

# Link

OCTOBER 1990 NO. 130

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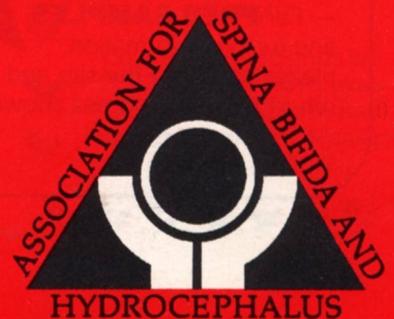
The magazine for people with  
Spina Bifida and/or Hydrocephalus



## IN THIS ISSUE

Photographs of the Royal visit

A look at the Disabled Facilities Grant



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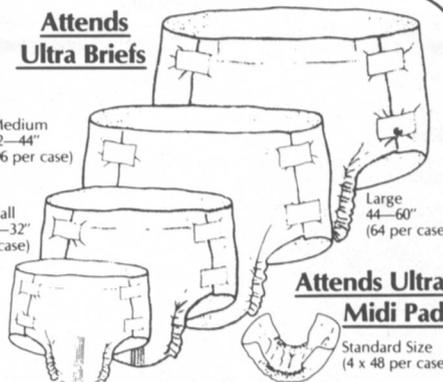
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## CONTENTS

▲ Update	4
▲ Disabled Facilities Grant	8
▲ Royal visit	10
▲ Appeals	12
▲ Mothers with spina bifida	13
▲ Sport	14
▲ Out & about	16
▲ Reviews	18
▲ Classified Ads	19

The magazine for people with spina bifida and/or hydrocephalus

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# Link

OCTOBER 1990  
ISSUE NO 130

**T**his month sees a national rally in three major cities to bring the needs and rights of disabled people to the forefront of public attention. The 'fight' to achieve what the able bodied often take for granted is a constant demand on many disabled people. Whether your personal fight is trying to secure benefits, getting a disabled child into the school you want, appropriate housing or simply doing something well -from motherhood to sporting achievements -ASBAH can often help you to achieve success.

In this issue our accommodation officer, Dominique Cull, looks at the intricacies of the Disabled Facilities Grant and asks you to let her have your experiences; in 'Update' we propose a survey to see if the needs of children with hydrocephalus are being met in mainstream schools; and in 'Out and About' a national coach company invites you to tell them how they can improve their facilities for disabled travellers.

We can all gain inspiration from Tanni Grey - a top class athlete - who features on the sports pages; and from mothers with spina bifida - in our 'Experience' section - who fight to overcome prejudice and practical difficulties in bringing up their children.

## Over to you

If you have an experience which you would like to share with Link readers or comments on those we have featured write to The Editor, we look forward to hearing from you.



COVER - Pictured after the official opening of ASBAH House are HRH Duchess of Gloucester and our Chairman Mr Patrick Daunt.

## Christmas Cards from ASBAH

Our Christmas card brochure for 1990 is now available and we hope you will support us once again.

Copies of the brochure are available from the Appeals Department. Write to Roy Johnston, Marketing Manager at National Office



## Senior Staff

*Executive Director:*

Miss Moyna P Gilbertson, MCSP, FBIM

*Finance Director:*

Mr Derek Knightbridge, FCCA

*Appeals Director:*

Mrs Jennie Whiting

*Assistant Director (Administration):*

Mr Paul Dobson, BA (Hons), MIPM

*Fieldwork Manager:*

Mrs Teresa Cole, MICA

*Disabled Living Services Manager:*

Miss Rachel Stanworth, BA (Hons),  
SRN, PGCE, MSc

*Publicity Manager:*

Mr Tony Britton

*Research and Information Officer:*

Miss Pat Corns, SRN

*Regional Development Co-ordinator:*

Mr Phillip Watson, BA (Hons), RGN

*Five Oaks Centre Manager:*

Miss Joan Pheasant, NNC

*Marketing Manager:*

Mr Roy Johnston

## Education Appointment

Peter Walker has been appointed education co-ordinator for ASBAH with effect from 1 October. Mr Walker has many years experience as a head teacher of a school with a special needs unit and is also extremely familiar with the 1981 Education Act. Peter takes over part of the work of Sue Fenton (formerly education, training and employment co-ordinator) who left us in July to work for the RNIB in Liverpool.

Our Disabled Living Services department took this opportunity to split the job into two part-time posts - one for education and the other, which is expected to be filled shortly, concentrating on training and employment.

## SEARCH FOR NEW CHIEF EXECUTIVE



*ASBAH looks for a worthy  
successor to Moyna Gilbertson  
(pictured right)*



**ASBAH is advertising for a successor to Miss Moyna P Gilbertson, who will retire as the association's executive director next April. Miss Gilbertson has held the post for 14 years.**

Advertisements for applicants, who should have "the vision and direction to ensure the charity's future success", are appearing in selected national daily and Sunday newspapers in mid-October, and in the November issue of 'Disability Now'. The salary for the Peterborough-based job is projected at not less than £30,000 a year.

A specific discipline is considered less important for the person who becomes the association's next chief executive than "highly-developed management skills, a broad-based knowledge of disability and experience of the provision of services".

The advertisements state that responsibilities will include developing and implementing long-term strategy, as well as motivating and directing a committed team. Energy, flexibility, and the presence and stature to communicate effectively at the highest levels are also considered to be essential requirements.

Interviews will be held in Peterborough in early December, after applicants have had the opportunity to meet members of the executive committee and senior

officials on an informal basis.

Miss Gilbertson joined ASBAH on New Year's Day 1976. Her last post was superintendent physiotherapist, Hospitals for Sick Children, Great Ormond Street. She has steered the association to a position where it is now widely recognised as the leading charity in its field.

Almost 20,000 people with spina bifida and/or hydrocephalus can turn to ASBAH for practical help and support, and so can their families and professional attendants. As well as offering direct services, the association is dedicated to achieving equality of opportunity for everyone and to breaking down barriers in areas of life such as education, employment and housing.

