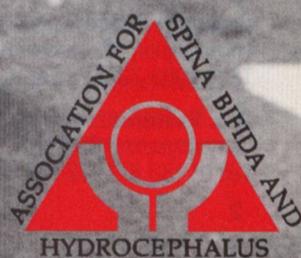


# Link

The magazine for people with  
Spina Bifida and/or Hydrocephalus

August/September 1997

Issue No 171 Price 80p



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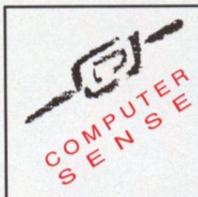
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A MOTHER has vowed that she will fight tooth and nail for a support teacher to be reinstated, after the local education authority announced it was making the staff cut a year away from her son's GCSE exams.

Paula Targonski, and her husband Roy received the letter from the head teacher out of the blue – effectively breaking a commitment for a support teacher in Andrew's Statement of Special Educational Needs.

The decision was made by Dudley Metropolitan Borough Council without consulting the parents of the six children in the school's physically handicapped unit who depend on the support teacher for extra academic help, counselling and liaison with other teachers. She also brings work to Andrew for subjects which are taught in classrooms which are inaccessible to him. An NNEB nursery nurse is also based at the unit.

An angry Mr Targonski immediately faxed a letter of complaint to David Blunkett, Secretary of State for Education, and spoke with Dudley's director of education.

Mrs Targonski contacted Central Television News in Birmingham

## Battle to keep support teacher

by Liz Cawthorne

and was filmed outside Coseley School which 15-year-old Andrew attends.

She said: "We've kicked up such a fuss, they are now going to review it. I told them they'd made this decision without assessing his needs and that they were shutting the door on him."

Andrew, from Sedgley, West Midlands, wants to go on to higher education which will hinge on his GCSE results.

Mrs Targonski said: "If the unit is not viable, at least let the children finish their exams. If the support is withdrawn, I will cause hell. I want that unit to stay as the choice in education for physically disabled children in this area is zero.

"Obviously my prime concern is Andrew, but I'm also fighting for other children whose rights are being eroded. Hopefully what we are doing will arm other parents."

Dudley Metropolitan Borough Council made the staff cut because it says it can no longer fund a full-time teacher for a small number of children but Mrs Targonski claims

the authority has not allowed the unit to take any more children.

Mrs Targonski said: "Up to now it's worked well. Academically, Andrew has come on in leaps and bounds. He has got 20 certificates for effort and a 'Gold House Point' which shows his dedication.

"He has got weak areas – needing extra support in maths and has received help with his handwriting – but he really tries hard and I'm not going to let his efforts go to waste."

### CSL loans scheme

WITH this issue of *Link*, you should find an eight-page supplement inviting you to consider loaning money to our computer company, Computer Sense Ltd (CSL), to help it have an even more brilliant future.

Please help, if you can. All the information you need is included in the supplement.

# Contents

ASBAH is a registered charity

E-mail: [postmaster@asbah.demon.co.uk](mailto:postmaster@asbah.demon.co.uk) Find us on the Web – <http://www.asbah.demon.co.uk/>

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Cover: Paula Targonski and her son Andrew, whose final GCSE year is threatened by a staff cut at his school's physically handicapped unit. Full story this page.



ASBAH receptionist Jill Whitmore, her guide dog Rea and sighted guide Rohan Wilson dip their boots into the sea at Robin Hood's Bay – marking the end of their epic walk across Britain



● JOHN Richards, whose training consultancy *Mind the Gap!* was featured in the Feb/March 1997 *Link*, took over the job of ASBAH adviser for Beds and Herts in July.

The former social worker and development officer for Milton Keynes Centre for Integrated Living has spina bifida and is visually impaired. He was appointed following the departure of Jacky Hockey.

## 190 mile walk for charity

● BRITAIN'S first visually impaired person and guide dog to walk 190 miles coast-to-coast across the north of England, completed their epic journey – splashing into the sea at Robin Hood's Bay in Yorkshire right on schedule.

Jill Whitmore, receptionist at ASBAH House, and guide dog Rea started walking on 11 May to raise money for ASBAH and Guide Dogs for the Blind. They were

accompanied most of the way by sighted guide Rohan Wilson, also from Peterborough – with additional back-up from postal sorting centre worker John Timings.

They followed in the footsteps of master hill walker Alfred Wainwright, who made the coast-to-coast route famous in a TV film a few years ago. Wainwright finished the walk in 12 days, so did the intrepid Peterborough duo.

