). Inset: Margaret White, county organiser for Sussex ASBAH.

Adults with spina bifida and/or hydrocephalus visit the clinic from all over Sussex and from Surrey and Kent.

Sister Deidre Browning, who advises on pressure sores, family planning and general health, said: "We initially started for ex-pupils of Chailey Heritage, so some came from further afield, but more recently we have tried to concentrate on those from East and West Sussex, which is much better because we are in touch with the other services they need, particularly neurosurgery and urology."

There is no upper age limit - someone as old as 60 has attended the clinic - although the service is mainly aimed at young adults. Each client makes an appointment with medical secretary Val Hall, who can also help to arrange hospital transport to the clinic if necessary.

Appointments last about two hours during which time clients see separately Dr McCarthy, Sister Browning, physiotherapist Ruth Cartwright and occupational therapist Mary Jones.

A SASBAH fieldworker is also on hand to offer advice on other non-medical areas like benefits and housing.

Mrs Browning, who last year won Yenny Snider Award at Chailey Heritage for innovation, said: "Seeing young people separately means they have several chances to mention things, and staff can pool ideas afterwards.

"We meet, get feedback and compare notes. By doing so we can look at the whole person in one go."

REPORT BY LIZ CAWTHORNE

more on page 10

What do readers think?

Gail Davis regards the clinic as a safety net and feels more confident going there than visiting her GP.

The 27-year-old has been going to the clinic, on and off, since she left school 10 years ago and now takes her 22-month-old daughter Elysia, (pictured).

Gail, from Haywards Heath, said: "The most useful thing is to see Dr McCarthy. She knows my medical history and is able to advise on anything, unlike a GP who is not quite so sure or specialised.

"I also see the physiotherapist. It's nice to go somewhere where the people know exactly what you're talking about. A lot don't have the experience."

Carrone Page, 28, lived and went to school at Chailey Heritage from the age of seven to 15 years. She now lives at The Disabled Housing Trust at Burgess Hill, but still regularly attends the Tissue Trauma Clinic due to pressure sores, and visits the SASBAH Clinic for an annual check-up.

Carrone said: "I go to the Tissue Trauma Clinic every fortnight so they can see if my back is sore and put on fresh dressings. I've got other people at home who can do it for me but it's better to have it done here."

Jane Denness, 29, attends the clinic twice a year. She sees the occupational therapist, the physiotherapist and Dr McCarthy separately over two hours. Jane, who also lives at Burgess Hill, said: "I've been going there since it started 10 years ago. I've got my own doctor, but there is no comparison because they know all about us here. They have more time and are more understanding."

Jane is pictured having a session with physiotherapist Ruth Cartwright at the clinic.

All-round service, from page 9

She added: "Dr McCarthy has an expert eye and picks up things which GPs miss - such as problems with valves.

"Getting the young adults and their parents heard is another thing. A lot of our work is backing parents up who go from pillar to post in their push for their children's independence."

Chailey Heritage

Pressure sore help

SASBAH

A SECOND clinic, looking at the prevention and cure of pressure sores, is run alongside the SASBAH service.

The Tissue Trauma Clinic was developed by Mr Matlhoko, associate specialist at Chailey Heritage, now retired, together with Sister Browning and Brian Waters, a plastic technician with special skills and experience in protective plasters.

The clinic also has input from an occupational therapist and rehabilitation engineers to find out the cause of a sore which can vary from being very minor or life-threatening. There are 14 technicians working on special cushions for seating at the Rehabilitation Engineering Unit.

Peter Tutt, rehabilitation engineer, said: "We work with therapists and medical staff. The biggest problem is seating and sores.

"We photograph the sores so we can see if there's any improvement. Some of the sores can be horrendous, so it's great to see when they start healing up."

Occupational therapist Mary Jones added: "It is very much a team approach. There are a lot of expertise and facilities here on site."

Sometimes home and work place visits are required to find out what is causing a pressure sore.

Mrs Jones said: "We work with social services to make homes better and our engineers go to shops and other work places to make cushions for seats."

Peter Tutt, rehabilitation engineer, looking at a seating system in the seating workshop of the rehabilitation engineering unit at Chailey Heritage.

Down under for 1995 conference

SYDNEY, Australia is the venue for the eighth international conference on Spina Bifida and Hydrocephalus, from 14-16 September 1995.

The conference, run by the International Federation for Hydrocephalus and Spina Bifida (IFHSB), will be held at the Collary Centre, situated on 10 hectares of natural bushland, with breathtaking views of the Pacific Ocean and Sydney's northern surfing beaches.

It will address a wide variety of issues concerned with the management of hydrocephalus and spina bifida, with a number of guest speakers from around the world.

The programme has sessions on:

- ✯ Advances in Hydrocephalus.
- ✯ The Young Adult and Spina Bifida.
- ✯ Mobility and Spina Bifida.
- ✯ Neurogenic Bladder and Bowel.
- ✯ Medical Problems in Hydrocephalus and Spina Bifida.
- ✯ Parent Panel Sharing Experiences.

Hotel accommodation is a 15-minute drive from the Collary Centre, (price $120-145) and group accommodation is at the centre and in the neighbourhood (price $50-80). Conference registration fee before 14 June is $250, after 14 June $280.

For information and registration forms, write to: The Secretariat, 1995 SBH Conference, GPO Box 128, Sydney, New South Wales 2001, Australia. Telephone: +61 2 262 2277. Fax: +61 2 262 2323.

Calling female fitness fans in London

A WOMEN'S gym and health club in North London is encouraging disabled women to use its facilities and take part in fitness classes.

The club - which is owned and staffed by women - is accessible to wheelchair users and has a lift, ramp and shower room.

Sequinpark Women's Health Club & Gym is based at 81/84 Chalk Farm Road, London, NW1 8AR. Tel: 0171-284 0004.

Pat-a-cake

THE Duchess of Kent played a game of 'pat-a-cake' with six-year-old Claire Youngman when she opened a £200,000 mobility centre at Treliske Hospital, Truro. The Duchess received flowers from Claire, who has spina bifida and comes from Penzance.

Claire's mother Helen, who is secretary of Cornwall ASBAH, works as a volunteer at the mobility centre. She said that she was delighted that her daughter had made such an impression at the opening.

Lost benefits

PEOPLE who do not understand the benefit system can lose as much as £77 per week.

The findings follow a roadshow in November staged by Disability Wales to highlight changes to benefits from April.

Folic acid helpline

A FOLIC Acid Helpline has been set up on 0181-994 9874 by a charity called the Medical Advisory Service to provide a confidential service to women wanting to know more about folic acid and spina bifida and other neural tube defects.

The helpline - staffed by nurses and open Monday to Friday 2pm - 10pm will run until April with sponsorship from English Grains Healthcare, makers of the Folic Plus supplement.

Calls are being charged at normal BT telephone rates, and the charity estimates that over 15,000 callers will use the service.

The helpline was launched at a reception at the House of Commons at the end of January, attended by agony aunt and novelist Claire Rayner, who is a vice-president of ASBAH.

The results of a recent survey of 150 midwives about what they perceive to be the state of folic acid awareness among women in general were annnounced at the reception.

Almost half the midwives replying to the English Grains survey said they believed that fewer than one in 20 women trying to conceive have taken a folic acid supplement and that almost one-third are being given dietary advice after their fourth month of pregnancy, when it is too late to prevent spina bifida.

Official advice is that all women planning a pregnancy should take a daily 400 mcg supplement of folic acid for at least a month before conception and continue to do so until the 12th week of pregnancy to help prevent spina bifida.

Women with previously affected pregnancies should ask their doctor to prescribe a larger daily dose of folic acid, and take this over the same period of time.

