

Link

The magazine for people with
Spina Bifida and/or Hydrocephalus

October/November 1995

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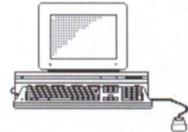
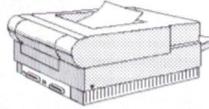
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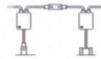
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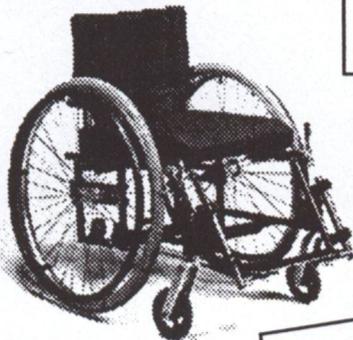
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Shambles greets Carers Act, says mum

A MOTHER, who has teenage twins with severe and moderate disabilities due to hydrocephalus and cerebral palsy, has described the local social services set-up greeting the new Carers Act as a shambles.

Social services has just withdrawn a paltry two hours a week help due to lack of money – even though the twin's mother has to be on call 24 hours a day at weekends and school holidays because both children have epileptic fits.

The support was only offered after a family doctor told social services that the mother, who prefers not to be named, needed help after a hysterectomy.

The mum, aged 45, said: "It sounds wonderful that carers are going to be assessed but, if no money is available, it's a complete waste of time.

"I've had an assessment and Social Services know what my needs are, but they haven't got the funding to help. This Act is purely political. It makes the Government look good but they can't put their money where their mouth is."

The demands of her 15-year-old twins are physical, mental and

emotional. Her son has uncontrolled epilepsy and fits every day; her daughter has irregular fits. They also have eye, orthopaedic, co-ordination and learning problems.

As he has grown older, the son's right leg has twisted. This has reduced him to crawling around the house, which is not adapted for a wheelchair, and hanging onto his mother when getting in and out of the car.

The mother, from Essex, said: "My needs haven't changed – in fact they're greater. I'm on 24-hour mental alert when the twins are at home and, even when they are at school, I could be called in.

"They have a lot of hospital appointments so they miss a lot of school. Having help two hours a week allowed me to take one to an appointment, leaving someone else to look after the other at home."

On doctor's advice, when treating her for depression, the mother has forced herself to get out of house and join a 'Ladies Morning' twice a week, but she finds this impossible to continue out of term time.

"When the twins were young, social services were bending over

backwards to help and I didn't really need help then.

"As they got older, when we were living in Brightlingsea and I had split up from my husband, a support worker would come every day to take the children out and accompany me to appointments.

"But as soon as we moved to Colchester – which we were told had better facilities for disabled people – my support worker was withdrawn.

"For a year I had no support at all but, after seeing my MP and becoming ill, social services gave me the two hours a week help from June 1994. Now they have informed me that they have got to prioritise cases and they haven't got the money to help me."

The family first received respite care from the local authority last year when the mother and her partner had their first holiday in eight years. Their annual respite care allowance is six weekends and two full weeks.

"Social services can't meet the needs of families now, so what's the point of this new law – unless you are able to take them to court if they fail to provide."

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Cover: Victoria Mason, who graces the covers of this LINK and ASBAH's Annual Report, is pretty as a picture!

ASBAH

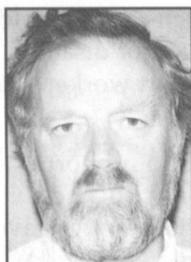
● STAFF

MOVES

● CONTINENCE adviser Mary White, who works from home in Derbyshire, has taken on a wider role in her field – in addition to her half-time work for ASBAH, covering the north of England.

Mary has set herself up as a consultant continence adviser, working with people affected by neuropathic bladder and bowel, regardless of the disabilities causing these conditions. Astra Tech are funding the training days with which she is involved.

“This means that funding need no longer be a problem with area health authorities and that special needs is getting the support it deserves. I am pleased to say that interest is high and my diary is filling up,” said Mary.



● ANOTHER education adviser has been appointed to help share Peter Walker’s increasing workload. The new adviser – Mike Dodd – is a former head teacher of two special schools for children with moderate learning difficulties.

He took early retirement more than two years ago and since that time has been a school inspector, independent trainer and school governor with responsibility for special education needs.

Mike, aged 56, was attracted to the ASBAH job because he says it is an opportunity to continue his belief that children with disabilities should be educated not coped with.

He added: “I think some local education authorities are abusing the education system by trying to define needs on a cash basis.

“I wanted to give children the education they deserve. To me it’s a human rights issue – giving children the equal right to take a full part in society. It only becomes an education issue when we are talking about providing those needs.”

He will work part-time at ASBAH Northern Region Office at Five Oaks, Ilkley from 16 October, covering the whole of the north of England.

As well as taking an active interest in education, over the last 10 years he has felt a great pull towards the Church. He is taking an ordination course through the Open University and is due to become ordained in the Church of England next summer.

He said: “For a long time, I avoided the Church like the plague because my identical twin brother was ordained 30 years ago.

“I particularly got involved when the women priests debate was going on as I felt strongly that there should be equal opportunities within the Church.”

● GWENT and Glamorgan now have full fieldwork cover after Margaret Stanton increased her working hours from 11 September. Margaret had previously covered the east of this area part-time.

The full-time post follows the death of Tom Davies, ASBAH’s longest serving fieldworker, which was reported in the last issue of Link.

Margaret’s ASBAH phone number is 01222-611244.

● MERSEYSIDE and South Lancashire have a full-time fieldworker from 1 September. Angela Lansley, who previously worked part-time as over-16s fieldworker for Merseyside, now increases her hours to full-time.

The change follows the departure of Val Cushing who left ASBAH as part-time under-16s fieldworker for Merseyside. Angela’s ASBAH number is 0151-733 8392.

● A NEW fieldworker has started in London following the move by Ann Wild to the post of mobility adviser.

Gill Yaz, aged 34 from Tottenham, is working part-time, covering north, north-east and east London.

Previously a school nurse at a school for children with physical disabilities in Finsbury Park, Gill is married with two children.

Gill started in September and will be based at South East Region office.

● NORTH Yorkshire and Cleveland fieldworker, Geraldine Potuszynskyj, has gained a BA Hons degree in psychology and media studies.

Geraldine, aged 33, was awarded a II (ii) after four years full-time study at Trinity & All Saints College – part of the University of Leeds. She said: “I did the course for personal interest and satisfaction and because I needed a new focus in my life.”

Geraldine fitted in the degree with being a single mum and working one night a week as a nurse. “You don’t need to be a super-mum to do a degree, all you need is motivation and commitment,” she said.

● JACKIE Dennison, secretary for Northern Region, left ASBAH at the end of August after five months in the full-time post.

She has become a school secretary in Otley which gives her time off in all the school holidays.

Northern Region co-ordinator, Joan Pheasant, said: “Jackie was a very valuable member of the team and we will miss her.”

Obituary: Bernard Williams MD ChM FRCS 1932-1995



BERNARD Williams was a man of vision, who pursued his beliefs in the face of considerable initial opposition. Mention his name to anyone in the

field now, and immediately his research into syringomyelia, and care and treatment of patients is acknowledged with awe and admiration.

Some 30 years ago this was not always so, but his conviction, dedication and tenacity enabled him to withstand the dismissive attitude of some of his colleagues and advance the knowledge of syringomyelia including its association with spina bifida.

He was an active member of The Society for Research into Hydrocephalus and Spina Bifida since 1969, and in that very special interdisciplinary forum his contributions to the debate – always pertinent, honest, full of humour but when necessary salutary – were admired and appreciated.

His long association with ASBAH flourished after a probationary period during which he assessed the professionalism of services

BERNARD Williams, senior consultant neurosurgeon and an ASBAH Medical Advisory Committee member for many years, has died after being involved in a motorcycle accident.

Mr Williams, aged 63, was based at the Midland Centre for Neurosurgery and Neurology in Warley, Birmingham.

For many years he ran the only known clinic in the world for patients with syringomyelia – the presence of longitudinal

cysts within the spinal cord which can be associated with spina bifida.

Mr Williams had been doing research on syringomyelia for 25 years and gave lectures all over the world.

All of his work was funded by Ann's Neurological Trust Society, a self-help and fund-raising group named after a former patient, Ann Conroy.

Mr Williams died on 9 August – 12 days after another vehicle collided with his motorcycle.

by Moyna P Gilbertson OBE MCSP

offered, and for many years, particularly as a member of ASBAH's Medical Advisory Committee, his advice and support to staff and families were invaluable.

At the Bristol meeting of The Society for Research into Hydrocephalus and Spina Bifida in July this year he said how much he would like to devote the rest of his life to his work on syringomyelia. He was due to present a paper on this, his absorbing interest, to The Society of British Neurosurgery meeting in Dublin in September. His untimely death has intervened, but we must hope that

his work will be continued.

The affection and respect in which Bernard was held was clearly demonstrated at his moving funeral service which was held at Edgbaston Old Church. His family was joined by more than 400 friends and colleagues, and formal tributes were led by Michael, one of his six children. The presence of many of his patients among his friends at the service and their informal tributes to him perhaps said more about his qualities than could anything else.

We were privileged to know him; he is sadly missed but will not be forgotten. Our thoughts are with his family.

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ASBAH families hit by cuts in social services



CONCERN has been raised by an ASBAH fieldworker that social workers are being withdrawn from hospitals as part of a round of budget cuts in her county.

The result, says Lynne Young in Cornwall, will be that ASBAH families without a social worker

will lose out at often their time of greatest need – when their child is in hospital and they need counselling or help with transport or accommodation.

Cornwall Social Services is aiming to make budget cuts totalling £3 million.

Lynne said: "Social services is saying that social workers will follow families into hospital but what about those who don't have a social worker?"

"If someone wants a social worker they will probably be sent a case co-ordinator, who is not trained to find out what the underlying problem is."

She added: "I can see what's going to happen – social services will allocate case co-ordinators to families who will have to go on the waiting list for a social worker, and meanwhile their problem is going to get worse rather than better."