Jill's worst moment? Going up a "very steep, very cold, very wet and very windy mountain. I really got to doubt the sanity of the whole thing at that stage, but we eventually got to the top."

The best part was meeting and talking with such a variety of people on the way.

Jill raised about £1,500 for ASBAH and Guide Dogs for the Blind by completing the long hike.



● IAN Morley has been appointed full-time appeals assistant.

The 35-year-old, who is visually

impaired, will be working on mail shots and administration in the appeals department.

Ian was an electrician for 15 years until he was found to have a brain tumour which had destroyed half of his optical nerves. After the tumour was removed, he retrained in clerical work at Portland College for the Disabled at Mansfield, Nottinghamshire.

Over the last four years he has raised £12,500 for the college by

organising and taking part in 24-hour cycle marathons.

Other spare time interests are golf, cycling and DIY around the house.

He previously worked on short-term contracts for Peterborough-based Pearl Assurance.

He said: "I've always thought I'd rather work for a caring organisation rather than lining someone's pocket so the ASBAH job advert jumped out at me."

NATIONAL SPINA BIFIDA WEEK IS 15 – 21 SEPTEMBER

## Awards to outstanding ASBAH young people



PHOTO COURTESY OF SHEFFIELD STAR

A SHINING example to others is how a 14-year-old, who won a Star Champion Child Award, has been described by her teacher.

Despite numerous operations and being doubly incontinent, Gemma Warris never complains but gets on with life.

Dorothy Stocks, Gemma's support worker at All Saints Comprehensive School, Sheffield, nominated Gemma for the award, run by the city's Star newspaper. She said: "This is an extremely large school yet Gemma has got herself around and doesn't ask for any assistance. She is a very nice person to have around the school, irrespective of her disability."

Jacki Dack, teacher for integrated resource pupils in the special needs department, added:

"Gemma is the sort of pupil who just gets on with it. She never complains and is a shining example to other pupils in the school."



PHOTO COURTESY OF JIM PRYLE

A YOUNG woman who has been fundraising for her local ASBAH since she was five years old has been honoured by her town council.

Thirty-four-year-old Karen Spencer, who has spina bifida and hydrocephalus, received a Volunteers Certificate of Appreciation from Wigan mayor, councillor Ken Pye.

Councillor Pye nominated Karen for her fundraising activities, not only for Wigan, Leigh and District ASBAH, but for other organisations including the RSPB, Christian Aid, Action for Children and Wigan Hospice.

Karen's mother Sylvia commented: "It was a surprise for Karen to receive the award. When you do charity work, you don't look for recognition, so it was a double reward for Karen to be recognised. We are very pleased and proud."

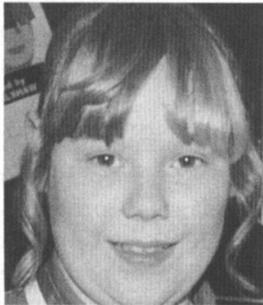


PHOTO COURTESY OF SHEFFIELD STAR

THE little things which Claire Cattermole does for her wheelchair user mum mean a lot.

And those little things added up to the 11-year-old winning a Shef-

field Star Champion Child Award. Claire was nominated by the Sheffield Association for Spina Bifida and Hydrocephalus.

Her mother Caroline, who has spina bifida, commented: "Claire helps with all those little things which are big things to me. She's just wonderful. I don't know what I'd do without her."

The awards were presented by local celebrities, dignitaries and professionals at Sheffield's Grosvenor Hotel in the presence of family and friends.

## Officers & Staff

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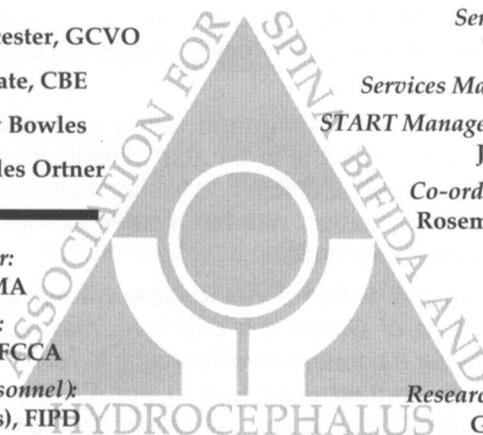
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# Gene study backs up calls for folate fortification

AS many as one in seven people may carry genetic mutations that can cause them to have deficiency in the vitamin folic acid (folate) even though they are taking amounts recommended by many nutrition guidelines, researchers have warned.