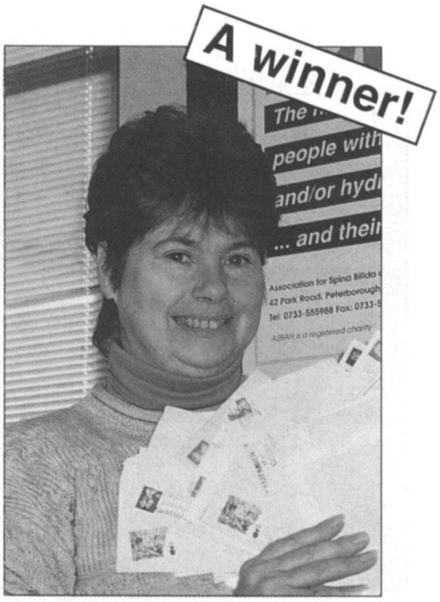
Hydrocephalus Network

News

NEW YEAR 1995

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

ASBAH, 42 Park Road, Peterborough
PE1 2UQ
Telephone: 01733 555988
Reg Charity Number 249338


A winner!

800 people sign up to our shunt campaign

OUR CAMPAIGN to alert the public and family doctors to the early signs of a hydrocephalus shunt blockage is proving a great success.

Since the campaign was launched last autumn, ASBAH's national centre in Peterborough has received over 800 inquiries from people with hydrocephalus wanting to sign up for an "alert" card and GP information sheet.

Our services department is delighted with the response which has seen secretary Wynne Green (*pictured above*) dealing with around a big post bag of inquiriesevery day.

However, if there is still time to take advantage of this free service offered by ASBAH.

Just send your name and address, together with your GP's name and address, to: Wynne Green, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ. Please enclose two loose 19p stamps.

Fear of flying

FOLLOWING the article on Charlotte Day in the last HN News, we have received a number of inquiries from parents worried about children with hydrocephalus flying over 3,000 feet.

Charlotte was likely to have been referring to parachuting rather than flying. Below is ASBAH's view in more detail.

THE QUESTION: "Is is safe for my child with hydrocephalus to fly?" is one often posed by parents.

Given our knowledge about the effects of hydrocephalus and the way shunting systems operate, our advice has been "Yes, as far as we know, there are no problems."

Unfortunately, it seems that many parents have been given conflicting advice by medical advisers.

If in doubt you must contact your neurosurgeon or you may like to talk to a disabled living adviser at ASBAH.

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 are sold 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.Please contact us on 01733-555988 for details. Prescriptions for drugs or medicines should <u>not</u> be sent to AlphaMed.

Why lumbar peritoneal shunts?

THE following article was kindly written for Link by Paul May, consultant paediatric neurosurgeon at Alder Hey Hospital, Liverpool.

It is in response to an upsurge in inquiries ASBAH has received from all over the country and the continent about lumbar peritoneal shunts. We hope this article will help to answer your questions.

ALTHOUGH a less commonly inserted form of shunt procedure, lumbar peritoneal shunts can and still remain an effective treatment in the management of some forms of hydrocephalus and of focal spinal cystic abnormalities.

They are more commonly used in the adult population and perhaps the main indication for their insertion at the present time is the condition known as benign intracranial hypertension in which there is an excessive pressure within the central nervous system, although there are not enlarged ventricles and hydrocephalus as our readers would understand it.

As you will know the main categories of hydrocephalus are:

1. Communicating - there is no mechanical obstruction between the ventricular and spinal CSF pathways.

2. Non-communicating or obstructive hydrocephalus in which there is some form of mechanical obstruction which blocks the flow of CSF either ventrical to ventrical, or from ventrical to the spinal CSF spaces.

Lumbar peritoneal shunting is only appropriate for the communicating form of hydrocephalus where the spinal and cranial CSF pathways are in direct contact and there is free-flow of fluid between the two.

In some situations, therefore, when the diagnosis of a communicating hydrocephalus is made, it might be appropriate as an alternative to ventricular peritoneal shunting to insert a shunt from the spine into the tummy.

This is usually done with the patient anaesthetised and lying on their side. A small incision is made over the lumbar spine, usually at the junction of the third and fourth, or fourth and fifth, lumbar vertebra and the tube, rather like a lumbar puncture is passed into the spinal sub-arachnoid space.

It is then tunnelled around and buried into the abdomen in the same way as the distal or bottom end of a ventricular peritoneal shunt is.

Another indication for lumbar peritoneal shunts is for the direct drainage of CSF cystic collections of the lower spine as a result of surgery to the various forms of spina bifida.

On some occasions following the repair of myelomeningocele, lipomyelomeningocele or other congenital variations of spina bifida post-operative collections of CSF under the skin can result in quite pronounced swelling and discomfort.

These collections can often be drained flat with the insertion of a lumbar peritoneal shunt. On some occasions it is not necessary to insert a valve but generally when dealing with communicating hydrocephalus a valve is inserted in the shunt tubing.

○ ***Any further information concerning lumbar peritoneal shunts can be obtained from the neurosurgeon responsible for the care of the individual or by contacting myself at the Royal Liverpool Children's NHS Trust, Alder Hey, Liverpool L12 2AP.***

Alternative therapists help toddler 'catch up' in her development

A MUM from South East London identifies with the "worried mother" of a child with arrested hydrocephalus, featured in the Summer '94 issue of *HN News*.

Forty-year-old Melanie has a daughter Kathleen, 3, whose hydrocephalus was not diagnosed until she was 10 months old.

"Kathleen was very ill in her early months, and saw many doctors. She could not lift her head or roll over until she was nine months old.

"We were offered a shunt operation when she was about 15 months old, and we decided to wait one month before going ahead with it, partly on the advice of three rather 'alternative' healers who all assured us that it was unnecessary."

By this time Kathleen's head was very large but she could walk, and her parents were very hopeful about her development.

"In that month her head stopped growing abnormally and no operation took place. We will never know how much the colour healers, homeopath and cranial osteopaths have helped Kathleen, and how much she has achieved naturally for herself, but I feel these people helped her a great deal and I am very grateful to them."

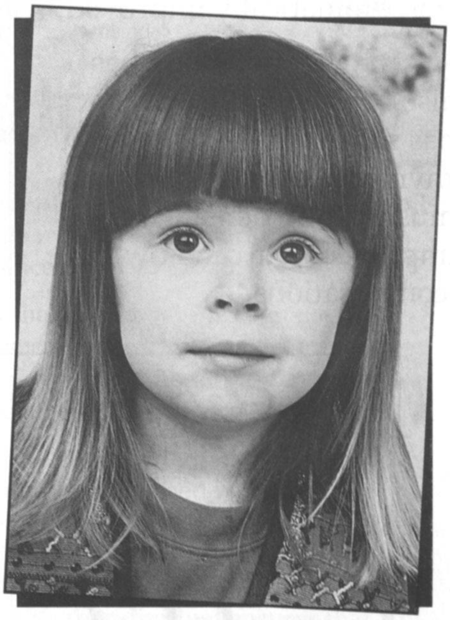
Kathleen still sees the homeopath and a cranial osteopath regularly.

"The main problem areas with Kathleen have been with her speech, emotional and social development. As a baby she just slept, fed, vomited and screamed. We missed out on so much communication and she surely must have suffered a great deal, she was so fearful and detached.

"It has only been recently that she has started to join in anything with any enthusiasm. The feedback from this play is giving her great rewards and so I feel that she will be 'normal' in this respect.

"We saw a speech therapist twice last year. It was obvious by the age of two that Kathleen had problems in this area. Although she understood what I was saying, she was only grunting a few sounds."