The association has a network of 42 fieldworkers and six counsellors who cover England, Wales and Northern Ireland, mostly working from their own homes. There are over 50 national office staff based at Peterborough, including sizeable appeals, fund-raising and disabled living services sections. All together, the association employs about 160 people, including staff at our award-winning residential care centre, Five Oaks, in Yorkshire.

## ASBAH strengthens its continence team

ASBAH has appointed *Mary White* as a national continence adviser, further demonstrating its total commitment towards training for independence.

Mrs White, who has been an ASBAH fieldworker for almost three years, becomes disabled living adviser (Continence) - working closely, from her home in Matlock, Derbyshire, with colleague Jane Williams at National Office.

Qualified as SRN Cert. (School Nursing) with a Diploma in Special Needs and Education, Mrs White will provide a professional, personal service to people with spina bifida and hydrocephalus in the Midlands and North of England and help train other professionals throughout England, Wales and Northern Ireland.

She has been fieldworker to about 200 families in Derbyshire, Nottinghamshire and part of Lincolnshire and will retain her links with families in the rest of this area. ASBAH is in the process of appointing another fieldworker for the area.

Mrs White will work most closely with children, aged three to seven, where she believes good continence management patterns established early on reap rewards in confidence and self-esteem which can endure throughout life.

"Quality of life and self-awareness from an early age are colossally important. I believe that incontinence over a long period, learning management in the hands of other people, leads to all sorts of behavioural problems later on", said Mrs White.

She has been involved with continence clinics in Sheffield, Nottingham, Chesterfield, Lincoln, Boston and Grantham during her time with ASBAH. Mrs White is skilled across a wide range of continence management skills - including assessment of bladder functions and showing people how to achieve intermittent self-catheterisation.

Mrs White became interested in continence management as a vital tool towards self-care when she worked as a school nurse in a special school in West Berkshire. There were 100 children on the roll, 17 of whom had spina bifida. She reported her experiences extensively in 'Nursing Times' earlier this year; the article was reprinted in this magazine in April, copies of which are available on request.



*ASBAH's continence advisory service can be contacted through National Office on 0733 555988.*

## New Flats for York

Several young people in York have been given a taste of independence with the opening of three new purpose built flats in the city. North Yorkshire ASBAH had a hand in the planning of the accommodation to ensure it would fit the needs of residents with spina bifida.

The project began in 1987 when the Joseph Rowntree Foundation prepared a survey into the housing needs of NYSBHA members aged over 16. The findings showed that many youngsters were living at home with their parents but really wanted to lead more independent lives.

A suitable site, just outside the city walls, was chosen for the project which offered ground floor accommodation in a central location with access to shops. The flats allow for special care where necessary and have been adapted to be suitable for varying levels of disability.



*Residents Geraldine Ferry, left, and Sara Meace with former president of NYSBHA, Roy Howell, and chairman of the Rowntree Federation, Sir Donal Barron, left. Photo courtesy of Yorkshire Evening Press.*

# A Balanced View

The risks run by pregnant women taking the epilepsy drug sodium valproate (Epilum) have been in the media again recently. It is said that the drug increases the risk of having a baby with spina bifida by two to three times. But says Professor Smithells, who wrote about the risks some years ago, "the balance of benefit for epileptic women rests on staying on treatment rather than stopping it" as severe epileptic fits could be harmful to the foetus. And changing to another drug could simply leave the mother facing different risks as all epilepsy drugs have "some capacity for causing malformation".

Professor Smithells advises prospective mothers-to-be to visit their doctors to check whether the treatment they are taking is still necessary and if so are they on the most appropriate drug and most appropriate dosage. He also feels that these women should be offered amniocentesis which in the great majority of cases will provide a reassuring message about their baby.

Sussex ASBAH found a novel way to raise funds and have a lot of fun recently when they organised a Teddy Bears Day Out. The afternoon's competitions attracted more than 70 tedds competing for titles ranging from the best dressed to the most huggable bear.

The climax of the afternoon was a daring parachuting event. The "Ted Devils" lined up for their death defying leaps from kites high above the crowds. The jumps were organised by Brighton Kite Flyers and the day raised approximately £500 for SASBAH.

## SUPER TEDS



## Education Survey for ASBAH

The need for more understanding, in mainstream schools, of the learning difficulties associated with hydrocephalus was a major concern raised at our recent Hydrocephalus Support Group study day. Parents felt that many teachers had little real understanding of what hydrocephalus is or the learning difficulties to which it can sometimes give rise.

At a recent meeting with Professor Wedell of the Institute of Education, London, our executive director, Moyna Gilbertson, discussed the need to improve teacher training in the area of children with special needs. ASBAH intends to pursue this issue and proposes a survey to see if parental assessments of pupils' needs are being met by the provisions which area education officers say already exist.

If the survey reveals a shortfall in the existing provisions the evidence will be used to ask the Government for an improvement in teacher training in this area.

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## CLUB SUCCESS

A suggestion from fieldworker Marion Baker led to the formation of a new social club for Dovercourt in Essex. Dawn Garnier, 24, who has spina bifida, told Marion there were few social activities in her home town for disabled people so Marion suggested Dawn set up a club herself.

The New Dawn Club was the result - a social club for disabled and able bodied people from 15 to 35 years of age - held fortnightly on Monday evenings. At their first meeting over 20 people turned up to play snooker, table tennis and board games. The club hopes to develop to cater for the interests of individual members with ideas for film nights, guest speakers and visits to the theatre. The Mayor of Harwich officially opened the club, at the Olive Tree Christian Centre, Hill Road, Dovercourt on 17 September.

## Having a Conference?

The Boys' & Girls' Welfare Society in Cheadle, Cheshire has a conference centre available for hire for courses, and workshops etc. It is accessible for disabled people and has a range of facilities.

Further information from Ann Faulkner, Boys' & Girls' Welfare Society, Central Offices, Schools Hill, Cheadle, Cheshire SK8 1JE. Telephone 061 428 5256.