Hospital social workers are not the only area being cut by social services which will affect disabled people in Cornwall.

- A part-time post dealing with families with disabled children under five at Cornwall Counselling and Assessment Unit for Children at City Hospital in Truro is also being axed. Lynne said: "The outlook for families who do not have the support of a fieldworker is very bleak."

- A respite care unit in Redruth which accommodates up to 40 children with severe learning difficulties – including those with severe hydrocephalus – is also to be closed. Its annual budget is £279,000.

- A rehabilitation hostel, which accommodates 85 adults with a physical disability at St Austell, is under threat of closure. Those living there have not been offered anywhere else to go. Its annual budget amounts to £267,000.

Lynne said: "The closure of this hostel means that adolescents aren't going to get the independence and personal care training they need. There is only one other residential unit in Cornwall but it is unsuitable for wheelchair users. Instead severely disabled children are being integrated into mainstream school, which has lots of advantages but there is a lack of facilities and experience to assist with their social development."

She added: "The outlook is really bleak for the adults living at the hostel who can't live independently, unless a group home can be opened for them."

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John Williams
ASBAH, 42 Park Road
Peterborough PE1 2UQ
Tel 01733- 555988

Film festival entry

A VIDEO on one man's struggle to overcome problems of incontinence and mobility, written by ASBAH disabled living adviser Mary White, could be in line for a European award.

Peter's Story: The Costs of Incontinence was shown in the medico-social category of the Italian Film Festival on 9-14 October.

Early reviews of the 13-minute video – which cost £4,500 to make and was sponsored by the Johnson Foundation and Gulbenkian Foundation – proved so positive that Mary was persuaded to enter.

Mary said: "It is essentially a training video and I was surprised at its success."

Copies have been sent to Holland, Germany, New Zealand, Australia, USA, Italy and Malta.

Mary said: "The important thing is not to win the festival awards but to raise the level of awareness and encourage education, health and social services to work together as a team because the problems can't be sorted out in isolation."

Folic acid plan rolls forward

PLANS have been announced for the Government's £2.3 million public education campaign to increase the average intake of folic acid in women who may become pregnant, and so help reduce the incidence of neural tube defects.

This follows an admission by health minister Baroness Cumberlege that awareness of advice on folic acid is still too low.

The planned three-year campaign, conducted by the Health Education Authority, aims to increase intake of folic acid by at least 400 micrograms before and during the first 12 weeks of pregnancy. Such an increase would be up to 75% effective in preventing neural tube defects – according to a Department of Health review of research in 1992.

Baroness Cumberlege said: "... it has become clear that awareness of ... this advice is still not high enough. That is why we think it necessary to undertake a new campaign, to get this simple but vital message across."

The campaign will target women

of child-bearing age and their partners (and younger women as part of their general health education). But first there will be an attempt to re-educate GPs, practice nurses and other health professionals.

Folic acid is a B vitamin, found naturally (in a form known as folate) in many foods, especially spinach, Brussels sprouts and other green, leafy vegetables. Some breakfast cereals and breads are fortified with folic acid. It is unlikely that most women would be able to obtain an additional 400 micrograms per day from these natural sources and for this reason a supplement is recommended for those women trying to conceive.

Neural tube defects (NTDs) affect about 1,000 pregnancies in England and Wales every year, most of which result in termination or still birth. They occur when the brain or spinal cord fail to develop properly – about four weeks after conception. NTDs include anencephaly, encephalocele and spina bifida.

2,215 votes not enough to win snooker cash

ASBAH failed to secure enough votes to win a share of the thousands of pounds earmarked for charities in the *Liverpool Victoria Charity Challenge* pro-snooker tournament.

Out of a total of 64 charities gathered in groups of eight, two had to be selected from each group by readers of the *Daily Star* in August in order to benefit from the cash.

In its group, ASBAH received a creditable 2,215 votes – less than group winners National Asthma Campaign (5,541 votes) and The Prince of Wales Hospice (4,489).

Senior appeals manager John Williams said: "Many thanks to everyone who voted for us. ASBAH didn't make it into the tournament but we will be invited to apply for the next tournament, to be held in January 1997 – another chance to raise funds for ASBAH."

Help & Advice

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

London, Surrey, Kent, West and East Sussex

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

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

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

Northern Ireland

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

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

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

Rest of England and Wales

ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ.
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Poor balance? Can't ride a bike? Help may be at hand!

**Product review
by Elin Richards
Gwynedd Fieldworker**

MANY parents of disabled children will identify with David Good as he watched his young sons learning to ride their two-wheeler bikes. How could he help Jeremy ride a bike like his brother Simon?

David and his wife couldn't even comfort Jeremy by saying: "Never mind, Simon's older than you," because he wasn't – they were identical twins. The difference was that Jeremy had hemiplegic cerebral palsy, which affected his balance, and Simon did not.

Many children with hydrocephalus have poor balance, and may have failed in their attempts to ride a two-wheeler, so take heart from this story.

David Good – Jeremy and Simon's father – happened to be an experienced chartered engineer, and as he watched Jeremy struggling to get his balance on his two-wheeler, his mind was ticking away trying to find a solution. Eventually, he designed special stabilisers which allowed the stabiliser wheels attached to an ordinary bike to be adjusted in by small amounts closer to the rear wheel of the bicycle as balance improved.

With the security of knowing that the bike would remain stable, Jeremy was able to concentrate on just going forwards and slowly, over the next few months as he practised, his balance on the bike improved, and as it did, the stabiliser wheels were brought in closer to the rear wheel of the bike. On a bike, Jeremy could keep up with his brother, and play with his friends on an equal basis. Jeremy's success led to other children with disabilities having a go – they, too, successfully learned to ride a two-

Parents with disabilities course

By John Williams, Senior Appeals Manager

I ATTENDED ASBAH's Parents With Disabilities course in July at Hereward College, Coventry. It was the third course I had been to and 'full participation' was required!

For my first task I was directed to the creche to assist my colleagues to look after very agile children and mobile babies. All the events were captured on film and I was amazed at the pace of events!

During the next session the course divided up between swimming outside the college and aromatherapy.

I attended aromatherapy and during the lecture the burner, used to heat the oil and deliver a pleasant fragrance, became engulfed in flames.

I had to move very quickly and eventually located a fire extinguisher not suitable for oil fires.

However, outside the lecture room there was a metal waste paper bin, the contents of which were removed,

and the fire was finally suppressed when the bin was inverted over the flames.

I did some baby sitting in the evening and had a request from a mother to assist in changing a nappy. The baby was very lively and I was very pleased when South East Region co-ordinator, Gina Broughton, appeared and relieved me of the responsibility.

I enjoyed the weekend very much, participating in various activities with the families.

These courses have given me a far better understanding of disability and, equally important, the positive aspect and determination to succeed.



I am grateful to the course organisers, Northern Region co-ordinator, Joan Pheasant and occupational therapist, Rose Hinchliffe for providing an interesting and very well run course!

wheeler. At this point, Jeremy's physiotherapist suggested a production run – David had hit on a brilliant idea, not just applicable to disabled children! With the help of a Welsh Office Innovation Grant, David Good was able to design, test and produce a less expensive adjustable bicycle stabiliser called Adjustabilisers.

Mr Good visited me to demonstrate the product. I am not a very technical person but I readily grasped that the Adjustabilisers were very easy to put on a bike, take off again and that they fit nearly all 12" to 20" diameter wheeled bicycles.

I hope this article will encourage children and young people, who have tried and failed to ride a bike because of poor balance, to try again!

Adjustabilisers may be purchased from: **GOOD DESIGNS, 60 Gwel Eryri, Llandegfan, Menai Bridge, Gwynedd, LL59 5RD.** Cheques made out to GOOD DESIGNS for £18.75. Larger adjustable stabilisers are available for those needing bicycles with over 20" diameter wheels for £68.70. Both prices include p&p. Leaflets/order forms available on request. Sets despatched within eight days of receipt of order.

SPECIAL Educational Needs Tribunals were set up a year ago for when there is a break-down in communication between parents and a local education authority (LEA), or both parties refuse to budge.

This communication break-down revolves around whether or not a child receives a statement – a six part legal document which details a child's educational and non-educational needs and spells out how the LEA proposes to meet those needs.

ASBAH's education adviser Peter Walker (*pictured below*) said: "It is important for parents, pupils, teachers, schools and LEAs to have a clear picture of a child's educational difficulties so they can be adequately addressed with the necessary appropriate resources.



"It is important for children, particularly with hydrocephalus, to have a statement – the earlier the better – as often the specific learning difficulties of children with hydrocephalus are not readily understood. Often they are labelled as being inattentive, lazy and forgetful!"

The normal route for statementing is via the school-staged procedure as outlined in the Code of Practice, but parents have a right under Section 173 of the 1993 Education Act to ask the LEA directly for a statutory assessment to determine their child's special education needs.

If the LEA agrees to assess, this may lead either to a statement or a "note-in-lieu". The Code of Practice sets down time limits for the various aspects of the statementing process but a final statement should be forthcoming after 26 weeks.

Making the most of education tribunals

Some LEAs are reluctant to make statements if they feel that a child's special education needs can be met by the school's own resources, which are often delegated through Local Management of Schools budgets.

In many cases the production of a statement can command additional resources from the LEA's central funds.

ASBAH's educational adviser Peter Walker has been involved with Special Educational Needs Tribunals since their inception, both as adviser/representative and adjudicator.

He has given advice to and represented families at tribunal (*example below, Marie Preston*).

He has also represented families who were going to tribunal but, because the LEA changed its mind and reinstated a statement, the families withdrew the appeal.

Other ways in which Peter has

been involved include:

- Giving advice on the telephone.
- Going through a draft statement to determine its imperfections or omissions.
- Visiting schools to assess which he considers suitable for an individual child.
- Attending review meetings.
- Negotiating on behalf of parents with particular LEAs which may not fully understand the difficulties of a particular child.