Kathleen's parents were not offered any therapy, but given some advice on how to help their daughter. This was pretty difficult to follow - for example, keeping toys out of reach so that Kathleen had to say what she wanted before she could have it, resulted in tears of frustration.



Kathleen, 3, whose hydrocephalus was diagnosed at 10 months.

Melanie said: "We took her for a hearing test because her speech was so monotonal, it sounded like a deaf person's, but she hears very well. So we tried something different - a kind of sensory stimulation therapy which identifies areas on the body which over-react to gentle brushing."

The therapist claimed this showed there had been trauma during foetal development, slowing later development after birth. The therapy is mostly used for children with dyslexia.

Melanie said: "Kathleen had a very strong grasp reflex in her hands, just like a new-born baby. After several weeks of therapy (brushing the area repeatedly with a little paint brush) she has lost this reflex and other areas are being treated to help her develop "s" sounds."

more on page iv

Alternative therapists, from page iii

The therapist also been working around Kathleen's eyes and her eye/hand co-ordination dramatically improved.

An increase in talking has also been apparent. Kathleen has started to recite nursery rhymes and since going to a music group her singing has improved. She can now have 'conversations.'

Last September she started playgroup and also attends one-to-one music therapy to help improve her attention span.

Her mum Melanie said: "Now is the best time to do as much as we can. My aim is for Kahtleen to start school at five on the same footing as other children.

"I hope our daughter will get all the help and understanding she needs at school to make the most of what she can do. There should be no limits."

***Editor's note**: You must always take the advice of your neurosurgeon before starting on any alternative therapy. A properly trained alternative therapist will never say "don't have a shunt" if that goes against the advice of the neurosurgeon.*

ASBAH school booklet

A BOOK, published by ASBAH, which has proved to be of great help to parents, students, teachers, educational pshchologists, welfare assistants and all those having to deal with children with special needs has been revised.

Children with Spina Bifida and/or Hydrocephalus at School has been updated with the 1993 Education Act in mind.

The book shows that children with spina bifida and/or hydrocephalus have a multiplicity of needs. It has chapters on: The Effects of Spina Bifida and Hydrocephalus on Children; Assessment, Teamwork and Need for Variety and Flexibility of Educational Provision; Learning Difficulties; Behavioural, Emotional and Social Problems and Preparation for School Leaving: Further Education and Vocational Training.

It is available, price £2.75, inc p&p, from ***Information Dept, ASBAH, 42 Park Road, Peterborough, PE1 2UQ. Cheques should be made payable to ASBAH.***

More books and a video available from ASBAH

A NUMBER of useful publications for families affected by hydrocephalus are available from the information department at ASBAH's national centre in Peterborough.

Booklets:

Children with Spina Bifida and/or Hydrocephalus at School - Ed ASBAH, £2.75.

Young People with Spina Bifida and/or Hydrocephalus - Learning and Development by Leonie Holgate MCSP SRP, £1.60.

Hydrocephalus Information Pack for new parents, teachers and employers - ASBAH, £3.00.

Video:

Hydrocephalus: A Guide to Education. To hire for one week £16.58 (including VAT and returnable £10.00 deposit). To buy £23.50 (including VAT).

All prices include packaging and postage and apply in the UK only. Overseas charges are supplied on request. Orders under £50.00 in value must be prepaid.

Send your order to: Gill Winfield, Information Officer, ASBAH, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ. Cheques/postal orders should be made payable to 'ASBAH'.

Soothed by smells

A report on the practice of aromatherapy by Susan Humpherson

OVER the last three years, students with various types of learning difficulty or disability have benefited from the use of aromatherapy at Matthew Boulton College in Birmingham.

Although the college says some students, whose medical history or medication precludes them from using essential oils, the vast majority of youngsters find aromatherapy does have a therapeutic value and can produce very positive results.

The combination of touch and smell can be enormously beneficial to people, particularly those with learning difficulties and disabilities.

The practice of aromatherapy, using essential oils blended with a carrier oil, is an ideal medium for providing the student with the required stimulus appropriate to their individual needs.

Most of us are affected in some way by smell, be it pleasurable or offensive. Smells can create a feeling of well being and comfort. Alternatively, negative reactions can be felt if a smell is unpleasant.

Whilst developing an understanding with the student, it is important to recognise when a particular oil is pleasant or not. What is acceptable to one person may not be to another.

Smell, combined with massage in a warm, quiet, relaxed atmosphere, enhances the senses and allows the student to escape from pressures of the outside world, if only for a short period.

Students with learning difficulties or physical disabilities can be encouraged over a series of sessions to relax and gradually accept contact.
By beginning in a non-threatening manner with hand massage, possible for a few seconds only, contact can be made with an individual. As the students relax and gain confidence, they will begin to allow and enjoy arm, leg, face, scalp, and even back massage after a period of time. Students with physical disabilities gain benefit from the massage which reduces tension in body and limbs.

For some students an aromatherapy session could be the only time they spend having contact with another person who is solely concentrating on them. Agitated or aggressive students can be calmed by soothing oils and those students in need of support through traumatic experiences can be helped.

A further benefit that has been noticed is the improvement in social interaction between the recipient and their peers and members of staff because tolerance levels have improved.

It is important to have a thorough knowledge of aromatherapy and this, combined with an understanding of the students as individuals, will develop the relationship and understanding between aromatherapist and student. The close relationship which develops with an individual ensures that any slight change in their person can be noted and essential oils can be blended to counterbalance these changes.

Aromatherapy can overcome the limits of restricted verbal skills, allowing the students an excellent opportunity to interact with another person in a relaxed informal setting.

To know and understand an individual takes time. Aromatherapy can give you that time.

The following case studies briefly illustrate the effects of aromatherapy on students with disabilities and learning difficulties.

Manvinder

Manvinder has profound learning difficulties, no speech and physical disabilities. She attends a day centre five days a week. Her behaviour can be quite alarming - pushing a clenched fist against her throat or banging her head repeatedly against the floor, chair or wall. When restrained from any of these actions, she will dig in her nails or try to bite. For someone so slight, she is extremely strong.

Over a period of time, differing techniques have been tried and tested. Manvinder responds best to back massage and a combination of soothing and relaxing oils. On some occasions, she even falls asleep. On awakening she offers good eye contact, smiles, laughs and responds to further massage. The most notable achievement is that, during massage, Manvinder's self-abuse has been dramatically reduced.

more on page 18

Soothed by smells, from page 17

Paul

Paul is in his final year at a special school. He is tall, slim, very strong and tolerates little physical contact. If confined to a seat he will become agitated, try to remove his clothing and bite his hands. Some sessions are successful with Paul enjoying his back, shoulders and scalp massaged and he will calm down and relax. Other times he does not respond at all and rejects any attempt to massage him. Of all the students we have worked with, this student displays the least response of all.

Daniel

Daniel, in his 40s, has no vision and displays a very forthright disposition. He attended a course for visually impaired students at Matthew Boulton College, which included aromatherapy.

These sessions were conducted on a 'trial' basis whereby the students were encouraged to choose their own essential oils and then feed back to the group at the following sessions on their reactions and feelings after the massage.

Daniel responded very well during these sessions. On one occasion an oil that is known for improving confidence and mental clarity was chosen by Daniel. He claimed that, after the session, he felt very positive about himself and later that afternoon he made an important business call which he had been avoiding.

When Daniel was told of the identified action and benefits of the essential oils used during the session, he was convinced that this oil had affected him and in a positive way.

Conclusions

There is a growing interest in the use of aromatherapy and increasing demand for the delivery of these specialised techniques. Particular interest has been shown by special schools and day centres as parents, carers and teachers realise the potential benefits of this practice and have started to include aromatherapy in their timetables.

Matthew Boulton College will be willing to share its expertise and experience with anyone who has an interest in this area.