Folate plays an important part in the synthesis of DNA and in the formation of certain proteins. Low levels of folate are associated with often disabling neural tube defects such as spina bifida.

There is growing evidence to suggest low levels of folate may also increase the risk of coronary artery disease and stroke.

In the study, Professor John Scott, of Dublin's Trinity College, and co-workers took blood samples from two groups of healthy women, 242 of whom were pregnant and 318 who were not.

They measured folate levels and tested for a gene that codes an enzyme that enables folate to act within cells. In particular, they looked for a mutation in the gene

that greatly reduces the efficiency of the enzyme.

Ordinarily, each person carries two copies of the gene for this enzyme – one from their mother and one from their father. As a result, a person can have either two normal copies of the gene, two mutant copies of the gene, or one of each.

The researchers found that among women in both groups – pregnant and non-pregnant – women who had two mutant copies of the gene also had, on average, red-cell folate levels that were significantly lower than in those women with two normal copies. There was also a significant difference in red-cell folate levels between those with one normal and one mutant copy of the gene and those who had two normal copies, but only among the pregnant women.

"These results suggest that a substantial minority of people in general populations may have increased folate needs," the researchers write.

"If genetic variants that cause altered nutrient status are common, as this study suggests," the researchers conclude, "there may be no such thing as a 'normal' population with respect to nutrient requirements, as was assumed when dietary reference values were established."

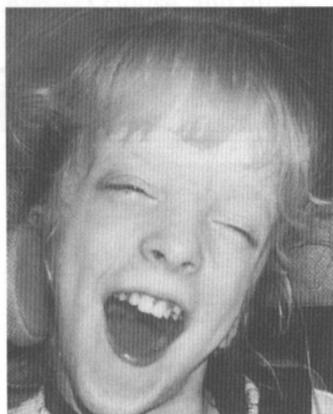
However, Professor Scott says these conclusions do not pave the way towards a screening process for the mutant gene, but rather for a blanket population approach through fortification of flour with folic acid.

He said: "If this mutant gene was 72% accountable for spina bifida (that is, the percentage of spina bifida which is reduced by taking folic acid), it would be worth screening for.

"However, it accounts for a small, but important percentage – about 13%. Thus it seems probable that there are a few genes that account for spina bifida, or perhaps even simple folate deficiency accounts for a lot of spina bifida.

"This study shows that genetic screening is unlikely to be effective. What is needed is mandatory fortification of folic acid as has already happened in the USA."

## NICOLA (date of birth 13/12/84)



**Greenwich Council**  
Social Services  
26/28 Powis Street,  
Woolwich  
London  
SE18 6LF



We are looking for a permanent family for Nicola. She attends a school for children with severe physical disabilities in South East London. Nicola is an affectionate, alert sociable young woman, with a great sense of humour.

Nicola communicates by Rebus; she has a severe learning disability, hydrocephalus and microcephaly. Although totally dependent on adults for her care, she is in good health. She especially enjoys swimming and horse riding.

Nicola needs a long-term family who will offer care until she is an adult, ideally in a family with other children. It is important that Nicola has contact with her mother, siblings and extended family.

*If you live within a reasonable travelling distance of Greenwich and think that you can offer a permanent foster home to Nicola, please contact Julie Hall in our Children with Disabilities Team. Telephone 0181-317 5665, ext 2730.*

*IN THE next Link, the Wearable Clothing Company will be introducing its range of fashionable winter wear – cut for people who spend most of their day in a wheelchair.*

*Denims, bomber jackets, a warm ski-suit with long zips, sweaters, thermal garments and fashionable waterproofs – based on the colourful designs used in hill walking gear – will be included.*

# You tell us about continence supply problems

**S**ERVICE-users and their parents, who have problems with continence supplies, have responded well to our appeal for more information to identify shortfalls in service provision.

The forms published in the last two issues of *Link* have so far been completed by about a dozen people. If you want to tell us about your problems in this area, it is not too late to do so.

Our survey has already uncovered some amazing stories. One couple in Middlesex were told by their local health centre to use newspaper on their bed when they asked about supplies of protective sheeting.

Another couple, in Sussex, have to spend £5 a week on taxi fares to personally collect continence pads because the health centre across the road no longer issues them.

Despite contacting their local community health council and the surgery, no one can help.