For many parents it has been useful to appeal to the tribunal system in cases where LEAs have:

- Refused to make a statement.
- Have made what parents consider to be an inadequate statement in terms of the authority not specifically describing either the needs or the provision of their

continued on page 10

Marie Preston

A SPECIAL Educational Needs Tribunal ruled in favour of five-year-old Marie Preston having a statutory multi-disciplinary needs assessment.

Marie, from Solihull, has spina bifida with severe continence problems. Her parents and ASBAH fieldworker say she needs a full-time classroom assistant to change her pads, nappies and clothing.

Before the tribunal hearing, the local education authority (LEA) had refused to assess Marie, saying her need for help with incontinence was a health not an education matter.

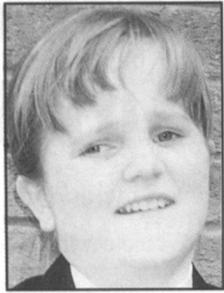
Eventually, the health authority



did offer classroom two-hours-a-day help but the Prestons were not satisfied with this and went ahead with going to tribunal.

The tribunal said it was disturbed by the LEA's failure to respond to the request for an assessment within six weeks and did not believe a discussion between the LEA and the health authority on funding for Marie's provision justified the delay.

continued on page 10



Katie Henderson

ONE case which nearly went to tribunal concerned 12-year-old Katie Henderson, who has hydrocephalus and cerebral palsy with trunkal ataxia.

Her parents, with help from ASBAH education adviser Peter Walker, had to push hard for the school they thought could best cater for Katie's needs.

Mother, Marjorie Henderson, explained: "You've got to fight for what you want. At first, our local education authority said Katie's needs could be met at one of their schools, but we felt strongly that this was not the case. We had to fight to send her to Featherstone High School, which is 10 miles away in Wakefield."

Katie, from Barnsley, South Yorkshire, has learning and mobility difficulties. Her parents and Peter Walker toured the secondary schools in the Barnsley Local Education (LEA) area and found none were suitable. They also visited schools outside the LEA area in Sheffield, Rotherham and Pontefract.

In order to convince Barnsley LEA that she must travel to a school out of their patch, Katie's parents – with Peter's help – asked for a revised assessment. They finally paid for an assessment by an independent psychologist.

Peter said: "After this independent assessment, the LEA agreed to send Katie to Featherstone High School. But, if it hadn't, Mr and Mrs Henderson were prepared to go to tribunal."

Marie Preston, from page 9

Moreover, the tribunal ruled that Marie's problem was educational and that an assessment should go ahead.

Its report stated: "In our view Marie does have a learning difficulty as defined in Section 156, paragraph 2 of the Education Act 1993, in that she has a disability which prevents or hinders her from making use of education facilities of a kind generally provided for children of her age and is likely to have continual difficulties throughout her school career and it is therefore necessary for the LEA to make an assessment of Marie's needs."

After the tribunal, David Pearson, education officer (special needs) with Solihull LEA, was still adamant that the help already offered was enough. He said: "Provision by the health authority of two hours a day non-teaching staff is in place and is adequate. An assessment isn't likely to increase that provision

Tribunals, from page 9

child in the statement or not having a suitable school, etc.

Almost 30% of appeals were against refusal to make a statement; 20% against refusal to assess; 25% against contents of statement; 1% against refusal to reassess; 1% against refusal to change name of school; 5% against decision to cease to maintain a statement; 18% against school named in a statement and 1% against failure to name a school in a statement.

However, although the tribunal system may appear to be the panacea for all problems relating to special needs, it is important for parents and local authorities to try and reach a consensus decision before entering into a confrontational situation which could be costly for both parties in terms of time and finance.

but will cost the LEA between £5,000-£7,000."

But ASBAH fieldworker for Birmingham, Geraldine Long, pointed out: "Without help with her severe continence problems, Marie can't receive an education. Her nappies and pads need changing regularly, at unspecified times of the day.

"We are delighted that Marie's problem has turned out to be a special educational need."

Marie's father, Keith Preston, added: "Marie's is a test case. We are doing it for her and for all the other children like her who are coming up to school."

Since the hearing, the LEA has done an assessment of Marie but the outcome was not due to be known until October. From this the LEA will then decide whether to go on and do a statement.

In the meantime, Marie's parents were hoping for a home teacher to help their daughter try and catch up with the year's education she has lost.

Peter said: "I feel that on many occasions parents have either not been appropriately advised or entered into a meaningful dialogue or negotiation with a representative of the local education authority. It is a pity that there is no form of arbitration available before a case is referred to a tribunal."

Going to tribunal does not always guarantee a successful result. Out of the 222 appeals heard so far, 121 decisions have been reached – 60% fully or partly in the parents' favour.

■ *Peter Walker and his colleagues are always available to advise and assist with educational problems.*
Contact ASBAH national centre, tel: 01733-555988, or ASBAH (Northern Ireland), tel: 01265-51522.

Glaxo Neurological Centre

MERSEYSIDERS are being asked what they want from the Glaxo Centre by ASBAH fieldworker Angela Lansley. The call has been made in a bid to try and make better use of a building in the city dedicated to the needs of people with neurological problems.

The Glaxo Centre opened two years ago after Liverpool won a bid for £1 million from Glaxo International to develop a project which was innovative and complemented what was offered by the NHS.

Liverpool's winning bid sought to bring together a range of local groups concerned with neurological disorders.

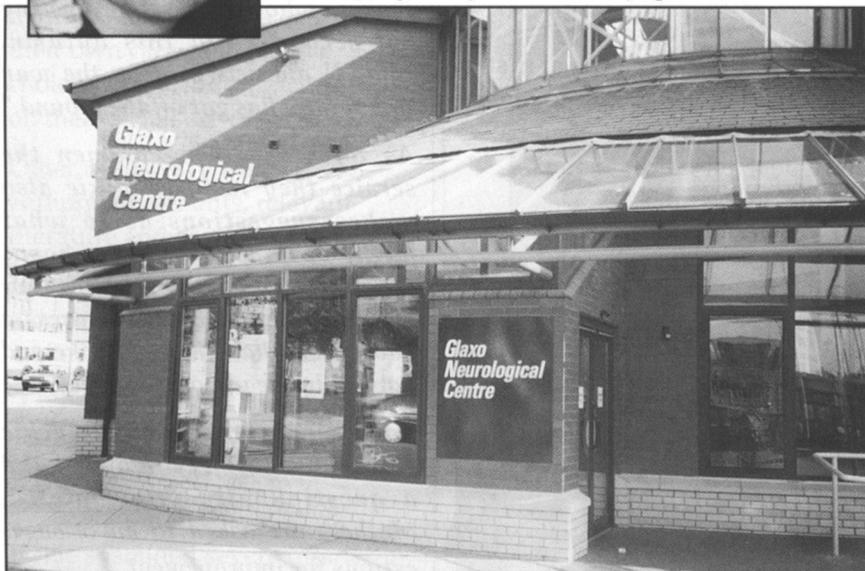
Centre manager Maureen Kelly explained: "The idea was to gather voluntary organisations under one roof so people can find them more easily and GPs can refer to one place. Networks are being built up for even very rare neurological diseases."

Several hundred people a month use the Norton Street centre and charities dealing with epilepsy, motor neurone disease, Alzheimer's Disease and multiple sclerosis have a permanent base there. Another 10 groups are available at the centre on a regular basis.

Angela Lansley (pictured below) says ideas are needed on how to



New pregnancy service, see pages 12 and 13



make best use of the centre's meeting, exhibition and reference library facilities.

Angela said: "I'd like to hear from anyone in my patch who has ideas on what the Glaxo Centre could do for them or who are interested in attending any sort of group or coffee morning there."

Angela can be contacted on 0151-733 8392.

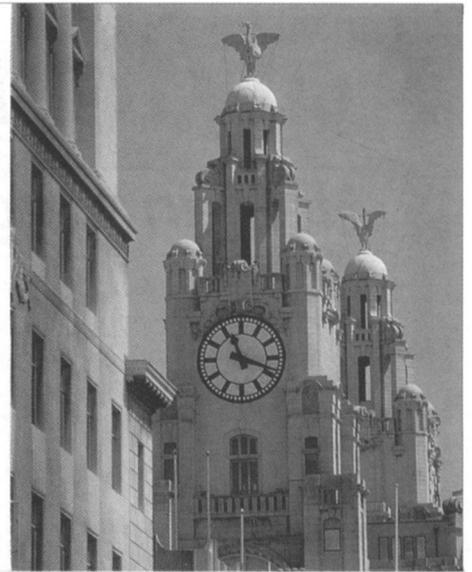
The Glaxo Centre is open Monday to Friday from 10am-4pm. It is fully accessible and there are rooms to meet both formally and informally, a snack bar, and six disabled toilets.

A city transformed!

After years of bad press, Liverpool is getting its act together. The famous Liver Birds now preside over a city unashamed to flaunt its vibrant architecture, development schemes and pavement life.

There's a buzz in the air which benefits disabled people too. LIZ CAWTHORNE spent a day there, catching up on just two good reasons for calling Liverpool your home. The Scouser is proud again!

Photo of Liver Building by Will Curwen for Liverpool City Council



A city transformed!

Help in pregnancy

LIVERPUDLIAN Michelle Rowlands, who has spina bifida, found everyone "dead helpful" at Liverpool Women's Hospital in the way she was treated during ante-natal care and childbirth. She continues to receive regular phone calls to find out how she is getting on at home from the hospital's special needs adviser Jackie Rotheram.

Michelle, a 25-year-old wheelchair user, gave birth to Jake on 10 July 1995 and had a normal delivery.

Her bed was height-adjustable and her partner could stay too.

She arrived on a Sunday night and stayed in until the following Wednesday.

Michelle said: "I was induced two weeks early and was in labour for three hours. Jackie had written my care plans four weeks before the baby was due and attached them to my records."

Her first contact with Jackie came after an ante-natal session at the hospital. After giving information about her special needs by filling out a form, Jackie got in touch.

Michelle said: "She phoned and came to the house right at the beginning - when I was about 12 weeks pregnant. She gave me books and information.