## German Contact



FIFTEEN-YEAR-OLD Jan Held from Germany, who is a wheelchair user, is looking for a boy of the same age, from the Enfield/London area, who would be interested in having a penfriend and taking part in a school exchange or visits to each other's countries. Jan's hobbies are letter writing, reading, playing basketball and his computer. He promises to answer every letter and you can write to him at Erlenstr 11a, 4390 Gladbeck, Germany.

## Congratulations

On one of the hottest days of the summer, former secretary of Surrey ASBAH, Trudy-Anne Bush, who has spina bifida and hydrocephalus,, walked down the aisle to marry Richard Eborn. Our congratulations and best wishes to them both.



## Driving Ambition

Active members of the Disabled Driving Association, Helen and John Robinson provided a unique entry into this year's final of the Car Driver of the Year - as the only disabled couple in the competition. The Robinsons qualified for the final after taking part in the heats at Newcastle earlier in the summer.

They were competing with dozens of able bodied drivers in a demanding 25 minute road test - accompanied by an officer of the law - followed by manoeuvrability tests and finally questions on the highway code.

On the day Helen, who has spina bifida, got the better of husband John notching up less than half as many penalty points. Though neither of them made the prizes they both had a "thoroughly enjoyable day".

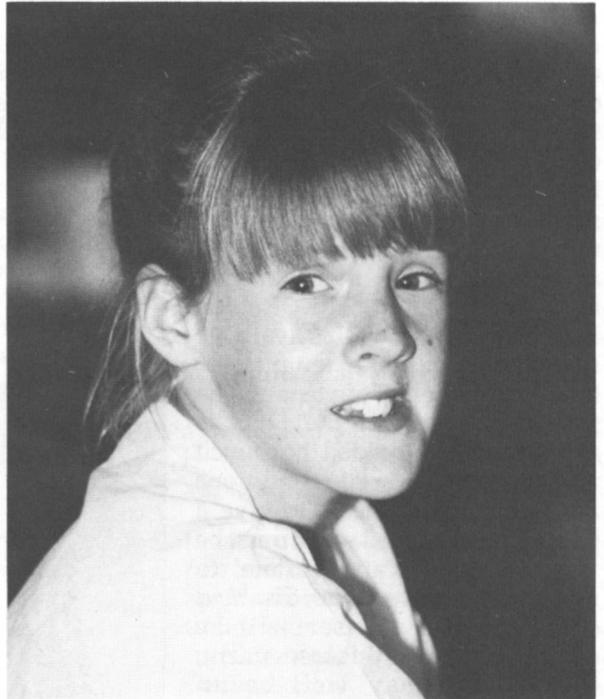


## On the Move

The Department of Health Disability Unit has moved from Alexander Fleming House to: Room 332/3, Richmond House, 79 Whitehall, London SW1A 2HS.  
Telephone: 071 210 5021.

## Keeping her Head above Water

An 11-year-old who "doesn't like getting her face wet" swam her way to a new wheelchair at her local pool. Jenny Savage from Swanton-in-Morley needed a new lightweight wheelchair and decided to raise the money to buy it herself. Her plan was to do a sponsored swim of nearly half a mile but Jenny surprised everyone by doubling the distance and swimming a mile in just an hour. Her proud mum, told us "the local television crew turned up to record the event and we think Jenny must have been inspired by the cameras!"



A look of determination from young Jenny.

Jenny's marathon swim may have left her with a temporary neckache, as she held her head up all the way to keep her face dry, but her efforts meant she reached her goal - her new chair should be delivered shortly.

## New Director for DLF

Paul Brearly has been appointed Director of the Disabled Living Foundation on a two-year secondment from his job as Assistant Chief Inspector of the Social Services Inspectorate of the Department of Health. Mr Brearly takes over from James McKinnon who held the post for a year.

The Chairman of the DLF, Barney Wilson, said "We are very pleased to welcome Mr Brearly to the DLF. We are developing our information services to people with disabilities and professionals using new computer technology. Mr Brearly's background and knowledge of work in local and central government, the health service and voluntary organisations will be invaluable to us".

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# The Good, the Bad and the DFG!

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A new home improvement grant came into existence on 1 July 1990 aimed at helping to make the home of a disabled person more suitable for him, or her, to live in and to enable people to manage more independently at home. If you (or someone in your house) are registered or entitled to register as a disabled person then you can apply for this grant. The Disabled Facilities Grant (DFG) is available to owner-occupiers, tenants, or landlords on behalf of a tenant. The good news is that the DFG is mandatory, so provided the council are satisfied that certain conditions are fulfilled, they have to give a grant. The proposed work must be 'necessary' and 'appropriate' to meet the needs of the disabled occupant. An adviser will be consulted to make this assessment; the adviser may well be an occupational therapist from the social services department. The work must also be 'reasonable' and 'practicable' given the age and condition of the property. The type of work which will qualify for a mandatory grant includes that which

▲ will make it easier for you to get into and out of your home

▲ allow easier access to the living room, bedroom, kitchen and bathroom

▲ provide suitable bathroom and kitchen facilities that you can use independently

▲ improve the heating system in your home

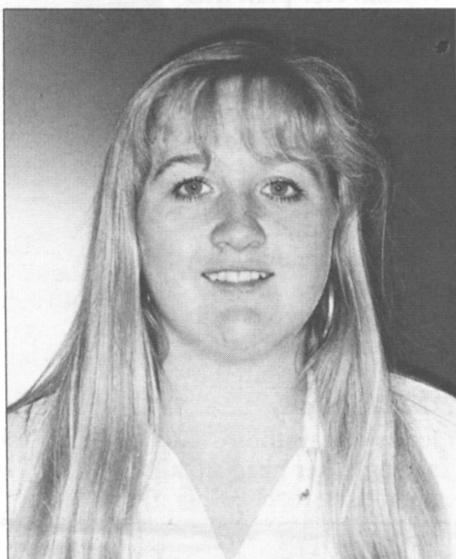
▲ make provision around the home to help you, as a disabled person, to care for someone living with you who is dependent on you for care

In addition to the above the council can decide whether or not to give you a discretionary grant for other work which will make a home suitable for a disabled occupant's accommodation, welfare and employment.