Parents of a little girl in Yorkshire told us that their local health authority would not provide reusable pants even though their daughter will not wear pads. Geraldine Binstead, specialist adviser (medical) for ASBAH North, explained: "I was already in contact with the family and helped them to get a welfare grant from ASBAH to buy some padded Ganmil pants.

"The child is very body-conscious and has a hang-up about wearing pads but her local health authority won't provide money for pants."

A little boy from Solihull has a similar problem. Although he will be entitled to free pads from the age of three, he prefers pull-ups

because he wants to be like other children of his age.

The family's local health authority will not provide pull-ups, so the boy's mother will have to continue buying them for day-time use.

Julie Llewelyn, specialist adviser (continence) for ASBAH East and national ASBAH, has advised this mother about reusable pants.

In other parts of the country – Glamorgan and Bedfordshire – service users reported a decline in the quality of pads issued.

A service user in Bedford says her new pads are less efficient than the

*continued on page 7*

## Your views on involvement in ASBAH

ASBAH adviser Angela Lansley would like to hear people's views on disabled people's involvement in ASBAH, both nationally and locally. She would like to know

the reasons why people get involved, or why they don't, for research she is doing for an MA. **Contact Angela by late August on 0151-733 8392.**

# Help & Advice

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

### London, Surrey, Kent, West and East Sussex

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

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

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

### Northern Ireland

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

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

ASBAH North, 1 The Wells Walk, Ilkley, West Yorkshire LS29 4LH. Tel/fax: (01943) 609468. Regional Co-ordinator: Joan Pheasant NNC.

### Rest of England and Wales

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

ASBAH welcomes and appreciates the support of its commercial partners.

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

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

## Continence supplies campaign from page 7

old ones, and that the health authority does not seem to understand that her needs vary. Some days she only needs two pads, other days four or five.

She was told that if four was insufficient, then she must change to a larger more absorbent size, but these are uncomfortable and show through her clothes.

This woman told us: "Anyone who is continent cannot begin to understand the needs of the incontinent."

The need for a variable number of pads, was echoed by a woman in Glamorgan, who also complained that current pads were not as absorbent as those issued previously. Although this service user does not always need the 90 pads a month she receives, she dares not ask for less as it would then be impossible to obtain extra pads when her need increases – eg in the summer when she drinks more.

Variable pad needs of another kind have been highlighted by a service user in Sheffield.

She previously used large pads for night time and small ones during the day. Now the authority has stopped supplying the small ones and only provides bigger ones, which are very conspicuous.

As a result, the woman has decided to buy her own smaller pads but is finding it very expensive.

Julie Llewelyn has responded to this woman by giving information on reusable padded pants.

Finally, a 36-year-old man from Cambridgeshire was found never to have received specialist advice on managing his continence, so Julie has given him information about local continence provision.

● If you have a problem with continence supplies, please let us know. **Write to: Julie Llewelyn, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.**

## ASBAH spurs trial of anal plug

YOUNG ASBAH service users are testing a new anal plug and, if the trial is successful, there are hopes that it could be made available on prescription.

Around 50 young people under 18 are trying out the Conveen Anal Plug which is designed to put an end to the worry of faecal incontinence.

Although it looks small when unwrapped, the plug expands into a bowel-like shape to prevent leakage. Its maker, Coloplast, says it is comfortable to wear and easy to remove and can be worn anywhere for up to 12 hours – even swimming with friends.

The ASBAH trial was initiated by specialist adviser (continence) Julie Llewelyn who spotted the anal plugs at a conference in Holland. When she returned home, she repeatedly asked Coloplast why

the plugs were not available in the UK and, as a result, the company agreed to run the trial.

Julie said: "Up to now, I have been advising service users who have this problem to use ordinary tampons, but these specially made anal plugs should do the job more effectively."

The three-week trial will involve participants recording how they get on using the anal plugs and whether they would wish to continue using the product.

The anal plug is available in two sizes and it is recommended that you try both to find the size that works best for you. Prices are £44.00 for a pack of 20.

**Order forms are available from Coloplast Ltd, Peterborough Business Park, Peterborough PE2 6FX. Tel: 01733-392000.**

## Stoma story

DETERMINATION not to be different is the theme running through the story of Kate Keays, who was born with spina bifida and underwent surgery for the creation of an urostomy when she was four years old.

Based on a desire to raise the public understanding of stoma surgery (allowing urine to be removed through a man-made opening or stoma), Kate has written a book which traces her life at school through teenage years to her marriage to a disabled man and pregnancy.