"My ante-natal care was given at home so I didn't have to go to the ante-natal clinic. I only went into the hospital for scans. Jackie would meet me there and make sure I had a parking space.

"I had a scan every month because I had a still born baby three years ago."

As well as information and advice, Jackie was able to help with practical things such as suggesting a height adjustable cot and discussing how best to bath the baby from a wheelchair.

Jackie and Michelle approached a local



manufacturer with design ideas on how a cot could be made which was the right height for a wheelchair user and could be opened by side gates.

The manufacturer offered them a specially-made cot at the same price as an existing model (see photograph below). A height-adjustable cot is also being designed by another manufacturer for use in the hospital.

Michelle said: "I found everybody dead helpful. Jackie still comes round and is bringing another girl in a similar situation to meet me so we can compare notes.

"I was a bit apprehensive at first but Jackie was really helpful. Being a disabled mother herself and a midwife, I felt I didn't have to explain all the time."



A REAL problem facing disabled women in pregnancy is that they have few role models. This is because there are precious few photographs of, or articles on, pregnant women or mothers in wheelchairs.

Jackie Rotheram, special needs adviser at Liverpool Women's Hospital, says disabled women want to be treated like everyone else but, on the other hand, they do not want their special need overlooked.

She said: "There is a need to raise awareness among health professionals that women in wheelchairs want to be mothers and pursue the role of motherhood.

"This raising of awareness is ever on-going in order to remove barriers, initiating more positive responses. Information and literature should therefore include more images of disabled women having children."

At Liverpool Women's Hospital (once Oxford Street Maternity), 23 women with varying disabilities have been helped by the service.

Two women with spina bifida were among those 23. Other types of disability have ranged from cerebral palsy, multiple sclerosis, rheumatoid arthritis, blindness, partial sight, deaf without speech, learning difficulties, stroke injuries and meningitis.

Jackie, who is herself expecting her second child this autumn, said: "I am delighted by the way this service has got off the ground."

As well as giving women the service they require, Jackie also makes suggestions as to what might be practical in the home, once the baby has been born. For example, how to bath and dress a baby if you have had a stroke and have only the use of one hand!

To evaluate the service, Jackie interviews all the women and a questionnaire is completed. Mothers are asked to make suggestions for improvement.

A new hospital service for women with disabilities

HOSPITALS throughout Britain could learn a thing or two from the new Liverpool Women's Hospital (pictured right) which gives a tailor-made service to women who are disabled.

This approach is best illustrated by the care given to pregnant women from the first ante-natal appointment to childbirth and the post-natal period.

All women are sent an information sheet requesting, among other things, any special needs that they may have. Once this information is to hand, any referrals are made to special needs adviser, Jackie Rotheram (pictured below).

Women can choose whether or not they see Jackie, who offers to visit them in their homes, explaining what the hospital offers in relation to their special needs.

Jackie said: "The majority of women say they want the extra support offered."

The type of support pregnant women who are disabled want varies according to their disability.

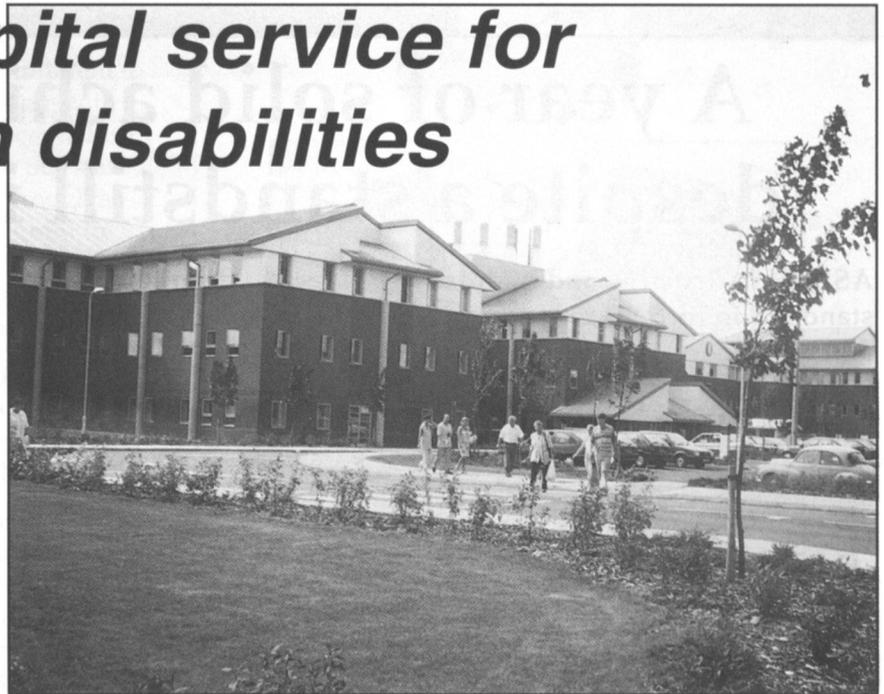
However, continuity of care; a named midwife; being central to their own care; able to have choices; and an advocate to speak on their behalf are often requested.

Other needs vary from type of equipment, benefits, relevant literature and so on.

Jackie's experience as a disabled woman, a midwife and a mother make her credible for this specialised role.

She said: "I have quite a unique experience, which would not be easy to emulate elsewhere."

Jackie sustained severe injuries in



a car crash in 1982. She now has stroke injuries, down her left side and all its underlying problems.

Because of her own experience she is sensitive to disabled people's needs and is keen to communicate these needs to other hospital staff, including doctors.

Jackie said: "I liaise and link with other professionals and clients. I perform needs assessments and aim to fulfil those needs. I am also here to inform people about those needs."



She was a member of a disability working group which put forward ideas to the hospital's architects at design stage.

As a result, the hospital, which opened in March 1995, has:

- ❑ Disabled car parking spaces at every entrance; a low level reception desk; tactile floors for blind people; and lifts which can be operated from a wheelchair.
- ❑ There is also a pictorial signing system to help people with poor English find their way around the hospital.
- ❑ In the maternity unit some of the rooms are larger, making them suitable for wheelchair users and there are wheel-in shower areas.
- ❑ All doors are large enough for wheelchair access and the disabled toilets have low seating and handrails.
- ❑ Women who have normal deliveries go to the residential wing of the hospital. All rooms are private.
- ❑ Those who have any complications stay on the maternity ward; some of these are in private rooms also.

A city transformed!

A year of solid achievement, despite a standstill in income

ASBAH is changing and improving its services despite a standstill in income, executive director Andrew Russell told the annual meeting in Peterborough on 16 September.

The closure last August of Five Oaks which, although a centre of good practice, had for so long been a major drain on income, had allowed us to set up the START assessment service, and given us breathing space to improve services and launch two new regions.

He said ASBAH was developing new sources of income. Much depended for the future on the success of our subsidiary company, Computer Sense.

The Five Oaks property had been on the market for almost a year. Interest has been sporadic but ASBAH hopes for a sale next year. Plans had been completed to separate Denton View and Wharfedale from the main house by providing new access. Bradford Social Services will run Wharfedale and Denton View as eight flats for disabled tenants.

Appeals had been revamped to produce an efficient and effective department working in the fiercely competitive market against competition not only from traditional charities, but increasingly from state services such as schools and NHS Trusts.

"The effect of the National Lottery in blotting up the spare pound or two in the pockets of almost everyone remains to be seen. ASBAH will bid vigorously in every round of the Lottery, and we are awaiting the result of our first bid to the Lotteries Board," said Mr Russell.

"The biggest single contributor to ASBAH's funds continues to be telesales. I pay tribute to their dogged and determined progress, day-by-day, month-by-month in providing the lifeblood of income that ASBAH depends on."

The launch of START at the House of Commons earlier this year had been followed up by a stream of inquiries about detailed assessments and requests from social workers. "Several reports say that Community Care is failing. START is part of our strategy to ensure that it doesn't fail spina bifida and hydrocephalus."

The new service had also been chosen as the UK entry in the latest European Union HELIOS competition for functional rehabilitation schemes, and we were awaiting the results of the judging, said Mr Russell.

In the field of prevention, ASBAH had persuaded the Department of Health to fund an information campaign about folic acid with a £2.3m campaign. We are now working closely with the Health Education Authority to implement the campaign and make sure that its message is clear and forcefully put.

The prevalence of spina bifida in pregnancy had come down from 24 per 10,000 in 1980 to eight per 10,000 in 1990, including live and stillbirths and terminations. But there were still about 1,000 pregnancies affected by neural tube defects in the UK each year, most of which could be avoided through widespread folic acid consumption.

ASBAH was also working with the

Wolfson Institute of Preventive Medicine to encourage voluntary programmes of fortification of basic foods with folic acid - fortification being the key to



We wish bo... v

DIPLOMAT, ideal chairman, a restless visitor, these are some of the qualities which ASBAH bid farewell to when Patrick Daunt retired as chairman at our annual meeting.

A former community school headmaster and member of the European Union's Bureau for Action in Favour of Disabled People, he had worked for many months ago to start casting round for his successor. He had never intended to be chairman for more than five years; he would stay a bit longer if he had to, but . . .

After executive committee member Peter Grounell had presented him with three boxes from his 'want list,' Mr Daunt revealed that he would have more time to do more for disabled people in one

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ng higher folic acid levels of
od of women who do not
eir pregnancies.

civil rights of disabled
Mr Russell said he
ed in touch with MPs who
try to improve the
ment's package of anti-
ination measures when
turned to the Commons
e summer recess.



He said ASBAH's commitment to the involvement of people with spina bifida and hydrocephalus in our committees and on our staff had been recognised through a Department of Health grant to 'Your Voice in ASBAH', to help it develop its influence and presence in the regions over three years.

"This is especially significant, since all charities will tell you how difficult it is to get Department of Health grant money these days."

ASBAH's regional teams were developing well and a determined bid is being made, through a Welsh discussion forum, to enable ASBAH to make its presence felt by the Welsh Office, the new local authorities and other organisations.

Mr Russell paid tribute to the contribution made to our medical advisory committee over many years by the late Bernard Williams, the Midland neurosurgeon and world expert on syringomyelia cysts in the spine, who died in August.