**THE BAD NEWS** is that although the grant is mandatory this does

not mean that you will automatically get 100% of the cost of the work paid for you. The amount of grant you will receive is determined by a means test, or 'test of financial resources'.

This test takes into account your income plus savings over £5,000 and compares this with an amount reckoned to be adequate for someone in your position to live on



**DOMINIQUE CULL**  
*ASBAH's Accommodation  
Officer*

- called your applicable amount. If a family is in receipt of Income Support they will probably receive the full 100% grant. Others, who are expected to find a percentage of the costs, may be entitled to a loan or top-up from their social services department, depending on their circumstances and their council's policy.

The massive flaw in this method of means testing is that although income is looked at in detail, a family's expenditure is not. Those families with a fairly low income but huge expenditure may find they're expected to find a percentage that is realistically too high. When setting up this system the government felt it would be acceptable for owner-occupiers to add this percentage to their existing mortgage but increased mortgage rates have hit many families' budgets. And some adaptations may

well reduce the value of the property on the open market leaving the family unable to pay off their mortgage when they sell the house.

In the few months that the DFG has been in existence many cases have come to light where applicants are expected to contribute an unrealistic amount to the cost of the work. Because of our concern

over the number of families who might be going into debt, or simply not accepting the grant, ASBAH is eager to collect information to monitor the situation and present it to the Department of the Environment who are responsible for the implementation of the system.

If you have any experience of the DFG please contact me with the following information:

▲ the name of your local authority

▲ whether you are a council/housing association tenant, owner occupier or whatever

▲ your household's composition and ages

▲ your household's income

▲ household expenditure, stating rent/mortgage etc

▲ how successful you were with your application.

I would prefer to have your name and address to contact you at a later date but realise that you may wish to remain anonymous.

**EACH LOCAL AUTHORITY** has the right to interpret the DFG in any way they feel is acceptable. As a result different councils have different departments in charge of processing applications - it could be the social services, environmental health or even the housing department. If you don't know whose department is responsible for applications in your area start with social services and they should be able to point you in the right direction.

There is no standard application form for the country - each council has its own - and because of the details needed the forms can be long and complicated. Ask for help if you find it confusing.

Processing applications can take a

long time as several different people need to determine whether the conditions for the grant are fulfilled. However, the council must give an answer within six months of the application being made. Whatever you do **DON'T** start the work before you have received an answer or you may well get no grant at all.

If the answer you get seems unfair - you are refused a grant, or can't afford your share of the cost - then express your concerns to the official in charge of your application. If this does not resolve the problem approach the Citizens' Advice Bureau or complain to the Ombudsman. If you have tried all other avenues you may wish to write to your MP.

#### TIPS

▲ Photocopy your completed application form (in case it gets lost)

▲ Make a note of the date it was handed in

▲ If you post the form enclose an sae and ask for acknowledgement that the form has been received

▲ Find out which official is in charge of the application and any others involved.

#### SPECIAL NOTE

Any applications for grants under the old system in England and Wales that had not been assessed by midnight on 30 June 1990 automatically fail. In these cases it is necessary to submit a new application under the new system.

If an unreasonable delay in processing your original application means that you lose out under the new system you can consider making a complaint to the Ombudsman.

If an application was approved before 30 June 1990 you will still be covered by the old system, even if the work is due to be completed afterwards.

## Housing Project

A shared housing project is being set up in Ealing, London for young people with spina bifida and/or hydrocephalus.

The project has been set up by Ealing Family Housing Association, North West London ASBAH and National ASBAH and should be ready for occupation by October this year.

#### THE AIMS

The aim is to give young people an opportunity to experience independent living in a shared community. By living and working together as a household, young people will gain confidence in caring for themselves while learning the importance of relying on others in daily life.

It is hoped that young people will see the house as a first step to other independent accommodation options, thereby allowing it to be a resource available to young people in the London area and throughout the country.

#### THE HOUSE

The house itself is a 1930s style property, in a residential area of Ealing, which has been renovated to create a four-bedroom, four-person shared house with communal facilities. The kitchen area will incorporate up to date equipment including specially designed worktops and units. There is a separate utility room with washing machine and tumble dryer and the dining room and lounge provide spacious living areas. The bathroom contains a toilet, bath and shower - all accessible to a wheelchair user with a second toilet upstairs.

The first floor of the house has four large bedrooms, each with separate washing facilities and built-in cupboards and may be reached via the staircase or the lift. The house has a good security system with entry phones and lighting in the front and rear gardens.

#### THE SUPPORT

The support provided at the house is aimed towards training - nursing/medical care is not provided. The house will be linked to an emergency warden call system and a worker will be available during the day to give help and advice to the residents regarding statutory services. An element of the weekly charge made to residents will include the cost of support as well as rent, rates and other services.

*For further details and an application form contact Dominique Cull, at National Office.*



# Royal Welcome

## Duchess of Gloucester opens National Office

ASBAH received a royal welcome to its new home in Peterborough when our patron HRH Duchess of Gloucester officially opened ASBAH House on 11 September.

The Duchess, wearing a red, two-piece suit with navy and gold hat, pearl choker and matching accessories was greeted by the Lord Lieutenant of Cambridgeshire, Michael Bevan. Her Royal Highness was introduced to our president, Jeffrey Tate, who has spina bifida, and chairman, Patrick Daunt, before being escorted round the building by Moyna Gilbertson, ASBAH's executive director.

During her visit our royal guest met all 50 of the National Office staff and spent over an hour chatting with staff and officials, catching up with all the latest news about the association.

Local ASBAH members also took part in this royal occasion. Nine-year-old Mark Marsh presented a bouquet and five other young disabled people were able to tell the Duchess about their hopes and achievements and how ASBAH has helped them.