Kate, aged 39, from Bognor Regis, West Sussex, says: "As the years progressed, I discovered that there were many people out there facing similar surgery who needed help and encouragement. Very often, just meeting someone else who had already undergone surgery and who looked every bit as normal as the next person in the street, was enough to give them confidence. It is my heart's desire that this book should encourage stoma patients of all kinds."

*Life In All Its Fullness – One Person's Story Following Stoma Surgery* costs £5.95 plus 55p per copy towards postage and packing. **It is available from: Life-line Books, PO Box 107, Bognor Regis, PO22 8YX.**

## Latex-free urisheath

A LATEX-free urisheath with anti-kink tubing and leg bag are now available for men with urinary incontinence.

Called Conveen: Security+, the collecting system is available on prescription and is made by Coloplast.

Three sizes of urisheath and uriliner, and two sizes of leg bags, are available.

**For more information, call free on 0800-220 622.**

## Music points scheme

A MUSIC shop, which donates five per cent of what you spend to ASBAH, has been getting an order a week from *Link* and *Lift* readers.

IME Counterpoint, run by *Your Voice in ASBAH* member Drusilla Henley and her brother Tim, has been receiving orders for CDs from as far afield as Wales, Sussex, Somerset and Hampshire.

Providing you mention ASBAH on whatever type of transaction you undertake – cash sale, credit or debit card sale on orders by mail, telephone and Internet – IME Counterpoint will earmark five Counter Action Points for every pound spent.

Each point will be worth one penny. A full price CD, for instance, will attract around 65 points.

At intervals during the year, Counter Action Points will be totalled and the full amount paid over to ASBAH.

Tim said: "The scheme is going well. We get about an order a week for ASBAH of two or three CDs. We hope it will build up and that we'll get repeat orders, especially in the run-up to Christmas."

*Link* and *Lift* readers have also taken advantage of IME's search service, which uses the Internet to track down obscure recordings.

*IME Counterpoint is at Unit 1, 32 Church Street, Malvern WR14 2AZ. Tel: 01684-561860. Fax: 01684-577563.*

E-mail:  
[musicshop@enterprise.net](mailto:musicshop@enterprise.net)

Web site:  
[Http://www.malvern-net.com](http://www.malvern-net.com)



### How you and ASBAH benefit

- Five per cent of what you spend will go to ASBAH – providing you mention ASBAH when placing the order.
- Ten per cent off any order over £29.99.
- Free delivery on orders over £29.99.

## Pregnancy register for anti-epilepsy drug

WE HAVE received the following information on the anti-convulsant drug Lamictal and its use in pregnancy from Lamictal's makers Glaxo Wellcome Ltd.

Phil Parnham, scientific adviser epilepsy at Glaxo Wellcome, says limited data exist on the use of lamotrigine (sold as Lamictal) in pregnancy. Lamotrigine, like many other drugs, should not, therefore, be used during pregnancy unless, in the opinion of the physician, the risks to the foetus are outweighed by the potential benefits of treatment to the mother.

Lamotrigine, unlike many of the older anti-epileptic drugs, did not produce effects on the developing foetus in animal studies. However, it is known that animal tests do not necessarily accurately predict the effects seen in man. Therefore, in order to identify the risks of treatment and to help physicians reach

a decision, Glaxo Wellcome has established the Lamotrigine Pregnancy Registry, an international registration and follow-up study of women exposed to Lamictal during pregnancy. Collected data are reviewed by an independent advisory committee of neurologists and scientists.

In September 1996, the register had details of 85 pregnancy outcomes in which there was exposure to Lamictal during the first trimester. The observed proportion of births with defects following Lamictal exposure in the first trimester did not differ from the proportion expected in women with epilepsy. Furthermore, there was no pattern to the birth defects reported. However, with the small number of subjects that are currently registered, no conclusions can be drawn at this time on the effects of lamotrigine in pregnancy.

We urge any physician treating a woman who has been exposed to Lamictal during pregnancy to inform the registry, as we can only gain a greater understanding of the effects of lamotrigine in pregnancy by significantly increasing the number of cases available for evaluation.

This may be done via the Medical Information Department at the address below. Prospective evaluation is encouraged as this provides the best evaluation of risk.