Pictured: Patrick Daunt (right) greets his successor Godfrey Bowles as the new ASBAH chairman.

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Katrina
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emerging democracies of eastern Europe.

He will be revisiting Romania, where he has been working as a consultant advising the country's voluntary sector.

"Voluntary organisations were not allowed to exist under the old regime. Nowadays they exist in a way very familiar to us.

"If you can get the government to do what you want, so much the better and if you can't – well the hell with it, you have got to do it yourself!"

World famous conductor and ASBAH president Jeffrey Tate, who travelled from Paris specially to be with us, said: "Patrick Daunt's leadership has illuminated us for five years."



Our new chairman

GODFREY BOWLES, former chief executive and chairman of Pearl Assurance, has succeeded Patrick Daunt as the chairman of ASBAH.

Born and brought up in Swindon, Wiltshire, Mr Bowles undertook two years National Service and studied for three years at Oxford before emigrating to Australia, where he became a highly respected figure in the insurance industry.

Mr Bowles spent 30 years 'down under' – including three in New Zealand – before he was brought back to Britain by his company Australian Mutual Provident Society to run the Peterborough-based Pearl Group as its managing director after its acquisition by AMP in December 1989.

Mr Bowles, who celebrates his 60th birthday this October, retired from full-time employment at the end of last year.

"I was in the position of reorganising my life round a number of new part-time activities when somebody recognised that I was around when ASBAH's chairman was about to retire," said Mr Bowles.

"The timing was fortuitous. I was very anxious to make at least one significant contribution in to the voluntary sector. ASBAH, being Peterborough-based and a major activity for a large number of people, fitted the bill."

Although Mr Bowles has also recently become

Continued on page 16

ASBAH AGM 1995

Empowering a reality

TERRY Denyer recognised the need for diversity of approach when he spoke about the work of the *Your Voice in ASBAH* users' forum – in that it was not the only route by which people with spina bifida and hydrocephalus could aspire to positions of influence within the organisation.

But YVIA was a useful structured approach which, through its slowly developing regional activity, aimed to encourage people with spina bifida and hydrocephalus to become involved with ASBAH, both nationally and locally, said Mr Denyer, who has chaired the group for a year.

Regional meetings had been held in the Manchester area and in Leicester, and one was due in Yorkshire. The work was slow and painstaking "for almost as many reasons as there are people," but it had purpose and clear aims.

YVIA had also been involved in a number of outside activities, including the Long-Term Medical Conditions Alliance, preparation of a charter for disabled people in hospital under the auspices of the Royal College of Physicians and the National Association of Clothing Workshops. He thanked outgoing chairman Patrick Daunt for inspiring the work initially.

New chairman, from page 15

chairman of the Greater Peterborough Partnership – the body guiding the economic growth of the Peterborough area – his involvement with a disability organisation is "quite new."

Mr Bowles has been following our progress closely since our extended executive committee meeting in April. He was elected chairman by the executive committee after ASBAH's AGM on Saturday, 16 September.

Patrick Daunt stood down after five distinguished years in post. In our latest *Annual Report*, he writes that his five years have been so much more happy than stressful because "ASBAH's aims, values and styles coincide with everything I admire and believe makes life worth living. But also there has been a splendid willingness on the part of everyone to take his or her own responsibility, so that my own cares have always been lightened.

"All this has been crowned by the richest prize a retiring chairman can ever have, the knowledge that the next chairman will be a better one."

Prejudice springs 'eternal'

ASBAH president, the conductor Jeffrey Tate, told the meeting that the prejudice against disabled people was still rampant.

Dr Tate, who has spina bifida, said that prejudice – fear of difference – was still an eternal problem.

"I see overcoming of this fear of difference as the main aim of ASBAH – in giving all the help possible to those who are more severely disabled than I am, and helping them enter society and making them feel they are human beings.

"I still encounter prejudice. In Baden Baden last week, a couple of teenagers were making fun of my gait. It was unpleasant and unnecessary. Here I am – articulate and successful – and yet I still have to fight that."

Care for the carers

A GUIDE for carers has been produced by the UK's central source of holiday information for disabled and disadvantaged people.

Care for Carers, from Holiday Care Service, highlights holiday and short break accommodation particularly suitable for carers, either travelling alone or with a disabled companion.

Holiday Care director, David Phillips, said: "This publication is long overdue. Carers are a

dedicated but often forgotten group and it is important that they have the information they need to get away for a holiday or short break. The main purpose of this booklet is to enable them to do this."

The 40-page guide is available free from: *Holiday Care Service, 2nd Floor, Imperial Buildings, Victoria Road, Horley, Surrey RH6 7PZ. Tel: 01293-774535.* Please send four first class stamps per copy with your order.

Disability awareness day

A DAY of training workshops for people working in disability information and advice will be held at Manchester Town Hall on 16 November 1995.

Information Enables in the North starts with an address on disability discrimination legislation, followed by workshops on: incapacity benefit; taking cases to tribunals; training new workers; fundraising; and

also advocacy and access.

The cost is £10. For application forms contact: *Mark Hall, tel minicom: 01302-310 123* or write to: *The Alliance of Disability Advice and Information Providers, c/o DIAL UK, Park Lodge, St Catherine's Hospital, Tickhill Road, Doncaster, DN4 8QN.* This event will also be held in Birmingham and London in March 1996.

■ We apologise that, due to lack of space, there is no Film Column in this issue of *Link*. Paul Darke will be back next issue (Dec/Jan '96). ■

Hydrocephalus Network News



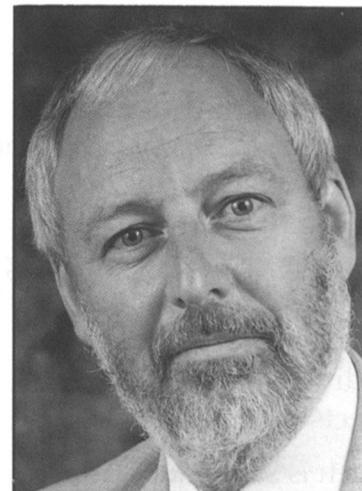
AUTUMN 1995

ASBAH, 42 Park Road, Peterborough PE1 2UG

Tel: 01733 555988 Fax: 01733 555985

Reg Charity Number 249338

Network co-ordinator: Rosemary Batchelor



Dr Roger Bayston

The second in a series of 'back to basics' articles specially written for *HN News*

The effects of hydrocephalus

IN THE first article in this series, I explained that hydrocephalus involves accumulation of cerebrospinal fluid (CSF) in the ventricles of the brain, with an increase in the pressure inside the head.

There are two sources of this pressure. One is that of the CSF itself, but a much higher pressure is produced by the heart in order to pump blood to the brain. If the CSF pressure rises, it eventually interferes with the blood supply to the brain, depriving it of oxygen and glucose which it needs in constant amounts to continue to function. Initially this causes tiredness, irritability and drowsiness, but if it progresses then loss of consciousness will result as the brain begins to shut down.

The immediate effects of this interference with the blood supply disappear if the CSF pressure is returned to normal, such as by

**By Dr Roger Bayston
MMedSci MRCPATH**

**ASBAH's Honorary
Consultant in Hydrocephalus**

ventricular tap or insertion of a shunt.

However, in most cases the process has been continuing for some time before diagnosis of hydrocephalus is made. During this time the interference with the blood supply leads first to a "dying back" of the very fine blood vessels in the brain. Even this process is largely reversible if prompt action is taken, but at this time there is often

insufficient clinical evidence to suspect hydrocephalus. The next stages involve progressive damage to the actual nerve cells in the brain and to their eventual destruction, and this cannot be reversed.

Because of the areas of the brain most affected, functions associated with thought and learning as well as with co-ordinated skilled movement begin to deteriorate. The precise effects differ between individuals and are further complicated by other abnormalities as well as by

continued on page ii

Free offer from the USA!

THE NATIONAL Hydrocephalus Foundation, based in the United States, is offering *HN News* readers a free copy of its journal.

The 20-page quarterly is called *Hydrocephalus News & Notes*. It includes features on parent-to-parent networking, a national calendar of events,

book and journal reviews, educational perspectives and concerns, and research news updates.

To receive your complimentary copy write to: Ann Marie Liakos, 1670 Green Oak Circle, Lawrenceville, Georgia, 30243, United States.

The effects of hydrocephalus, from page i

the pre-existing degrees of ability and personality of each person affected. It is not surprising therefore that while, for instance, learning disorders are common amongst those with hydrocephalus, their exact effects vary considerably.

Much is said and written about intelligence, and particularly about IQ (intelligence quotient) in people with hydrocephalus. In fact this is far more complicated, and a good deal less informative, than many believe. The IQ is made up of several components which can be thought of as verbal and non-verbal, or performance-related tests. People with hydrocephalus generally score better on verbal IQ than on performance IQ and this is thought to reflect the distribution of nerve damage in the brain as described above. Certainly during periods of rising CSF pressure, such as in untreated cases or when a shunt is blocked, the effect on performance IQ is more marked. Generally speaking, people who have had hydrocephalus since birth or childhood have, as a group, a lower average IQ than a comparable group without hydrocephalus, but it is important to realise that there is a wide range in each group, and some people with hydrocephalus have very high scores.

The practical implications of these features of hydrocephalus are that there may be subtle problems of co-ordination of hand movements with what the person sees, as well as a degree of clumsiness, which make it difficult to perform certain tasks or do certain jobs. With regard to learning in the home or to education in school, there may be real problems with concentration and reasoning which require a sympathetic but skilled approach. For instance, it will often be necessary to teach simple every day tasks like getting out of bed, washing one's face, dressing and going downstairs as separate short items rather than all at once, and to keep them consistent and repetitive. This does not indicate "stupidity" but is caused by damage to the nerves in the brain which normally allow us to learn very quickly how to do a complex series of things. Much can be done to help, and professional advice should be sought where needed.