*The Duchess, with Patrick Daunt and Moyna Gilbertson, prepares to sign the Visitors' Book*



*Sue Church, Gill Winfield (editorial staff) and Rachel Stanworth, DLS manager talking to HRH*



*Austin Crowther introduces Teresa Cole, fieldwork manager and Mary Malcolm, asst. fieldwork manager*



*HRH meets Dominique Cull, Jane Williams, Frances Woodgate, DLS*

*Executive members; John Lewis, Eric Ithell, Philip Brown and Dennis Paul, vice chairman*



# to Peterborough



*Steven Marsh presents the bouquet*



*Jeffrey Tate and Moyna Gilbertson listen attentively whilst Dave Gough Telesales, chats to our Royal visitor*

Weightlifter Neil Howard told how he hopes to join the team in the next Disabled Olympics, Karen Desborough explained how she set up her own fashion design company called 'Pastiche'; Ian Lea revealed that ASBAH helped him obtain a computer to assist him in his bid to take up accountancy and Alan Young said he was enjoying life again after a spell in hospital. Ashley Marshall even brought an example of his work to show the Duchess, he is a wood-turner.

*Neil Howard and Ian Lea talk about their achievements watched by fieldworker Mary Castle*



Before leaving us Her Royal Highness unveiled a plaque to mark the occasion.

*The plaque is unveiled*



*Looking at equipment in the Telesales department with manager Tom Logan*



The architect was amongst those present for the official opening of ASBAH House which was originally intended to be four separate suites of offices. However, the builders, Peacocks, swiftly changed the specification when the association showed an interest in taking the whole site. The building has been designed for full wheelchair access with wider than standard doorways and easy to reach switches.



*The architect and representatives from Peacocks, the builders of ASBAH House*



# Up to Strength

OUR APPEALS department at National Office is now at full strength having recruited 10 new



Donna Treanor accepts the cheque from Danny Aimes (left). Photo by kind permission of Birmingham Evening Mail

members of staff.

A cheque for £2,000, towards their target for this year was received from Birmingham Police following a Round Britain Teddy Bear Run in the summer. The event was the idea of detective Danny Aimes, in memory of his daughter Charlotte who had hydrocephalus. The £4,000 raised by the run was divided between ASBAH and Birmingham Children's Hospital.

JOE LAVERS Managing Director of UIC has again raised over £6,000 for ASBAH with his charity football match.

\*\*\*

IT'S NOT all hard work for the Appeals team, pictured below getting ready for an after-work rounders match.

*In the swing Jennie Whiting, appeals director faces bowler (alias marketing manager) Roy Johnston.*



## Bursary Fund Donation

A covenanted donation has been made to the Bursary Fund in memory of Penny Ehlers who would have been 21 last year.

This fund was set up in 1989 and interest from the money invested will be used to pay expenses for young people attending training courses approved by ASBAH.

*Application forms for funds can be obtained from National Office.*

## JUNIOR CONVERSATIONALIST OF THE YEAR

Later this month more funds will be raised by the *Junior Conversationalist of the Year* contest which will be held at the Glaziers Hall, London Bridge on 29 October.

Adapted from our unique annual Conversationalist of the Year competition this version is designed to suit those aged between 15 and 19. It should be a fun contest as well as an educational experience as the participants battle it out to make

the wittiest, most lucid and interesting conversation in 12, 20-minute sessions.

"If you are articulate, enjoy a friendly chat, an interesting conversation, putting over your views on anything from pop music to the power of the press, this is the supreme test of ability" says Jennie Whiting, appeals director. "Contestants will not need to have a great knowledge about any of the subjects put up for discussion - just an ability to

keep a real dialogue going."

Exciting prizes await the winner of the title and the school and individual which bring in the most sponsorship. Celebrity judges for the event are Edwina Currie, Sheridan Morley, Jill Dando and Peter Preston, Editor of The Guardian - who are also giving the opportunity for the winner to have a day behind the scenes of a national newspaper.

Contestants are asked to raise at least £100 each in sponsorship to go towards the work of ASBAH.

More details are available from Jennie Whiting at National Office.

# ABLE MOTHERS

## *Some experiences of mothers with spina bifida*

Sue Ley may be only four feet, six inches tall but her small stature belies a strength of character and determination typical of the mothers we talked to. She has spina bifida and her husband also has disabilities but that hasn't stopped them having three children. As Sue said, "Once I've decided to do something not much will stand in my way".

Some mothers had genetic counselling before they decided to start a family as there is a risk that, whichever parent has spina bifida, the baby might be so affected. Any risk to the mother's health is also a very important consideration and Ann Roberts, mother of a five year old, feels it's even more important for a disabled woman to be healthy and fairly fit than it is for an able-bodied woman who intends to have a baby. Pregnancy puts an additional strain on the kidneys and the mothers were closely monitored for any kidney infections during this time. Some did experience infections and were treated with antibiotics. Other problems included "shortness of breath towards the end of the pregnancy". One mother complained that her urostomy leaked as she "couldn't see over the lump" when changing the bag, although another had no such problem and found her urostomy plaster actually adhered better to the taught surface of her 'bump'.

**"I felt I had to be better than every other mum"**

Many women tend to be more emotional during pregnancy and just after the birth of their child and for a disabled person this might mean being extra sensitive to any perceived criticism of her desire to have a child and ability to look after it. As one mother told us "I felt I had to be better than every other mum" - otherwise people's prejudices would come to the surface implying that you cannot properly care for a child if you are disabled. Some able-bodied people can make unhelpful comments - "how did you have it then?" was the surprised question from a neighbour of one mother, on discovering that the baby had not, as she assumed, been adopted.

Fortunately, the medical profession

emerged in a much more favourable light, "really great", "brilliant" "very positive and supportive", "fantastic" were some of the superlatives used to describe GPs' and particularly gynaecologists' support for the mothers-to-be. Assia King's gynaecologist would pop in to see her even when he wasn't on his rounds, and Ann Roberts' consultant came in on a Sunday morning to see her.

**"The gynaecologist was great - he treated me just as another patient"**

The births of their babies were as varied as with any group of women - some were pre-planned caesareans, some came early, others surprised everyone. Assia went into hospital two weeks before her baby was due expecting him to be born by caesarean section but "woke at 5.15 in the morning in a pool of water" and 15 minutes later her baby was delivered.