*Glaxo Wellcome UK Ltd, Stockley Park West, Uxbridge, Middlesex UB11 1BT. Tel: 0800-413 828.*

### Correction

THE anti-convulsant drug Epilim contains sodium valproate and **not** sodium valproate and tegretol as stated in the June/July issue. We apologise for this error.

# Care in the community – is it working?

● A SEVERELY disabled woman could be forced to go into a nursing home because the only agency in the county that offers 24-hour care issued a five-day notice after she complained a carer was stealing from her.

Before agency care was available through Social Services, Mrs F's daughter Annie (not her real name) gave her 24-hour care.

Mrs F, aged 61, has Friedrich's Ataxia – similar to multiple sclerosis – which has left her very physically disabled. She cannot get in and out of bed or a chair, she cannot dress, wash, feed or give herself drinks. She is losing her head control and cannot pick up the phone.

But although 32-year-old Annie, herself a wheelchair user due to spina bifida, was free at last to lead her own life when the Community Care Act came in, she had the constant worry of not knowing what blunder agency carers were going to make next. The worry and the fact that agency carers used to phone her for assistance, led to Annie losing her own job.

"Over the last four years I have suffered more stress than in the 17 years I was caring for mum seven days a week," Annie commented. "But now that the agency has withdrawn its service, I must go back to being a prisoner and a slave as neither mum nor me can bear seeing her go into a home."

Annie believes the agency was more interested in the £600 a week payment than in providing good standards of care. "The times I was called out from work when the carer on duty couldn't cope," Annie said. "I couldn't claim my £3 an hour for the time I lost. Or they might call me and say so and so's sick, you'll have to do it. What were we employing them for?"

"The agency just didn't have the

resources to do the work it took on. All it saw was the £600 stamped on mum's head."

District nurses, too, are often too busy to do a thorough job. "Once mum was left for more than 10 hours with a bleeding and painful pressure sore because the district nurse was too busy and it had to wait until the twilight service," Annie recalls. "Mum never had a pressure sore while I was looking after her. I've been called out three times because mum has been crying with pain."

Recently, a carer phoned wanting Annie to help lift her mum. "As soon as I got to the patio I saw that mum was grey. The carer hadn't noticed she wasn't breathing as she had sunk too low in the chair. I dashed in to prop her up and give her oxygen. The carer said 'Her speech was going so I thought she was thirsty.' And the agency said all its carers were fully experienced!"

Annie had several heated discussions with the agency and Social Services about standards of care, but the problems remained. Her knowledge of her mum's condition and needs were often ignored by the agency.

"Mum was exploited in her own home. She is entitled to complain, but we were blackmailed by the agency because, if we didn't like it, they could serve a five-day notice and she could go into a home. That's not fair. Agencies should be more accountable to Social Services and there should be more control."

**TWO young people with spina bifida were among those interviewed on a Radio Five talk show which heralded the start of Carers' Week.**

**After Hours heard from carers of all ages who gave an insight into how care in the community was working.**

**Annie spoke about the lack of quality of care and the lack of accountability of agencies over the telephone on the late-night programme. Annie's severely disabled mother was served a five-day notice by an agency after complaining that a carer stole from her.**

**Neil Lewis and his wife Belinda travelled to the studio from Oswestry to say how inflexible agencies can be to the changing needs of their clients.**

● TWENTY-one-year-old Neil, who has spina bifida, is annoyed because the agency that helps him for an hour every morning is not able to change to an earlier time now he has started college.

His asthmatic wife Belinda is also on call to help her father who is very ill with a brain tumour – a half-hour drive from their home in Oswestry.

Even now that Neil goes to college, Belinda finds it impossible to have a life of her own. At lunch-times, she goes to college to help Neil fold up his wheelchair so he can self catheterise in a small disabled toilet.

Belinda, aged 23, said: "The agency comes in at 9am to help Neil get round in the morning so I can have some time off. But now Neil has to be at college by 9am, we requested changing to 7-8am, but the agency refused."

"So Neil either has to go without a bath, which means his skin deteriorates, or he arrives at college at 10.30am, missing the first lecture."

She added: "It's been a three-year battle for me to get Neil to go back to college and this is not making his start there any easier."

## INTRODUCTION

It is important that babies born with spina bifida and/or hydrocephalus are seen by a physiotherapist soon after birth. The timing of the introduction of the physiotherapist should be carefully considered whilst parents are still learning about the diagnosis. It is also important to discuss the expectations of physiotherapy at the very beginning in order to allay misconceptions and lay the foundations for a trusting relationship. In this way partnerships can be formed with parents and extended family members to encourage them to hold and handle their baby and learn how to carry out the physiotherapy programmes.