Psychological development in children and adolescents with hydrocephalus may proceed normally, but sometimes the changes associated with puberty (breast development, body hair growth etc) appear much earlier than expected, and the intrusion of psychological aspects of sexual development into a mind which is emotionally still very immature can cause distressing problems. Again,

specialist advice should be sought if necessary.

Other effects of hydrocephalus may also be seen, and some of these are difficult to explain. For instance, some people are very seriously distressed by every day noises such as vacuum cleaners or washing machines.

One effect of raised CSF pressure may be seen in the eyes, and this is why your doctor sometimes looks for "papilloedema". This is caused by pressure on the blood supply to the back of the eye. It is important to realise that it may not always be present, even when the pressure is high. If CSF pressure remains high for too long, damage to the optic nerves can become permanent resulting in blindness, though fortunately nowadays this is uncommon. Another appearance, particularly in babies, is the so-called "sunset" eye sign, where the eyes are fixed in a downward position. This is due to CSF pressure affecting important nerves running from the brain which control eye movement.

If untreated the rise in CSF pressure can cause other serious problems in the brain, unrelated to blood supply. Many of our vital functions such as heart beat, breathing etc are controlled from the brain stem, a structure joining the spinal cord to the brain. Very high CSF pressure can compress this sufficiently to

continued on page iii

In my own words: Vicky Rose, aged 16, from Dronfield, SouthYorks

I HAVE hydrocephalus which is a build-up of fluid on the brain. I need this fluid in order to move easily and to prevent any damage to my spine when I do activities. This can also cause you to be in a wheelchair and be totally handicapped.

As well as being born with hydrocephalus, you can also be born with spina bifida, which means that when you are born your spine is not straight and prevents you from walking. I was one of the lucky ones because I did not have spina bifida. Also when I was born I was able to see and hear. Because I got a lot of help before I started school I was able to walk and talk.

When I was born the doctors told my mum and dad that I not be able to walk, talk, hear, or even see. In fact the doctors didn't know themselves what sort of things to expect. (I showed them). This all happened in the first seven weeks of my life.

My hydrocephalus is controlled by a shunt. There are different kinds of shunts. Mine is called a Hakim shunt with a Rickham Reservoir and an anti-syphon device which is my head and carries on into my stomach.

When I was in the infants and juniors, because the children were small they didn't know the difference between me and normal children, but when I went to secondary school everything changed.

We were all growing up and people started picking on me and calling me names.

I felt left out because all my friends made new friends and I felt really lonely. I also felt angry and sad and thought about running away and wishing I was dead. I knew I couldn't but I still felt that way. I just wanted to leave Gosforth. I felt nobody understood.

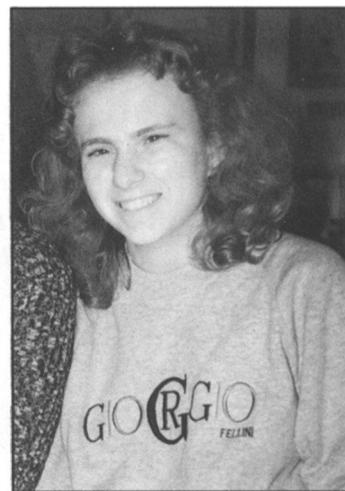
I was too scared to tell my parents. I thought it would be better when I got to Fanashawe.

When I went to upper school the bullying wasn't as bad although I still got picked on a bit but it was a lot better

The effects of hydrocephalus, from p ii

cause the heart and breathing to stop. Once again this is uncommon as signs of raised pressure are usually recognised before this. A similar problem might sometimes arise, particularly in those with spina bifida, due to compression of the cerebellum, a part of the brain lying at the back of the head. This can also give rise to breathing, speaking and swallowing difficulties.

Reading a catalogue of effects of hydrocephalus such as I have produced here can be very alarming. However it should be realised that some people with hydrocephalus may have very few of these



Vicky Rose

than when I was in lower school.

I have now been accepted at Broomfield College in Derby to do a year's course on Small Animal Care as a residential student, which I am very pleased about.

I am very keen on small pets and hope eventually to work at a kennels to help with grooming and shampooing.

problems, and hopefully none of the more serious ones. Also, many of those which I have described are found either in untreated hydrocephalus or when the treatment fails, and when successful treatment has been promptly introduced they often improve or sometimes disappear. On the other hand, the more subtle learning and reasoning problems are usually present in some degree and are very important where a child's development and education are concerned.

In the final article in this series, Dr Bayston will discuss the treatment of hydrocephalus, what happens when this goes wrong, and how doctors try to put it right.



“The MRI Scan”

By Liz Galfskiy

Liz, aged 45, from Winchester, wrote the poem below after having an MRI scan. She acquired hydrocephalus two years ago and has been in and out of hospital four times this summer. Her shunt is now working and she is beginning to feel better after complications with brain swelling. She hoped to return to work in September.

Going for a scan
It doesn't sound too bad,
Doctors say it doesn't hurt.
No injections, no risks.
Just lie still
Only for a while.
Then – it's over
And that's that.

I believed them:
I suppose they told the truth
But not quite the whole.

You lie upon a table,
Head held fast,
A helmet with bars,
Ear plugs fixed in place,
A mirror just above.

The machine, large and cream
Inside you're slid –
Encased in a tomb,
Just knees and feet outside.

In the mirror
Strain to see
Faces behind window, yards away.
Eerie voice on intercom speaks
'Lie still,
Machine just starting,
It will make a noise,
Only five minutes.'

Nothing moves,
You just lie still.
Trapped
Only the noise intrudes,
The sound is all around.
Drumming, throbbing
On, and on, and on.

Fear attacks

Thoughts go wild
I can't believe I'm stuck in here!
Keep still, don't move,
I tell myself.
Think pleasant thoughts –
The sea, a beautiful view,
Oh! the noise,
A helicopter just overhead!
Circling round and round and round.

One scan done
What! four to go
Five minutes, four minutes, five minutes
Then nine minutes more.

You just lie there in-between
While they 'set the machine.'

Then, the noise seems louder,
Gone are pleasant scenes.
Help! help!
No! don't shout, I tell myself.
Please keep still and quiet,
Can't be much more.

Oh! that noise.
Why there's a workman
Pneumatic drill, digging up the road.
His rolls of fat vibrating
Trousers nearly falling down.
I'm smiling inside,
Oh, what stupid thoughts.

Finished – silence – peace.

Out I come knowing
The only thing that kept me there,
Was the thought
If I had shouted
Get me out!
Later, drugged
They'd have only put me back.

Bikers with attitudes!

MORE than 60,000 people went through the turnstiles of the world's biggest motor show for disabled people this summer.

Attendance over the three days of the Mobility Roadshow at the Transport Laboratory, Crowthorne, Berkshire, was up by almost 10,000 the previous year.

One of the most popular stands that the crowds seeking new forms of mobility made a beeline for was that of the National Association for Bikers with a Disability (NABD).

Disabled people, who never dreamed they could ever ride a motorcycle, were amazed by the two vehicles on display – a trike adapted for a lad, paralysed from the chest downwards, and a share chair outfit with a mid pad allowing transfer between bike and wheelchair.

Rick Hulse (pictured above right), chairman of the NABD, whose hard looks belie his gentle manner, said: "We were inundated all weekend. We got 15 people started on the road, the bulk of whom were chair users and never dreamed they could ride a bike.

"Two had cerebral palsy and had been toying with the idea of a moped but we showed them they were not limited to some granny machines. We're doing the work on a motorcycle for them with engineers we know."

Terry Poole, who has spina bifida and hydrocephalus, and is the group's county representative for Dorset, said: "It's always a good show – I'm hoping not to miss the next one. It's a good way of keeping abreast of everything that's happening in mobility."

The NABD – which was featured in the summer issue of *LIFT*, our



At the Crowthorne event are Rick Hulse (left) and Martin Fowler from the National Association for Bikers with a Disability

ASBAH kept busy at show

THE PURPOSE of the Mobility Roadshow is to 'provide disabled and elderly people with an opportunity to look at, evaluate and compare all the available options to solve their mobility problems.'

There are over 200 exhibitors, of which ASBAH has been one from the beginning in 1983, writes disabled living adviser Leonie Holgate.

It is the world's foremost event in the field of mobility and this year this was recognised when Her Majesty the Queen opened the event on Friday 14 July.

Liz Clayton and I set up the stand early on the Friday just before the first visitors started to arrive. Although, officially the show does not open until 10am, there are 'early birds' coming around at 8.30am. From then on the numbers just escalated and, apparently, caused an exceedingly long tail-back for parking, although the space for this is massive by most standards.

We were kept very busy handing out ASBAH Guides to Services and other appropriate material, as well as answering queries on any and every topic, some far removed from mobility.

We managed to log 113 visitors but missed many because of the pace of the interest. The visitors were divided almost equally between professionals and families or people with the disabilities. The ASBAH stand was visited by people from Afghanistan, Japan,

continued on page 22

continued on page 22

ASBAH at the Mobility Roadshow, from page 21



Leonie Holgate and Liz Clayton on the ASBAH stand at the Mobility Roadshow

Romania, Canada, Malaysia and, we understand, there was a party of Russians somewhere but they did not come our way.

My husband, Derek, spent nearly the whole of Sunday putting all the names on Liz's lap-top computer.

Additionally, we demonstrated an exercise chair for which we were selling raffle tickets. It was a specially adapted wheelchair with modifications for building up strength in arms, legs and trunk muscles.

As I appeared to be one of the most frequent demonstrators, I have built up muscle power in all these areas! I am not sure I wished to do that but it was for a good cause – The Reading Friends, who give Liz very valuable support in her work.

Young people, unknown to ASBAH, arrived at the stand and it was exciting to see how well many were doing in the fields of employment and mobility.

However, I think that the general impression was that ASBAH's name is better known now, although some people required gentle reminders to use ASBAH's services.

The Mobility Roadshow is a place to meet every imaginable disability and to be encouraged by the ingeniousness of engineers and mechanics that so much can be done to enable people to maintain their mobility and independence.

Mobility Roadshows – don't miss the next one!