The birth of their first child is a pre-occupation with most mothers-to-be as they face this unknown experience and thoughts of the practical aspects of coping with a baby and growing toddler are often left to be dealt with as they arise. After all for the able bodied mum there is so much choice, for

example, on how she'll transport her new infant. Sadly there are not so many options available to disabled mums who use a wheelchair. A sling is one way to carry a small baby but holding on to a toddler and manoeuvring your chair at the same time could cause difficulties. Claudia Forster found wrist reins (which attach mother and child by a single cord) "an absolute god send" leaving her hands free to work her chair. Of course, some mothers are car drivers but actually getting the child into the seat can take a lot of effort.

The importance of support from family, friends and fieldworkers, when they took their babies home, was stressed "The main thing is to get back up ...someone to give you a break".

The world in which a mother lives can prove to be a harder one in which to operate than that she may have experienced at work. Playgroups are often held in old church halls and schools might also present access problems for the mother in a wheelchair - though some have the foresight to overcome these obstacles, when Diane Brook started taking her son to nursery they had disabled toilet facilities installed specially for her.

The difficulties can be faced one at a time but highlight the need as one disabled mother pointed out to "be independent, and get yourself sorted out first, before you take on the responsibility of looking after someone else" as a parent.

Gill Winfield



*Ann Roberts on holiday with her son Andrew*

# Winning Streak in a Wheelchair

**Tanni Grey is a world-class athlete with a string of gold medals and record-breaking performances to her credit. She has spina bifida but it seems ridiculous to call her disabled when she has achieved things beyond the grasp of many able-bodied people.**

Paralysed from the waist down, Tanni, 21, competes in a wheelchair and as far as she is concerned it is no different than competing with a bicycle, a racket or a ball.

Top-level sports for the handicapped are as competitive and professional as their able-bodied counterparts. That is why this Cardiff-born sportswoman dislikes it when disabled sports people are patronised and their achievements are subtly belittled.

## SELF-RELIANCE

"Some people think we just do this for fun at weekends. I get annoyed at that because I train as hard as any able-bodied athlete. I'm not messing around," she says.

Tanni certainly was not messing around when she won the bronze medal in the 400-metre wheelchair event at the Seoul Paralympics.

This year has seen more big wins. She set a new British women's record of 2hrs 20min 25 secs in the marathon at the World Wheelchair Games in Stoke Mandeville. She won the bronze medal at the Commonwealth Games 800-metre wheelchair event and picked up two silvers and a bronze at the World Championships in Holland.

Now her energy will be concentrated on qualifying for the 1992 Barcelona Paralympics.

A strong streak of self-reliance has served her well. All her life she has steadfastly resisted attempts to treat her differently.

It could have happened all too easily. Tanni, whose real name is Carys, was born with an abnormal spine. She was so small her older sister Sian, who expected a playmate of her own size, said she was tiny - pronouncing it "tanni" and the name stuck.

Tanni lost the use of her legs when she was six. It would have been dangerously simple to slip into disabled dependency. But she and her family were determined that she lead a normal life.

Tanni, who lives in Heath, Cardiff, went to the same schools as her able-bodied friends. When, at comprehensive school, she was expected to attend PE lessons at a nearby school for the handicapped she did not like the idea. "I did not see why I had to do PE with people I didn't know." But the experience awoke in her a fervent interest in sport which was not thwarted even by a painful operation to insert a metal rod into her spine to stop it twisting. She had the operation

when she was 13 and 18 months later she was back on the track setting records.

Some people still hadn't got the message that Tanni was going to live the way she wanted. "Just after O-levels, a careers teacher said I should take a secretarial course. The idea was that I should look for a safe little job. I didn't want to do it."

When, 10 O-levels and 4 A-levels later, she decided to attend university, she opted for Loughborough, partly because of its sporting reputation and facilities and also because of its policy of integrating disabled students into university life.

Tanni, who is a third-year politics undergraduate, joins in academic and social life with the rest but her sports training is a lonely affair. Loughborough's athletics training is geared to the able-bodied and the university was not going to change it for the sake of one disabled athlete.

"I don't want help from them," says Tanni with typical pluck.

She devised her own training schedule which involves lots of weight training, "slog work" in the winter. In the summer Tanni improves her speed by taking her wheelchair to the road and racing alongside traffic.



She has a special racing wheelchair that cost £1,000 and weighs a mere 11 lbs. "When I go downhill I can reach 38-40 mph - but don't tell my parents!" she says.

She says matter-of-factly that she never dwells on what might have

been had she been blessed with a normal spine. "There is nothing I can do to change it. All I can do is accept it. Being in a wheelchair hasn't restricted me in any way. If anything I have played more sports than I might have. To be perfectly honest, I am happy the way I am."

Tanni worries that some disabled children are discouraged from achieving their full potential and that special schools "nanny" them. She hopes her example will give them something to aim for.

*Nicole Sochor.*

*This article was reproduced by courtesy of the Western Mail.*

## Come Dancing

*Heather Bosley invites you to join a dancing club for disabled people*

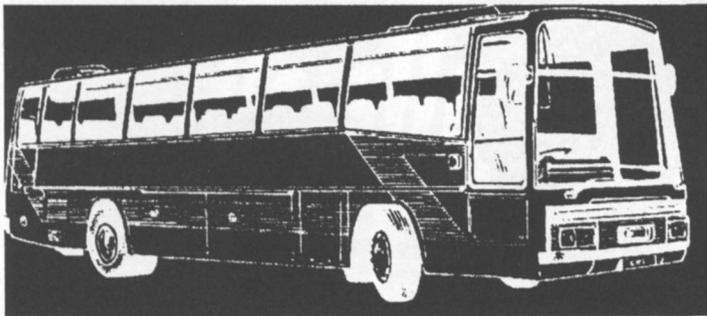
Of my many hobbies wheelchair dancing is the one I most enjoy. I started eight years ago meeting with a group of friends for one and half hours on a Tuesday afternoon. This year I qualified as a dance teacher at Hendon College. Over the past years our Tuesday group have become accomplished performers dancing at Finchley

Carnival, Covent Garden and many day centres. We are called 'The Spinning Wheels'.