For further information, please contact the Supported Learning Service on 0121-446-4545, ext 311.

SUSAN HUMPHERSON is a lecturer at Matthew Boulton College as well as practising aromatherapy with two groups of students with severe learning difficulties, offering aromatherapy to them as a form of communication.

Driving instructor list produced

SOME 1,400 Department of Transport Approved Driving Instructors with experience of teaching disabled learner drivers are included in the 1994 National Disability Tuition Register.

The guide also includes information about the range of disability experienced by each instructor and any special training which has been undertaken. And it shows where an instructor has such a vehicle or whether the learner may use his/her own car.

Free copies are available to national and regional organisations. Send a large (61p) SAE to: Information Officer, Banstead Mobility Centre, Damson Way, Orchard Hill, Queen Mary's Avenue, Carshalton, Surrey, SM5 4NR. Tel: 0181-770 1151.

Mobility leaflet

A LEAFLET to help disabled drivers choose the right car has been produced by the Mobility Information Service. In Two and Three Door Automatics, David Griffiths lists more than 140 accessible vehicles with wider doors and automatic transmission. Send an SAE to: 2 & 3 Doors, Mobility Information Service, National Mobility Centre, Unit 2a Atcham Estate, Shrewsbury, SY4 4UG. Tel: 01743-761889.

Access to Work scheme monitored

THE Government's new Access to Work scheme, which provides disabled people in employment with a broad range of free support services, is to be monitored by disability organisations.

Following a campaign by disability groups, the Government backed down on its original plan to force employers to pay half the costs of services such as equipment and job coaches - at least for the first year.

After that time, the scheme will be reviewed with the possibility of introducing employers' contributions left open.

A questionnaire, aimed at service providers, advice agencies and individual users, has been produced as part of the monitoring exercise, with a view to obtaining positive suggestions for improvements to be included in the Government's review of the scheme in June.

For more information, and questionnaires, contact Caroline Gooding, employment policy officer, RADAR, 12 City Forum, 250 City Road, London EC1V 8AF. Tel: 0171-250 322. Fax: 0171-250 0212.

BIG GUNS SOUND AGAIN ON DISABILITY RIGHTS

HOSTILITIES have resumed on the battlefield of civil rights for disabled people - with MPs and disabled people slugging it out to decide whether new government proposals or another private member's bill comes out the winner.

Tony Britton tours the battle lines

A new strengthened private member's bill was introduced to the House of Commons by Labour MP Harry Barnes earlier this month. *The Rights Now!* coalition of disabled people's groups, backed by the Labour Party and the TUC, threw its support behind Harry Barnes with a lobby of parliament and local pickets of MPs' constituency surgeries.

But new Minister for Disabled People William Hague rallied government forces round a Disability Discrimination Bill, published together with a white paper on 12 January.

The government measures - scheduled for enactment in the autumn - include limited civil rights for disabled people in the workplace, a National Disability Council and new rights of "reasonable" access to shops, places of entertainment, public transport and possibly housing.

The measures were immediately and predictably slammed by employer's organisations as "a blank cheque" which could drive shops, guest houses and commercial premises to the wall.

But Mr Hague presented his scheme as a fair compromise which could be widely supported.

The *Rights Now!* campaign would have none of it. Campaigners asked all their friends and allies to back the Harry Barnes Bill, which is broadly similar to the private member's bill which was talked out of the Commons last year.

The Barnes Bill differs from last year's Berry Bill because it has been strengthened in a number of ways:

- ▲ **extended protection against discrimination at work**
- ▲ **new section cover access to buildings**
- ▲ **more detail on areas covered**
- ▲ **new section banning discrimination in the sale of property**
- ▲ **new clause on access to polling stations**
- ▲ **gives local authorities a duty to counter discrimination**
- ▲ **stronger section on education**
- ▲ **gives Secretary of State powers to phase in changes.**

Rights Now! said the Government had a narrow definition of disability which excluded large groups of people, such as those with histories of mental illness or people with HIV.

The government also announced no proposals to enforce their law. "We want a Commission with enforcement powers. They are offering an advisory council - a talking shop", said *Rights Now!*

And campaigners added that the measures were too limited. They failed to cover education or transport and exempted firms with 20 people or less in their workforces.

The government bill will make it unlawful for an employer to treat a disabled person less favourably than other staff because of their disability. Small firms with under 20 staff will be exempt.

The legislation will require employers to make a "reasonable" adjustment to working conditions or the workplace, to help overcome the practical effects of disability.

Employers would be able to take account of the costs of the adjustment and decided whether these fall within the financial limits set. They would not have to make the best adjustment possible or to adapt premises for future employees.

Cinemas, restaurants and shops will be required to provide access but only within limits of between five and 10 per cent of their premises' rateable value. Only "reasonable" access is required.

A restaurant, for instance, could have one designated table for disabled people. A little corner shop would be within the law if there was a bell outside which a disabled person could ring to be served.

If discrimination in access is outlawed, it could end the practice whereby some upper-floor nightclubs refuse access to people in wheelchairs because they are "fire hazards". Young people with spina bifida frequently complain about this. But clubs might still be able to cite safety reasons in barring wheelchair-users. At present, the situation is unclear.

The proposed National Disability Council would have no powers to prosecute, unlike the Commission for Racial Equality or the Equal Opportunities Council. Its function would be confined to advice to government and discussion.

Power-chair survey

POWERED wheelchairs are not supplied to disabled people by more than 90% of wheelchair service centres, due largely to lack of finance.

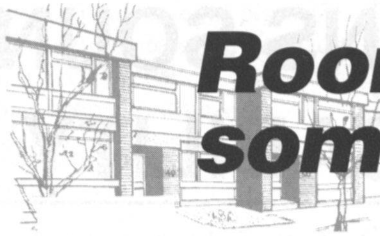
This has been revealed in a new nationwide survey carried out by the Muscular Dystrophy Group as part of its on-going *Batteries Not Included* campaign - aimed at securing state funding for powered wheelchairs.

Ninety-five per cent of wheelchair service centres in England and Wales took part in the survey. Of these, 93% make no provision of indoor/outdoor powered-wheelchairs to users in their regions. The main reason for this was shortage of money.

Copies of *Batteries Not Included - Wheelchair Service Survey* are available free of charge. Tel: 0171-720 8055.

On the move

PARENTLINE, the national telephone advice service for mums and dads under stress, has moved. The new address is: Endway House, The Endway, Hadleigh, Essex, SS7 2AN, tel: 01702-559900 (helpline).



Rooms with some views

A SPECIALLY adapted, fully furnished flat for a single disabled person for the purposes of independent living has become available in Stretford, Manchester.

Trafford & Salford ASBAH would like to offer this flat to someone who has spina bifida and/or hydrocephalus as it does not appear to have anybody on its waiting list.

The flat has a lounge/dining room, bedroom, bathroom and kitchen. It is situated on the ground floor with separate entrance, looking out onto a mature garden, and accessible by patio windows at the rear which leads to the gardens. It is opposite Stretford Arndale Shopping Centre which is fully accessible for wheelchairs.

Anyone interested in occupying this flat should write to: ***Mrs Tammi Gaynor, Organising Secretary, Trafford & Salford ASBAH, Davis Court, Cyprus Street, Stretford, Manchester, M32 8AX, tel: 0161-865 0222 (mornings only).***

FULL wheelchair access and 24-hour alarm-call system is available in a specially adapted flat in Ilkley, near Leeds and Bradford.

Sanctuary Housing Association would like to offer the tenancy to someone with spina bifida and/or hydrocephalus but will offer it to someone with a different disability if no such person comes forward.

The flat is located in a safe, exclusive residential area and has panoramic views across Wharfedale.