The next national Mobility Roadshow at the Transport Research Laboratory, Crowthorne, Berkshire will take place the year after next in June/July 1997.

However, a series of regional roadshows are being organised at three venues next year (1996). They are the:

■ Scottish Mobility Roadshow at The Royal Highland Centre, Ingliston, Edinburgh, open 10am-5pm from 24-26 May 1996. Free entry. Organised by Disability Scotland. Tel: 0131-2298632. Information leaflet available.

■ Northern Mobility Roadshow at Sheffield Arena, Broughton Lane, Sheffield, S9 2DF, open 10am-4pm on 30 & 31 August and 1 September 1996. Free entry. Organised by Sheffield City Trust. Tel: Eve Croft on 0114-2435355. Information leaflet available.

■ Northern Ireland Mobility Roadshow some time in June. Organised by Disability Action. For more details tel: David Patterson on 01232-491011.

Bikers, from page 21

sister magazine for young disabled members – consists of both able-bodied and disabled people with at least one thing in common – their love of motorbikes and motorcycling.

The group advises on and organises adaptations to existing machines for members, but it has also part-financed complete new-builds, particularly for paraplegics.

Rick, who himself has only limited use of his right arm and leg following a hit and run accident four years ago, said: "We put in half the bill cost as well as finding sympathetic engineers who charge us competitive prices."

Asked why the group's stall received so much attention at the Crowthorne event, Rick replied: "We were a little bit different and showed what can be done."

"A lot of people, even with minor injuries, think they've got to stop riding bikes. We show people that nothing's impossible. The only stumbling block is total blindness or current epilepsy. Anything else we've managed to adapt machines for."

■ The NABD needs your help in persuading Motability to include motorbikes and trikes, as well as cars, in its grant scheme.

The group has already written to MPs and a House of Commons all-party motorcycle club and has gained some support. But Rick wants people to write letters to him in support of motorbikes and trikes so that he can send them off en-masse to Motability.

He said: "People don't have to say in their letter that they would prefer a bike or a trike, only that they think people should be given a choice."

Write to: Rick Hulse, National Association for Bikers with a Disability (NABD), 39 Lownorth Road, Wythenshaw, Manchester, M22 0JU.

Local association treasurer Mrs Teresa Wallcroft is pictured (right) receiving a Certificate of Appreciation from the High Sheriff of Hereford and Worcester at a special evening which paid tribute to the work of over 80 organisations in the county.

Mrs Wallcroft, who has been involved with Worcestershire ASBAH for well over half of its 23-year lifespan, represented her colleagues at the Community Awards presentation at the Wadham Kenning's showrooms in Cotswold Way, Blackpole. Her 23-year-old daughter, Lisa, has spina bifida.

"We were included in the awards because of our long-standing involvement with disabled people in the county," said chairman Bob Kirkby. "There were 86 organisations honoured – you name it, they were there!"



LOCAL ROUND-UP

Graham does the business and opens second shop for Kent ASBAH

A LOCAL association has opened its second charity shop – rent free – thanks to the tireless efforts of one of its members.

Kent ASBAH now has shops in Gillingham and Sittingbourne which are managed by dedicated volunteer Graham Ball (pictured below).

Both shops are let on a rent-free basis until such time as a paying tenant or buyer is found by the estate agents.

Graham, who has hydrocephalus and had to give up paid employment four years ago after losing his left leg, said: "I just go into the estate agents and tell them who I am and what we do.



"It's all down to me really – my determination to raise funds for the children. I beg, borrow and ask for things and nine times out of ten I am successful."

As well as securing premises, arranging the shop fittings and finding a pool of reliable volunteers, Graham spends his weekends collecting second hand clothing, bric-a-brac, books and anything else which could sell.

At other times he does his own fund-raising at places like local garden centres. Last year he raised more than £4,000 and Kent ASBAH presented him with a certificate and clock as a way of saying thank-you.

Secretary Sandy Stevens said: "Graham is wonderful. He's raised an awful lot of money for us off his own back, let alone through the shops."

The first shop turns over anything from £200 to £450 a month – and most goes to the local association.

Mrs Stevens said: "Graham works tirelessly for the shops – the one in Gillingham has changed premises three times and each time he's got the new shop into shape. He's full of enthusiasm."

But although he enjoys his work, there have been times when he has considered giving up.

Graham, aged 43, said: "It's all down to me and I do as much as I can. I get a lot of appreciation – that's what keeps me going."

LOCAL ROUND-UP



Good buddies in Sussex

A VOLUNTEER 'buddy' scheme for young adults with spina bifida and/or hydrocephalus has been launched by Sussex ASBAH.

The aim is to find buddies for some of the associations' 200 young adults with spina bifida and/or hydrocephalus. So far, about 50 have said they would like a 'buddy' – someone to share activities and interests, go out with or just 'be there' for a chat.

"The launch of the scheme, during Spina Bifida Week, coincided with Horsham Volunteer Bureau Week. We had several inquiries from people interested in becoming buddies – more from west than east Sussex," said assistant county organiser Anne Bush.

No special skills are needed – just the time and a willingness to turn the buddying into a regular commitment.

National ASBAH executive director, Andrew Russell, talking with local association representatives at the North-West Local Associations' consultation meeting at Stockport in July



National meets local

AS part of national ASBAH's continuing efforts to improve communication with local associations, consultation meetings are being arranged throughout the regions this year.

In recognition of the importance of this consultation process, each of these meetings will be attended by members of the Executive Committee as well as senior ASBAH staff.

The aim is to ensure that local and national ASBAH understand each other's aims and activities.

The first of these meetings was held in the North West during the summer. Bob Ithell, Executive Committee, was chairman, and national ASBAH executive director and senior services manager were also present.

Local association representatives

from Chester and District, St Helens and District, Stockport, Trafford and Salford accepted invitations to the meeting, and apologies were received from others who had other commitments on that date.

Matters discussed included Services (and the changes in its structure), Research, Lobbying of Government, Folic Acid, Voluntary Visitors Scheme, YVIA Group and the progress made with the involvement of the group in ASBAH affairs, START, and communication with national office generally.

More study days for the area was high on the list of requests and unanimous agreement of the value of this meeting concluded the evening with a request that this become an annual event.

News from North Yorkshire ASBAH

THE NEW Lord Mayor of York has chosen North Yorkshire ASBAH as one of his charities this year because his wife has a child with hydrocephalus.

In August, the White Rose Charity presented the Lord Mayor's Fund with a cheque, some of which will benefit us at the end of the year.

During Spina Bifida Week I was invited to join in a discussion on Radio York along with Joan Pheasant and a representative from the health authority.

**by Hon Secretary
Miss Faith Seward MBE**

Listeners may have thought that we were joined by Dr Miriam Stoppard and Tony Britton from ASBAH but their contribution had been pre-recorded.

The broadcast brought home to me just how little the general public know about spina bifida when the interviewer, who was a very charming and intelligent lady,

turned to me and said: 'You presumably have had spina bifida all your life.'

I did point out that it was a congenital condition! Other than that the programme went well.

On a rather sad note, we have lost two of our young people this year which came as a great shock and sadness to us. We had known Alistair Gordon and Paula Connolly since they were very young. Our deepest sympathies go to their families.

THE CHIEF of a Netherlands umbrella organisation for several disabilities, including spina bifida and hydrocephalus, visited ASBAH's national centre.

Klazien Kruidenier and her husband Ries (pictured below while out sightseeing) called at ASBAH House during a week-long holiday in Britain.

Mrs Kruidenier is president of the board at BOSK, an association which has 500-600 members with spina bifida and hydrocephalus.

During a tour of the building, Mrs Kruidenier was impressed with the range of help and support given by ASBAH.



She was particularly interested in our fund-raising team, saying she would take the idea of developing this type of specialism to her own board of directors. "I want to ask them to spend a bit of their money on fund-raising," she said.

Her husband, who is an inspector of fire service for the Netherlands, had a rather more dramatic time when he visited London three years ago to compare notes with British fire chiefs.

While he was at the Home Office he witnessed the IRA mortar attack on 10 Downing Street.

Mrs Kruidenier is in regular contact with our senior services manager Teresa Cole in the efforts being made to re-establish a European Union for Spina Bifida and Hydrocephalus.

Negotiations have taken place for

The LINK diary

This and That!

this union to become part of the International Federation for Hydrocephalus and Spina Bifida (IFHSB).

There have been further discussions with officials in the HELIOS division in Brussels and union members will now make a decision regarding the new constitution and close links with IFHSB at its General Assembly in Belgium in November.

WHILE on the subject of visitors from abroad, we report a particularly pleasant contribution to the proceedings of the Society for Research into Hydrocephalus and Spina Bifida at its recent meeting in Bristol.

Monique Jouet, a post-doctoral research assistant in the University of Cambridge's Department of Medicine, was presented with the society's Casey Holter Essay Prize at the tender age of 29. She won the £250 prize for 3,000 words about a rare form of inherited hydrocephalus.

Age did not count against her, nor by all accounts did the years condemn, as Dr Jouet (pictured below) employed a combination of straightforward language and Gallic charm to ensure that veterans of these gatherings were



hanging on her every word! Her essay covered the same ground as her doctoral thesis and described, how X-linked hydrocephalus is caused by a disruption in neurone migration due to a faulty gene on the long arm of the X chromosome.

Dr Jouet completed her PhD in July. She is now undertaking a three-year research programme into another gene mutation on the X chromosome which can lead to learning difficulties.

Her work at Addenbrooke's Hospital in Cambridge is being funded by the Medical Research Council. She has been studying in Britain for 10 years.

The Casey Holter memorial prize was endowed by American engineer John Holter in memory of his young son, who was fitted with one of the first hydrocephalus shunts. It is awarded once every three years.