Five years ago we formed a new club, 'The Happy-go-lucky Dancers' for those unable to join us on Tuesday afternoons. This Monday evening session consists of a warm-up, adagio (*slow piece*),

followed by a disco session. After a tea break we continue with anything from square dancing to the Can-Can.

The club is based at Woodhouse VI Form College, Woodhouse Road, Finchley from 7.30 to 9.30 p.m. Contact Heather on 081-958 7676 for further details.



## On the Buses

Coaches may be a cheap way to travel but do they offer the disabled traveller a convenient method of transport? If the answer is no then David Mortimer, Customer Service Manager for National Express Ltd., Western region, would like you to tell him why.

Mr Mortimer was once a teacher in the physical handicap unit of a comprehensive school and his background means he has a genuine interest in National Express's large number of disabled passengers. But he says you "seldom complain" and the real reason for the admitted lack of facilities for disabled travellers is that they "don't ask". As one of only four regional customer service managers, he is in a good position to pass on your comments and suggestions to his three colleagues. You can contact David Mortimer on 0272 724414 or write to him at National Express Ltd, Unit C, Central Trading Estate, 275-277 Bath Road, Arnos Vale, Bristol BS4 3EB.

### Mobility bus routes for NE London

Eleven new mobility bus routes are due to start in Ilford, Barking and Romford this month. The routes numbered 951 to 961 will be run by East London buses using single deck buses which will carry up to five wheelchairs as well as seating 22 other passengers. The services are designed to provide links between shopping centres, local hospitals and main housing areas.

And two new London Transport Saturday Mobility bus routes which are wheelchair accessible have been introduced in the same area. The 920 and 929 will link Leyton, Hackney, Ilford and Romford, and Walthamstow to the Isle of Dogs. These new services replace route 923.

### Greenwich For All

This leaflet, produced by the London borough of Greenwich, details access, transport, toilet and parking facilities for disabled visitors to the tourist attractions of Greenwich.

The Greenwich For All guide is available free from the Tourism Section 147 Powis Street, London SE18 6JL, tel: 081 854 0055.

## A Night with the Royal Ballet



If you've haven't been to the Royal Opera House before then here's a chance to go for as little as a £1.00 during a special week for people who have NEVER attended the Royal Opera House, sponsored by the Paul Hamlyn Foundation and the City of Westminster. There will be a week's performances from the 12 to 17 November by the Royal Ballet. Tickets range from £1.00 to £6.00 and priority will be given to applications from groups or organisations. At the time of going to press, tickets were still available for performances of *The Pagoda* on Monday and Tuesday and on Friday for *La Bayadere*. Further details from Camilla Whitworth-Jones at the Royal Opera House, Covent Garden, London WC2E 9DD, telephone 071-240-1200.

### Come to Sweden

IN OUR FEBRUARY issue we gave advance notice of the 1991 conference of the International Federation for Hydrocephalus and Spina Bifida (IFHSB) which will be held in Sweden in August next year.

The entire centre at Djuronaset in the beautiful archipelago near Stockholm will be taken over for a full week even though the conference only runs from Wednesday 14 August to the weekend. The organisers hope that by having the facilities available for a week people who are interested in coming to the conference will bring their family and make it a holiday. There will be many opportunities for sports and activities within the complex.

The programme for the conference includes sessions dealing with incontinence problems, physiological aspects of growing with disability, adults with Spina Bifida and the Arnold Chiari Syndrome.

Instead of a static exhibition in the conference hall there will be five separate activity units set up in five houses in the complex. They have been given titles of Fashion House, Hygiene House, Nutrition House, Education House and Sports and Leisure House. Parents and professionals in Sweden are working hard to ensure that each house contains many items of interest. So when you're thinking about where to go for your holidays next year give Sweden some thought and we'll bring you more details of the conference as we get them.

# A Life on the Ocean Waves...



...COULD BE YOURS - from a weekend round the Channel Islands to a fortnight sailing to the Canaries - if you take up the challenge of a voyage on the Tall Ship, Lord Nelson. The Jubilee Sailing Trust has berths for both disabled and able bodied 'sailors' and runs summer and winter sailing programmes.

It's not a trip for spectators, everyone takes an active part in running the ship but, says the Trust, "don't worry the duties are tailored to individual ability". To man the ship 24 hours a day the crew, which means everyone on

board, is divided into watches each led by an experienced crew member. The Lord Nelson is adapted to enable everyone to take part on an equal basis with facilities such as power-assisted steering and wide companionways.

Berths start from £125 for a weekend. Disabled voyagers can book with an able bodied 'buddy'.

If you would like to know more write to *The Jubilee Sailing Trust Limited, Test Road, Eastern Docks, Southampton SO1 1GG.*

## Benefits Rally

Up to 15,000 disabled people are expected to take part in a national rally organised by the Disability Benefits Consortium on 20 October, from 1pm to 4pm. The rally will be held in Trafalgar Square in London, Albert Square in Manchester and George Square in Glasgow. The aim of

the event is to make politicians and the public more aware of the needs of disabled people. The Consortium believes that the extra costs of disability should be met as of right and that the Government must put new money into benefits for disabled people.

*For further information phone the DBC on 071 739 0810.*

## Diary Dates

**7 - 9 November - PERCEPTION - A HIDDEN HANDICAP.** A course for teachers, therapists and those involved with children coping with learning difficulties, Castle Priory College, Wallingford, Oxon, £165 inc. accommodation, tel: 0491 37551.

**10 November - ASBAH HYDROCEPHALUS SUPPORT GROUP STUDY DAY.** Venue is the Willesborough Baptist Church, 262 Hythe Road, Asfhford Kent. 9.45 am, £4 parents, £10 professionals. Speakers include Mr Henry Marsh, consultant neurosurgeon. Details, Jane Williams, 0733 555988.