There is also a housing support worker on hand for help and advice.

Anyone interested should contact: Mark Best, Five Oaks Centre, Ben Rhydding Drive, Ilkley, LS29 8BD, tel: 01943-609468.

Deirdre goes to the law!

ASBAH went to the law when national centre fundraiser Deirdre Pawsey (pictured right) had dinner with Peterborough Young Lawyers group.

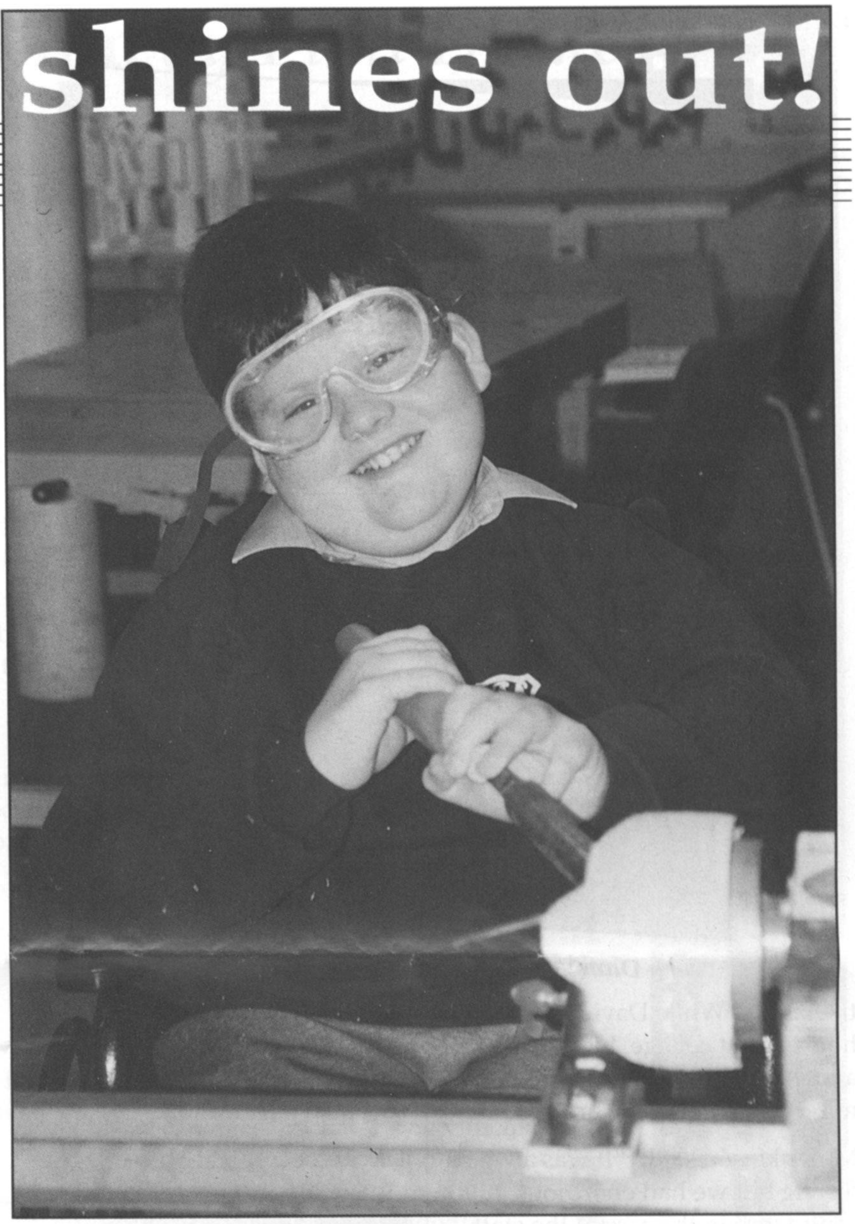
The Young Lawyers presented Deirdre with a cheque to support our work in the eastern region.

Team point to all those who recognise the young lady standing immediately next to Deirdre. She is none other than Lisa Naudé, wife of our mobility adviser John Naudé. Lisa recently qualified as a solicitor before joining a law firm in Peterborough.

David shines out!

by Liz Cawthorne

A 12-YEAR-OLD boy with spina bifida has outshone his parents' expectations by becoming ever more independent at the boarding school they fought so hard for him to attend.



David Jenkinson enjoying woodwork at Lord Mayor Treloar College.

David Jenkinson, from Barnsley, South Yorkshire, made so much progress that he won a house independence prize at the end of his first year.

Parents Geoff and Helen are amazed and delighted at what their son can do - which they say boils down to him having the appropriate role models.

Mr Jenkinson said: "David is seeing others doing things and has never had anyone to look up to before. At mainstream school, all he had was able-bodied children pushing him around.

"When we see him in the Treloar environment, he is very much at home and his own person. He knows what he wants to do and does it."

However, when David comes home, he doesn't try quite so hard.

Mr Jenkinson said: "He goes back to watching the world and doesn't try to be independent."

An example of this occurs at shower time. At college, David gets himself out of the shower, dries himself, gets changed and into bed. At home, he slips into the old way of rinsing himself and then waiting to be helped to do the rest.

It was this type of independence training which was the main reason for David's parents insisting the local education authority allow him to attend Lord Mayor Treloar College in Hampshire.

David started at the school just before his 11th birthday and just months after a major operation to enlarge his bladder and bring it out at the tummy button, so he could catheterise himself.

Mr Jenkinson said: "David has made tremendous advances in being able to do this himself and acquiring skills to transfer himself from wheelchair to bed, and bed to wheelchair.

"He is now able to get from A to B under his own steam by making a decision to do it and working it out himself."

David added: "I still find it difficult to get to places on time but I realise that I am expected to do so and will get very little sympathy if I don't!"

However, the adjustment from living at home to boarding school did not come easy.

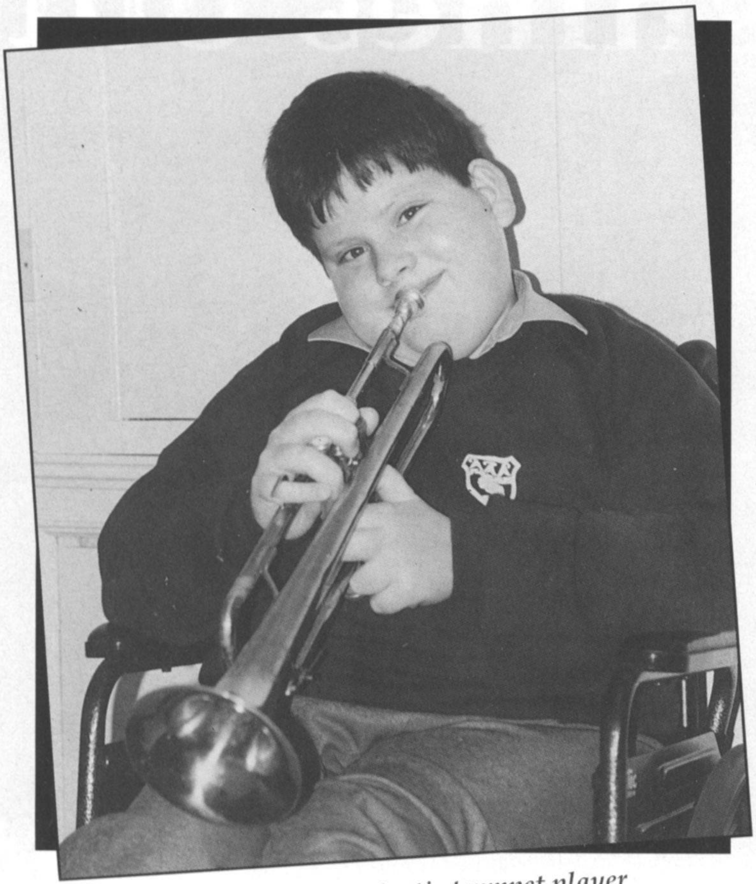
On his first night at college in September 1993, David phoned his parents wanting to go home.