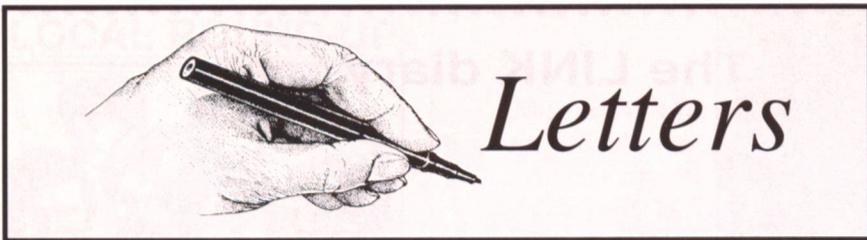
NEWS from television where actor John Henry-Hughes, who was on ASBAH's services committee for a while, reports that producers are starting to choose disabled actors for wheelchair roles instead of casting able-bodied wannabees who haven't got a clue.

"I get very irritated when I am watching TV and see actors in wheelchairs who don't know what to do with their legs", said John, from his home in Cambridge.

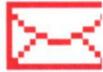
"I am pleased that more producers are going through Equity's Disabled Performers Register. All we ask is that they first audition disabled actors for disabled people's parts and, if they can't find anyone good enough, only then employ able-bodied actors."

The register worked for John in September. Although he no longer uses a wheelchair, he landed himself a wheelchair part on *Kavanagh QC* starring John Thaw which goes out in February. "It's a fine part, not the least bit patronising and the money's good. It would not have happened unless someone was using the register. I'm well chuffed," added John.

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



I FEEL now people are more aware of spina bifida and do not treat people with the defect like they used to.

I have a form of spina bifida which does not affect me physically at all. It used to bother me as a child at school mainly because I was teased about the scarring and extensive skin grafting that was sometimes exposed when I changed for games. I actively took part in sport at school, resulting in me being in the county junior netball team.

I gave up netball on reaching secondary school as I found myself enjoying horse riding more. I

regularly competed under The British Horse Society rules which entails show jumping and riding across country, jumping fences at speed.

After a couple of not-so-good relationships with partners who were not prepared to understand my spina bifida, I got married in August 1990, when I was 26.

In 1992 we decided to start a family, so I made an appointment to see my GP and then a consultant to talk about the risks involved. I was advised to go on a course of folic acid for at least six months before I conceived.

Both my pregnancies went well and I had normal deliveries. Because of my history of spina bifida I was advised to have all the relevant blood tests and scans, and the results were explained to us very clearly so that we understood what was going on.

This story may not be special but may help to get the folic acid message across – that it can reduce the risk of spina bifida – and this can only be a good thing.

*Amanda Whitehall
Rugby, Warwicks*

DATES TO PUT IN YOUR DIARY

Wednesday, 1 November

Hydrocephalus Study Day (focus - education), arranged by Sussex ASBAH, Uckfield Civic Centre, Uckfield, East Sussex. 9.30am - 4pm. Speakers include consultant neuropaediatrician Gillian McCarthy, ASBAH disabled living adviser Leonie Holgate and Mary Rudling (ex-education adviser, Sussex ASBAH). £15 professionals, £6 parents/adults with SB/H. Mrs Anne Bush, Oakwood Farm, West Chiltington, West Sussex RH20 2LU, tel/fax 01798-813663.

Saturday, 4 November

'Learning to live with neuropathic bladder and bowels: surviving the school years', one-day conference for professionals organised by ASBAH service and Continence Foundation, Northern General Medical Education Centre, Sheffield. £25, inc lunch and refreshments. Booking form: Joan Pheasant, ASBAH North, Five Oaks, Ben Rhydding Drive, Ilkley, W Yorks LS29 8BD, tel 01943-609468.

Monday, 13 November

'Who Cares?', one-day conference and AGM of the Association for Children with Life-threatening or Terminal Conditions and their Families (ACT), Centennial Centre, Birmingham. Study sessions on high-tech therapy in the home, symptom and pain control, running a helpline. £55 for members of ACT, £65 for non-members. Details: Nicky King, ACT, 65 St Michael's Hill, Bristol BS2 8DZ, tel 0117-922 1556.

13-17 November

START Lifeskills Course, five-day course for boys and girls aged 12 - 16, Nell Bank, Ilkley, W Yorks. Details: Joan or Rose, ASBAH North, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorkshire LS29 8BD, tel 01943-609468.

January 1966

ASBAH Northern Regional Day, Get Moving, looking at mobility issues for 13 - 16 year olds, and their parents. Joan or Rose, ASBAH (North), Five Oaks, Ben Rhydding

Drive, Ilkley, W Yorks LS29 8BD, tel 01943-609468.

March 1996

START understanding behaviour course, three-day midweek course to help families where a child with spina bifida and/or hydrocephalus is displaying behavioural problems. Venue to be arranged. Details: Joan or Rose, ASBAH (North), Five Oaks, Ben Rhydding Drive, Ilkley, West Yorks, tel 01943-609468.

21 - 23 May 1966

Midlands Naidex, National Exhibition Centre, Birmingham

24 - 26 May 1966

Scottish Mobility Roadshow, The Royal Highland Centre, Ingleston, Edinburgh, 10am-5pm daily. Free entry.

30 Aug - 1 Sept 1966

Northern Mobility Roadshow, Sheffield Arena, Broughton Lane, Sheffield, 10am-4pm daily. Free entry.

HOLIDAY ACCOMMODATION

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

ISLE OF WIGHT ASBAH

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

STAFFORDSHIRE, ALTON

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

SELSEY, SUSSEX (ASBAH)

Purpose-designed mobile home for wheelchairs. Sleeps six, colour TV, midi stereo system, payphone, ramp and veranda. Clubhouse, indoor swimming pool. Details: Mrs B Nunn, tel: 01903-763473.

Advice on special arrangements for examinations

ASBAH education adviser, Peter Walker, has produced four pages of advice on the special arrangements available when sitting GCSE exams.

The document, available free from ASBAH House, defines what the special arrangements might be, who to consult, how decisions are made about special arrangements and who should make the application.

The paper notes that candidates with special educational needs do not automatically qualify for special arrangements for GCSEs.

The times to apply for special arrangements are:

■ Where special versions of questions papers are required, 15 January of the year of exam for summer exams, and 30 September for autumn/winter exams.

■ For all other cases, 28 February of the year of exam for summer exams, and 30 September for autumn/winter exams.

For a copy of the advice sheet write to: Peter Walker, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ.

CLASSIFIED

Link Training Organisation - the largest training provider in the UK, with 116 branches, was delighted to be able to support ASBAH's autumn extravaganza balloon race 1995.

Link offices at Ipswich, Colchester, Basildon, Croydon, Dartford and Southampton Row pooled resources to provide financial sponsorship for six balloons.

In addition to helping a worthy cause, the coincidence of the *Link* name for the charity magazine prompted the staff at Link Training Ipswich to encourage their local colleagues to join in the sponsorship.

With such a widespread network, Link Training can assist everyone, including the severely disadvantaged, to further their education.

A glance through your local telephone directory or Yellow Pages, or alternatively contact with Talking Pages, will reveal your nearest Link Training Office.

MEMBERSHIP

INDIVIDUAL ASBAH membership - receive publications and voting rights at twice-yearly Council meetings. £17.50 a year (waived for those on benefit).
Details: Company Secretary, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.

LINK Rates

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£4.25 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, 4 November. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

AFFILIATED ASSOCIATIONS

BARNSELY

Mr Geoff Jenkinson
12 St Leonard's Way
Ardley, Barnsley
S Yorks S71 5BS
Tel: 01226-292546

BEDFORD

Miss C Merry
6 Thurne Way, Brickhill
Bedford MK41 7XD
Tel: 01234-346344

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Mrs G Lanning
23 Seaway Avenue
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10 Newlands Road
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42 Gowandburn, Sunderland
Tel: 0191 415 1725

SURREY

Mr Alan Twyford
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Tolworth, Surbiton
Surrey KT6 7RK
Tel: 0181 390 0853

SUSSEX

Mrs M White
Averys, Rusper
Horsham, W Sussex RH12 4PR
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Davis Court, Cyprus Street,
Stretford, Manchester M32 8AX
Tel: 0161 865 0222 (A.M. only)

WARRINGTON & DISTRICT

Miss Nancy Gleave
16 Hilltop Road, Woolston,
Warrington, Cheshire WA1 4PD
Tel: 01925 819329

WESSEX

Mr T Poole
123 Gerrards Green
Beaminster, Dorset DT8 3EA
Tel: 01308 862614

WIGAN, LEIGH & DISTRICT

Mrs Pat Stridgeon
24 Greendale Crescent
Leigh WN7 2LQ
Tel: 01905 676091

WIRRAL

Mrs M Appleyard
28 Stavordale Road
Moreton
Wirral, Cheshire L46 9PR

WORCESTERSHIRE

Mrs G Doleman
9 Pelham Road
Droitwich
Worcs WR9 8NT

YORKSHIRE NORTH

Miss Faith Seward MBE BA
45 The Paddock, York YO2 6AW
Tel: 01904 798653

WALES

Llanelli

Mrs Anthea James
61 Westland Close
Loughor, Swansea SA4 2JT

Mid Wales

Mrs J Carter
12 Lambeth Close, Craven Arms
Shropshire SY7 9QY

North Wales

Mrs L D Morris
Penrhyn Arms
Pendre Road, Penrhynside
Llandudno LL30 3BY

South Wales

Mrs Brenda Sharp
4 Lakeside, Barry
S Glamorgan CF62 8SS
Tel: 01446 735714

NORTHERN IRELAND

Mr J Rippey
Long Eaves
24 Tullywiggan Road
Cookstown, Co Tyrone
Tel: 0164 87 62290

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde

Mr John Dewhurst
40 Edmonton Place
Bispham, Blackpool FY2 0VT
Tel: 01253 592807

Calderdale

Mr A L Crowther
12 Elm View
Huddersfield Road
Halifax HX3 0AE
Tel: 01422 341497

Cannock & Walsall

Mr Ken Hall
17 Wallhouse Street
Cannock, Staffs
Tel: 01543 504847

Chesterfield

Mrs K Tomlinson
23 Hathern Close,
Birmington Common
Chesterfield, Derbys

Association secretaries requiring changes to this list should contact: **LINK EDITOR, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733 555988 Fax: 01733 555985.**