Early intervention will also ensure that the baby receives an assessment, although even when done early it is impossible to predict the outcome with accuracy as all children are different and should be treated as individuals.

An in-depth knowledge of child development is essential so that individual physiotherapy programmes can be planned. These are taught through play, as this is how children learn, so that physiotherapy is seen as fun rather than a chore.

## ASSESSMENT

There are many aspects of assessment:

### 1. Joint ranges

A baseline measurement of joint ranges will alert the development of any potential contractures. Care is needed as the bones may be thin and susceptible to fracture.

### 2. Muscle power

The testing of muscle powers can be graded on a scale of 0-5, where grade 5 is a contraction against maximum resistance, and is more accurate on older children. It can however be attempted on small babies by noticing whether the particular muscle can work against gravity in which it is at least a power 3 on the scale.

# Physiotherapy – how it can help

by Carole Sobkowiak

Carole Sobkowiak is superintendent physiotherapist at the Child Development Centre, Darlington Memorial Hospital, and serves on ASBAH's Education Committee. Previous to this, from 1982-1992, she served on our Medical Advisory Committee.

Miss Sobkowiak became a fellow of the Chartered Society of Physiotherapy FCSP in September 1996, together with former ASBAH executive director Moyna Gilbertson and ASBAH vice-president Baroness Masham, who became an honorary fellow.

Miss Sobkowiak is also a director of the Independent Panel of Special Educational Advisers.



The distribution of voluntary muscle activity may be varied according to the level of the lesion. For example, if the lesion is at the level of the 3rd and 4th lumbar vertebrae then only the muscles in the leg which straighten the knee and pull up the foot will be working, whilst a lower lesion in the sacrum may only affect the small muscles of the feet and produce clawing of the toes. These sacral lesions, though not causing major motor problems, can still cause incontinence as the same nerve roots supply the bladder.

It can however be misleading to presume that just because a certain level in the spinal cord is affected that only those muscles supplied automatically by those nerve roots will be affected. This is because there may be abnormal nerve function two or three segments above or below the lesion as well as other abnormalities in different parts of the spine, eg bony spurs or small cavities which are known as syringomyelia. These factors highlight the need for a thorough baseline

assessment with regular re-assessment especially as the child grows.

### 3. Sensation

The nerves from the spine carry sensory fibres as well as motor fibres. Sensory testing should be carried out for touch, hot and cold. The child with a lesion at 3rd and 4th lumbar level can have loss of sensation over the front of the knee, lower leg and foot whilst the child with a sacral lesion may only have a loss of sensation between the great and first toe.

### 4. Muscle tone

*Hypertonia* is a term used to describe increased muscle tone which can be as a result of either hydrocephalus or it can be spinal in origin.

*Hypotonia* is a term used to describe low muscle tone when the muscles feel floppy. This can be found in the upper limbs of those with hydrocephalus. Hypotonia should not be confused with muscle weakness as indeed some

*continued on page 12*

## *Physiotherapy, from p 11*

children with hypotonia can be quite strong.

*Ataxia* is a term used to describe unsteadiness of balance and is frequently associated with poor co-ordination. Ataxia may be present when there have been changes in the hind part of the brain known as the cerebellum.

### **5. Gross motor activities**

Babies and young children should be given the opportunity to play on the floor and to follow the usual developmental milestones such as rolling, sitting and getting on to all fours etc. It is important to develop good quality sequencing of movement at this time as it will have bearing on other sequencing activities such as scanning for reading and writing in later years.

### **6. Upper limb function**

It is known that hydrocephalus can affect the developing brain which may cause problems with fine motor control. The small cavities in the spinal cord mentioned earlier can also be present in the neck and affect the nerves which supply the arms.

The arms and hands should be thoroughly assessed. There is a test battery designed by the author which looks in detail at hand function, all sensory aspects of touch, eye-hand co-ordination, spatial/perceptual problems and hand-writing.

### **7. Language development**

If there is concern then this should be checked by a speech and language therapist as some children may have receptive language problems, ie the understanding and processing of language, whilst others may have difficulty with expressive language, ie the articulation of sounds.

**Early intervention** is therefore paramount in identifying areas which require remediation during the time the nervous system is rapidly developing in order for optimum results to be achieved.