Mr Jenkinson said: "Had we been nearer the school it would have been worse - we would have gone to fetch him."

That first term was difficult for all

continued on page 22

David shines out!, from page 21



David is an enthusiastic trumpet player

the family. While David was homesick at college, his parents and younger sister and brother missed him not being around.

Mr Jenkinson said: "It was a weird feeling but we had enormous confidence in the care of the staff at Treloar and those looking after him after school hours. They were remarkably good at reassuring us that they were looking after our child."

Then, after a three-week break at Christmas, David returned to Treloar and seemed to settle down very quickly and, as more was expected of him, got down to work much better.

From then on, David began to shine at Treloar and - to cap it all - was picked out of 60 pupils to win his house independence prize.

Mr Jenkinson said: "There's been a great improvement on what he was 12 months ago. We hope he can stay at Treloar until he's 16. It's unlikely that the local education authority will withdraw support half-way through secondary education."

David took part in the college summer concert in front of 200 people, giving him and his parents enormous pride and pleasure.

He has now moved on to the secondary phase of his schooling and has begun to learn French.

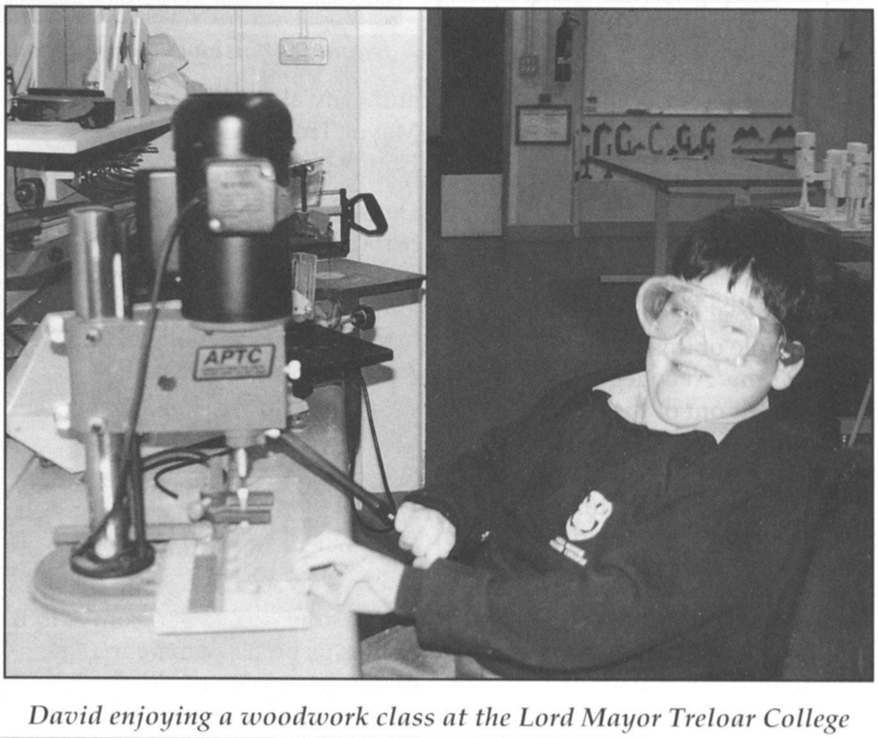
He plays the trumpet - though he says he has insufficient time to practise regularly - and has joined the art club, scouts and youth club.

David said: "I have found it easier to make friends here than in my previous school. I like the competitive element of life and work here, and feel I can compete on equal terms."

The toilets are more accessible and David has improved his wheelchair skills. He is coping well with boarding and appreciates being able to "phone home whenever I want to."

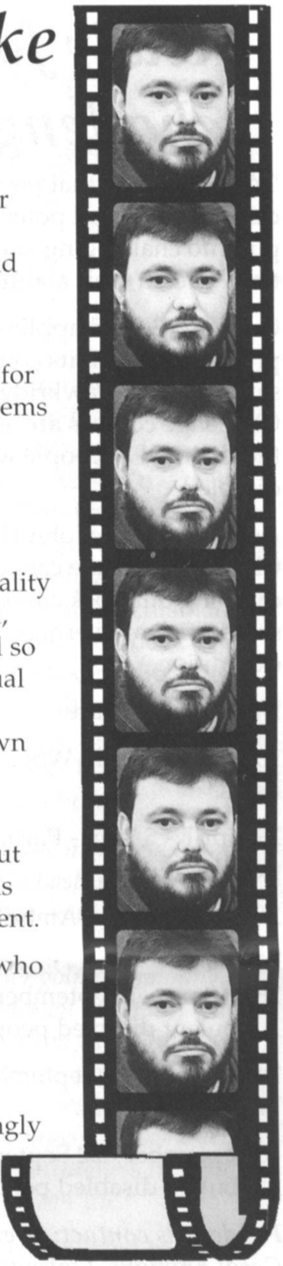
He now goes home, by taxi, twice a term for the weekend, in addition to the half term break.

But he is still some way short of functional independence. Work is continuing on his personal hygiene routine, his dressing programme, his mobility and his transferring skills.



David enjoying a woodwork class at the Lord Mayor Treloar College

Disability On Film *by Paul Darke*



A COUPLE of letters in December/January *Link* took me to task for not acknowledging a couple of positive films that have people with spina bifida at their centre.

And, although one of them was a documentary, I accept that the profile of the conductor Jeffrey Tate and the kids' film *Mac and Me* can be seen as positive.

Positive in so much as they act to provide role models and proof that personal perseverance can pay off with the dividend of social valorisation and integration for the individuals and characters concerned.

But - the inevitable retort of a quibbler - by their very nature they are also very negative.

Various critics would argue, myself included, that the very fact they portray spina bifida as being insignificant in their characters' lives, ignores the very real social isolation and discrimination that they - or disabled people in general - would undoubtedly have endured (or if they didn't, it was the exception rather than the rule).

These films ignore the immense barriers (social and attitudinal) that people with spina bifida - all people with disabilities for that matter - have to face every day of their lives. *Mac and Me* is especially guilty of such a misrepresentation of life in a wheelchair.

The way in which films make all problems individually orientated - the individual must surmount them or educate those around them to accept that individual for who or what they are - ignores the structures upon which discrimination and isolation are based and reinforced.

Problems that are really social (discrimination against disabled people, for example) are made into individual problems requiring supreme effort or sacrifice to overcome. So, at worst, the "Supercrip" stereotype is created and, at best, the disabled as really "normal".

Neither is helpful in the struggle for equality for all disabled people. In any given film, "problematic" groups are individualised so that social problems are seen as individual rather that social ones. This makes the individual solely responsible for their own problems, and the solving of them.

Society is left unscathed and as such unchanged; and, in the case of films about people with a disability, discrimination is seen as self-inflicted or simply non-existent.

The result for the viewers of such films who are more severely disabled (or have to endure other complementary social discriminations: racism, classism, even unemployment or educational disadvantages) is that they are increasingly devalued because they do not have the ability to - or do not want to - fight the whole of society single-handedly.

Dream come true

ASBAH'S computer company has helped 17-year-old Kim Riseborough find her dream job. Kim, who worked for Computer Sense Ltd after leaving school this summer, is now working for Hertfordshire travel agency Haven Warner.