**19 November - RADAR** conference on 'Community Care and the Contract Culture' (The implications for disabled people and their organisations). Tel: 071-637 5400.

**7-9 December - WORKING WITH THE PRE-SCHOOL CHILD WITH SPECIAL NEEDS.** Castle Priory College, £169 limited accommodation for wheelchair users.

## Same Difference

This Channel 4 programme dealing with issues of concern to disabled people returns to our screens from mid October with new faces and a new time slot. The first edition on 16 October at 5.30 p.m. is repeated on 20 October at 9.30 a.m.

The series of 10 programmes promises to cover stories from the UK and around the world, on topics ranging from access to pubs and community care provisions, to disabled people in Nicaragua and what the European Community is doing for its citizens.

## Holiday House Exchange

Swap your home for a week or a fortnight. Under a new scheme set up for people who have adapted or specially designed homes. The scheme should allow disabled people to have an economic holiday with no access problems as both parties involved can ensure their requirements are met by their 'holiday home'.

Further details from *Diane Christopher, Choices Holiday Home Exchange, Woodstock, Red Road, Wootton, Isle of Wight PO33 4PW. Telephone 0983 79385.*

## Child's Play

A parent information day on play and leisure activities for children with special needs is being organised by the Newcomen Centre, Guys Hospital, London.

Talks cover sport, holidays, books and play for the special needs child.'

The fee will be £2.50 for the day on 16 January 1991. Please contact Janet Badcock on 071-955 4636 for further details and an application form.



## ADVERTISING

FOR THE USE OF LOCAL ASSOCIATIONS  
AND OTHER READERS

Rates: £3 for 30 words max; £4.24 for 30-45 words;  
£5.50 for 45-60 words.

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

Small adverts for the next issue of Link (December) should be submitted by Friday, 9 November. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

## HOLIDAY ACCOMMODATION

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

### CLACTON, ESSEX

Six-berth chalet, sleep six, club and swimming pool on site. 10-minute walk to village for shops and banks etc. Details Mrs Bashford 071-735 5489, leave message on answerphone.

### SELSEY, SUSSEX

Fully-equipped, six-berth mobile home. Ramp access, and designed for wheelchairs. Site near sea. Heated pool. Clubhouse. Details Mrs C Bugden, 27 The Grove, Sholing, Southampton SO2 9LT, tel 0703-444921.

### RED CROSS HOUSE, INVERNESS

Offers respite/care activity holidays throughout the year to disabled people over 16 years of age. A 24-hour facility is provided by skilled care staff and voluntary helpers. Accommodation is single, hotel-standard bedrooms. For details of

what we have to offer, please contact Mike Webster on Inverness (0463) 234939.

### BLUE ANCHOR, WEST SOMERSET

Views of sea, Exmoor, steam railway, close to beach. Privately situated terrace of four, fully accessible bungalows equipped to high standard. Colour television, video, laundry, games room. Linen, electricity included. For full details, tel Lorraine or Martyn Babb, Dunster (0643) 821200.

### WINTERTON-ON-SEA, GREAT YARMOUTH, NORFOLK

Chalet 6 Berth. Pleasant site with all amenities, pool, shop, and bar with live music. Play areas for the children, cycle hire, snack bar and take away food. Further details telephone Mr F Simmonds (0628) 783413.



### SUNNY TENERIFE OR SCENIC WALES

For 10 years families have taken holidays at our self-catering bungalow (sleeps 4/5) in Mold.

Now, as the UK Representative for the beautiful, fully accessible Mar Y Sol resort in Los Cristianos, Tenerife, I can arrange a holiday you won't forget!

*"Brilliant, amazing" says BBC TV's The Travel Show. You won't be disappointed.*

Brochures - Mold or Mar Y Sol, contact Lynne James, 7 Overpool Road, Ellesmere Port, South Wirral L66 1JW. (Tel: 051-339-5316).

## FOR SALE

**TWO BEDROOMED DETACHED BUNGALOW** with garage; adapted for wheelchair user. Ramp to front, wide doors. Flat location, ideal for town of Prestatyn. Friendly neighbourhood. Tel Prestatyn 857807 for details.

**THREE-BEDROOMED HOUSE** with garden, specially adapted for disabled. Low work surfaces, ramp to front door, stair lift, wide garage. Full gas central heating. Whole area around house ramped at kerbs. £67,500. Also **CARTER ELECTRIC WHEELCHAIR** with kerb climbers, recently serviced, new batteries - offers please. Tel 0273 693327, or write to Vanessa Hayward, 208 Wild Park Close, Brighton, East Sussex.

**SECONDHAND** Lightweight wheelchairs for sale. Tel 081 742 1620.

**CHILTERN SHOWER CUBICLE** complete with anti-scald device, curtains, pump. Can be used in almost any room. Ideal for the disabled or infirm and suitable for the able-bodied. Extremely good condition, £400 ono. Tel 0635 40480 or 48212 or fax 0635 40405.

**1989 POIRIER PE 42** Electric wheelchair with table tray. Gentle indoor use for approx 6 months. Excellent condition, £1,000 ono (new price £2,461). Contact Mr E Sansom, Head of Home, Greenhill House Cheshire Home, Timsbury, Bath BA3 1ES. Tel 0761 70533.

**PARKER CARE EASY CHAIR** - electronically operated adjustable foot and leg rests, back and seat of chair. Adjustable head rest, padded sides and casters on rear legs. Excellent condition, £650 (was £1,300 when new). Tel Mr A W Bartram, 0303 56589.

**BEC FIREBALL**, suit 6 to 10 year old. Four years old, hardly used. New batteries. Offers please. Tel 0582 461462.

**BEC ACTIVLITE WHEELCHAIR**, 16" red pushrims, anodised aluminium, platform flip-up foot rests, seat depth 16". Back rest height 9" - 17" straight angle, spokeguards, calf strap, seat belt. £350. Tel (work) 0923 244366 (home) 0442 49468 Diana Dicks.

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