Kim, who has spina bifida, worked in telesales at Macintosh-dealers Computer Sense Ltd in Hemel Hempstead for 10 weeks - getting a working knowledge of how to cope with 'cold' calls to businesses. Now she has moved on to making bookings for the travel agency, where she was sent on work experience from school earlier in the year.

"Computer Sense gave her the confidence in dealing with strangers on the telephone and all sorts of situations", said her mum Mrs Susan Riseborough.

Which car?

A NEW leaflet to help disabled drivers choose the right car has been produced by the Mobility Information Service.

In *Two and Three Door Automatics*, David Griffiths lists more than 140 accessible vehicles with wider doors and automatic transmission.

Vehicles offering power-assisted steering as an option are also included, and there is a short section on alternative solutions for wheelchair users who wish to be independent behind the wheel.

The free leaflet can be obtained by sending a stamped addressed envelope to: 2 & 3 Doors, Mobility Information Service, National Mobility Centre, Unit 2a Atcham Estate, Shrewsbury, SY4 4UG. Tel: 01743-761889.

Ready for a challenge?

"WE BELIEVE that people only discover their full potential when put into challenging situations that truly stretch their abilities."

Outward Bound applies this philosophy to all its courses and says the John Hawkridge Challenge courses are as testing as those aimed at people who are not disabled.

Activities on the John Hawkridge Challenge include canoeing, camping out, rock climbing and a self-sufficient overnight expedition.

Dates for 1995 are:

1 April - 7 April - Wheelchair users.

29 April - 5 May - Partially sighted people.

3 June - 9 June - Ambulant disabled people.

26 August - 1 September - Ambulant disabled people.

2 September - 8 September - Wheelchair users.

16 September - 22 September - Ambulant disabled people.

For details contact: Steve Prior or Carol Emmons, Outward Bound Eskdale, Eskdale Green, Holmrook, Cumbria, CA19 1TE. Tel: 09467-23281. Fax: 09467-23393.

New book on special needs

Reviewed by ASBAH's education adviser Peter Walker

THE Advisory Centre for Education has published the 6th edition of its *Special Education Handbook: The Law on Children with Special Needs.*

It is an excellent book written especially for parents of children and young people who have special educational needs.

It clearly explains the present educational system, explaining about the different types of schools available, the meaning of the widely used jargon, the key definitions in special educational needs, the role of schools and governors, and important information for parents.

One chapter is devoted to formal procedures for assessment and the statementing process. It helps parents to understand their role, the role of the local education authority (LEA) and gives a list of all the related regulations, circulars and guidance relating to special educational needs.

Advice is also given to parents who feel that they cannot agree with the decision of the local education authority, outlining how they can appeal or complain.

Other topics covered are maintaining the statement, annual reviews, annual review of students aged 14 and over, special education after 16, the National Curriculum, exclusion from school, and other important matters relating to a child with special educational needs.

Nottingham's day for disabled students

NOTTINGHAM University is holding an open day for students with physical or sensory disabilities who are planning to apply to the university.

You will get the opportunity to look around the university in general as well as see the facilities for students with disabilities, and also meet other students who are already at the university.

Full details about the day - on Wednesday, May 10th - are available from: Mary Foley, Coordinator for Disabled Students, The University of Nottingham, Registrar's Department, University Park, Nottingham, NG7 2RD. Tel: 0115-9515506. Fax: 0115-951 5540.

More university open days

Wednesday, 1 March

Higher Education Information Day for Students with Disabilities at **University of Wales, Swansea.** Bookings deadline: 15 February. Cost, including lunch, £7. Booking forms and programmes available from Skill, 336 Brixton Road, London, SW9 7AA.

Wednesday, 15 March

Higher Education Information Day for Students with Disabilities at **Lancaster University.** Bookings deadline: 1 March. Cost, including lunch, £7. Booking forms and programmes available from Skill, 336 Brixton Road, London, SW9 7AA.

Wednesday, 22 March

Higher Education Information Day for Students with Disabilities at the **University of Dundee.** Bookings deadline: 8 March. Cost, including lunch, £7. Booking forms and programmes available from Skill, 336 Brixton Road, London, SW9 7AA.

Wednesday, 29 March

Higher Education Information Day for Students with Disabilities at the **University of North London.** Bookings deadline: 15 March. Cost, including lunch, £7. Booking forms and programmes available from Skill, 336 Brixton Road, London, SW9 7AA.

The LINK diary

This and That!

READERS of our sister magazine *LIFT* have been asked in the last couple of issues to compile *Disability Diaries*, a record of the bad things that have happened to them - and the good - over the space of a fortnight as a result of their disability.

For these requests, they've got Brenda Sharp to thank. Brenda, the redoubtable secretary of South Wales ASBAH, was brushed with the brilliance of the idea when she attended the last meeting of Wales Council for the Disabled where the keynote speaker was an American who described how a disability diary campaign in the United States helped the all-encompassing Americans With Disabilities Act on to the statute book.

Brenda mentioned the idea to the *LIFT* editor and the rest, as they say, is history, Well. . . almost.

LIFT - the free magazine which goes out on request four times a year to ASBAH's disabled members - plans to run a series of disability diaries, starting from the next issue which will be out in March, and the editor would also welcome disability diaries from *Link* readers.

We do not want to know what you had for breakfast or what the weather was like, unless it was particularly relevant. What we do need to know is what discrimination you suffered, or what positive reaction you had, because of your disability.

Please send a diary of a fortnight's ups and downs in your life - together with a recent photo of yourself - to my colleague Liz Cawthorne at ASBAH, 42 Park Road, Peterborough PE1 2UQ. She will then consider publishing your disability diary in a future issue. You can at the same time ask to be put on the mailing list for *LIFT*, which has vastly improved in recent months.

***ON NEW** Year's Day, Margaret Holmes was tracking elephant on a wildlife safari in Africa - not bad going for an ASBAH fieldworker who had retired officially the day before.*

Margaret, who worked for us in south London for seven years, had timed her retirement to be in Zimbabwe just after Christmas for a three-week cricket tour with the Gloucestershire Gypsies, a gentlemen and players outfit that she and her partner Geoff Harrison had first encountered, again in the bush, while travelling in South Africa with a London club team a couple of years ago.

There was space on the tour with the Gypsies for a scorer and an umpire and, when the call came for them to fill the places, Margaret and Geoff jumped at the chance.

"I come from Yorkshire and learnt about cricket virtually at my dad's knee. He played in a league in Bradford and, although I was never able to play because of my disability, he had taught me to score by the time I was eight years old", said Margaret.

"We've had a tremendous holiday. It was an experience we wouldn't have missed", said Margaret a few days after their return to wet and windy London.

Margaret and Geoff travelled round Zimbabwe with the Gypsies, who won seven out of eight games played against over-rested local club teams, who don't normally play in the Zimbabwean summer because it is too hot. The touring party included Gloucestershire first-class players Reggie Williams, Bobbie Dawson and Mike Cawdron, and an assorted collection of amateurs - gentlemen farmers, a stockbroker, a solicitor and a doctor. "It was British club cricket at its best," added Margaret.

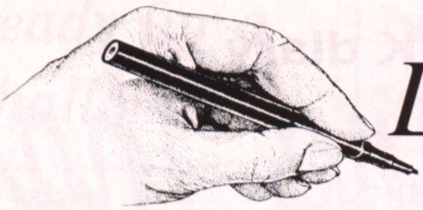
THOSE super-efficient ladies in the ASBAH information department, Gill and Margaret, have had their wits tested to the utmost since the New Year. Not content with their rapid response to inquiries on family records, research statistics, holidays, insurance, leaflets and the rest, telephone callers have asked them recently to hire out a steam train in Dorset and supply a navigation chart to an intrepid yachtsman wanting to cross the Wash. The callers had mistaken ASBAH for some other equally long-titled associations. G & M know they are good at their job, but some things are even beyond them.

***HOME** early one night and chanced to switch on to EastEnders, where Arthur had gone mutt 'n jeff, apparently (though it seemed out of character) after going swimming. "He's got water on the brain," suggested one bar-room wag. Quick as a flash, the barman retorted: "He better put a tap on it!" What repartee! What rot! Time, me thinks, for some decent hydrocephalus awareness training down at the Queen Vic.*

A CALENDAR posted to us by a print firm left me feeling confused at the start of 1995. The calendar, while successfully demonstrating the printer's vast range of typefaces for dozens of languages round the world, kicked off with a page for January starting on 26 December 1994 and finishing on 5 February. And it repeated this format of calendar months occupying six weeks on every single page. It was all a bit much for a chap who sometimes has difficulty remembering what day it is today.

The destination for this calendar. Yup, you've guessed it . . . the WPB.

T B



Letters

IN 1993, the British Journal of Nursing published an article *Spina Bifida: the personal and financial cost of incontinence* by Mary White, ASBAH'S disabled living adviser (continence).

This compelling article - as well as discussing the many specific issues related to continence - brought attention to the possible problems of spina bifida and hydrocephalus, family needs, the aims of health care, educational needs and the services required to overcome them.

Mary used a care study experience with a young man called Peter to focus attention on real life experience and showed how ignorance, mismanagement and incompetence can affect the quality of life of disabled people. The article demonstrated how Peter's story was, ultimately, a success story illuminated by high courage and endeavour supported by sensitive professional initiatives but which, so easily, could have become another tragedy.

Mary advocated in her article that ". . . a holistic approach to management, from birth onwards should facilitate the interdisciplinary co-operation which is vital if these human tragedies are to be avoided."

A number of professionals thought this message should reach a wider audience and, at a conference at the Charing Cross and Westminster Medical School on 13 January, there was the first public showing of a video *Peter's Story: The Cost of Incontinence*. It has been written by Mary White and made by Mary, Maddie Blackburn (hon research fellow), Brian Walsh (deputy head of social work, Nottingham Trent University), the Community Paediatric Research Unit at Chelsea and Westminster Hospital, and the medical illustration group of Charing Cross and Westminster Medical School.

The conference, entitled *Disabled Adults: are we meeting their needs?*, was chaired by Dr Martin Bax, who is well-known to ASBAH.

Peter's Story was designed as a multi-disciplinary training tool raising many issues - disclosure, sex, bullying, education and access are only a few - in multi-professional settings. But the artistic and human success of the video cannot be over-emphasised. The visual and sensitively to give access to a world known only the disabled.

Copies of ***Peter's Story*** *may be obtained from Anthea Hewitt, Secretary, Derby and District ASBAH, St Merryn, 20 Burley Hill, Allestree, Derby DE3 2ET. Price £25, inc p & p.*

Michael Flynn
Derby and District ASBAH

FORTHCOMING ASBAH EVENTS

Saturday, 4 March

Council meeting, ASBAH

Wednesday, 8 March

ASBAH study day, 'Bridges to Confidence', Devon Drivers' Centre, Westpoint, Clyst St Mary, Exeter, Devon. Speakers include: Mr J Mohun, consultant neurosurgeon, Derriford Hospital, Plymouth; Dr Chris Williams. SPOD (Dept Clinical and Community Psychology, Exeter); Leonie Holgate, Disabled Living Adviser, ASBAH. £7 individual service-users, family members and carers, £20 professionals. *Apply: Wendy Rattray, ASBAH, Ashclyst Centre, Hospital Lane, Whipton,Exeter EX1 3RB, by 22 February.*

Saturday, 11 March

Professional conference 'From birth to adolescence with neuropathic bladder and bowel', jointly organised by ASBAH and Manchester Children's Hospitals. Venue: Research and Postgraduate Centre, The Children's Hospital, Hospital Road, Pendlebury, Manchester, 9am - 4pm. Fee: £20 each delegate. *Details: Janet Fishwick, Paediatric Urology, Royal Manchester Children's Hospital, Hospital Road, Pendlebury, Manchester M27 1HA, tel: 0161-794 4696.*

7 - 9 April

ASBAH South East region 'Music and Drama Weekend' for young people aged 10 to 16, Meldreth Manor, Royston, Herts. Funded by BBC Children in Need Appeal. *Details: Gina Broughton, ASBAH, 123 East Barnet Road, New Barnet, Herts, tel: 0181-449 0475.*

Easter Bank Holiday weekend

Olympic hopeful Rob Barsby attempts Wash Windsurf Challenge in aid of ASBAH. *Details: Deirdre Pawsey, ASBAH, tel: 01733-555988.*

ASBAH SCHOOL BOOKLET

Children with spina bifida and/or hydrocephalus at school, 48 pages, fully revised at end of 1994. *From Information Dept at ASBAH, 42 Park Road, Peterborough PE1 2UQ. Price £2.75, inc postage and packing.* Please send cheque made out to 'ASBAH' with order.

Please say you spotted the advert in Link

SERVICES

FREE continence and medical product supply service from *AlphaMed Ltd*. Phone services floor at ASBAH, tel 01733-555988, for your introductory Freepost envelope. 48-hour turn-round offered. Do NOT send prescriptions for drugs or medicines. ASBAH receives a donation from each order.

PLAN your next group holiday, coach tour or business trip abroad with *Lincs Travel* (Travel Trust Association-bonded, member of Discovery Travel Group). Packages cheaper than main operators. 2% of value of business donated to ASBAH. *Pam Forster, Lincs Travel, 9 Stenner Road, Coningsby, Lincs LN4 4RP tel: 01507-523833, fax: 01507-523839.*

FOR SALE

CHILD's wheelchair, Quickie 2. Excellent condition, little used. 13"-frame, 20"-wheels. Lightweight, angled foot-plate, swing-away arm rests, moveable handles, anti-tippers. New cost: £1,400. Sell at £500. Tel: 01473-463255.

HOLIDAY ACCOMMODATION

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

NEW FOREST

Fully-equipped caravan designed for wheelchair access throughout, sleeps 5-6, club with indoor pool, shop etc, sited at Bashley Park, New Milton. *Contact Joan Searle tel: (01705) 376816.*

MID-WALES

Nicely furnished self-catering bungalow, sleeps five. Wheelchair-accessible. Grade 2, in beautiful valley. Maximum £220 pw. B&B and 6-8 berth caravan available. Ideal touring area - mountains, waterfalls, lakes, dams, steam trains, castles, fishing nearby. Astronomy holidays, 16" telescope - beginners welcome. *Details: Ann Reed, tel: 01938-810446.*

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, Ryde, IOW PO33 3PX, tel: 01983-564604.*

STAFFORDSHIRE, ALTON

Wheelchair-accessible holiday accommodation in country cottage, B-B or H-B. *Details: Jean Ditchfield, tel 01538-702189*

NAISH HOLIDAY VILLAGE, NEW MILTON, HAMPSHIRE

Fully equipped, completely wheelchair-accessible, two-bedroom bungalow. Sleeps six. Site near sea with access to New Forest, Bournemouth. Excellent site facilities 100 yards from chalet. *Details: Mr P Cash, tel: 01425-672055.*

LOOE, CORNWALL

Fully equipped, self-catering, two-bedroom bungalow. Sleeps six. Site near sea with easy access to beach, shop and camp facilities. Easily accessible for wheelchairs. *Details: Mr P Cash, tel: 01425-672055.*

LINK Rates

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£5.50 for 45-60 words.
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Small adverts for the next issue of *LINK* (April) should be submitted by Wednesday, 8 March. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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