## **AIMS OF TREATMENT**

### **1. Prevention of deformity**

Deformity occurs in a joint if there is an imbalance of muscle activity across it which is why it is important to have a good baseline assessment. Deformities can be treated with a combination of splints, surgery and physiotherapy.

Parents can be shown how to move the joints passively in order to try to keep them supple. If there is a great muscle imbalance across a joint then it is inevitable that the deformity will remain. When results are disappointing it is helpful to remind parents that, whilst they may not see any improvement, they are in fact preventing a more rapid deterioration which can occur especially during growth spurts. It is at these times when the bone grows that the muscles tend not to grow so quickly thereby becoming apparently shorter. Parents need to be made to feel that their contribution is helping to put off for as long as possible the need for tendon lengthening and tendon transfers etc.

Correct positioning of the child both during the day and at night may help to eliminate some deformities. Apart from the muscle imbalance problem, there is also a contribution from the effect of gravity on some deformities, eg drop foot, fixed outward rotation at the hips and curvature of the spine. Advice regarding good positioning in chairs and standing frames during the day and in bed at night time should be sought.

Children should be put into a standing position at around the age they would normally be on their feet. This is necessary to promote good bone formation and shaping of the hip joints. Without this early weight bearing there is an increased risk of fractures and if the hip sockets are poorly formed then there is a greater risk of dislocation of the hips over the long term.

There are a variety of standing frames on the market and different

kinds of calipers, swivel walkers and hip guidance orthoses.

In order to aid ambulation, attention should be given to strengthening the trunk, shoulder and arm muscles especially in those children who will rely upon the use of sticks. Strong trunk and arm muscles will also encourage independence as at least in theory they should be strong enough to lift the total body weight. Pulling and pushing activities are useful and young children can play wheelbarrows, tug of war, throwing and catching, swimming etc, whilst older ones could join a fitness centre. Wheelchairs may be a better alternative for some children to aid their mobility as self esteem is gained from keeping up with their peers and having the ability to make independent decisions and choices.

### **2. Sensory changes**

The child and his/her family need to be made aware of the areas which have either poor or no sensation. Sometimes the child may have body image disturbance especially if he/she cannot feel a limb properly. A child with sensory deficit has never known what normal sensation is like.

An estimate of body image can be ascertained by asking the child to draw him/herself. Absent limbs, usually the legs, will indicate problems with body image. Training for body image can be done by drawing round the child lying on the floor or round a friend or a doll. It is then useful to colour in the various body parts and name them.

For safety reasons families should be advised about hazards such as very hot tap water. It is important to put the cold water in first and then test the water with a hand before getting into the bath. Other hazards are hot water bottles, close proximity to radiators and hot water pipes and nylon carpets which can cause friction burns to knees if the child is crawling about.

*continued on page 13*

**Physiotherapy, from p 12**

Electric kettles and teapots should be in a safe place as even small scalds can take a long time to heal. These are some examples of heat damage. However, severe cold and ice can cause similar damage and circulatory problems. In children with poor circulation in their legs, it may be necessary to have a chair with elevating leg rests so that the legs are not hanging down all the time.

As they get older, children should be encouraged to inspect their own skin and a hand mirror can be used for awkward areas. Regular checks should be kept on footwear to ensure that shoes are not tight. In hot weather cotton socks are more absorbent than nylon. Frequent change of position and special cushions are advisable and now there are some very sophisticated materials available, eg Second Skin which can be applied directly to vulnerable areas.

Prevention is better than cure because once a pressure sore has developed then it may get infected and take months to heal up. Occasionally a skin graft is required.

**3. Gross motor activities**

Early therapeutic intervention includes stimulation of visual awareness. Sitting the baby up as vertically as possible rather than reclining back helps to stimulate the vestibular system in the brain which promotes observational skills and the control of balance. There is a strong link between the acquisition of sitting balance and the development of language.

Sensory integration techniques can be used to involve whole body orientation in space such as lying, rolling and sitting on different surfaces, eg partially deflated beach balls or air beds, sheets of plastic bubble which make a sound when the child moves. Toys which make a noise when touched will motivate the child to move as an action is then rewarded.

As the child matures and exper-

iences broaden, he/she develops more abstract concepts. The early vestibular and sensory play will enable the child to develop the form and space between perception that is the foundation for complex manipulative skills and for later abstract concepts such as the recognition of numbers and letters.

Tasks may need to be broken down into small stages and it is helpful to choose games and activities which are at the child's developmental age in order to ensure that vital stages are not missed out. As previously mentioned an in-depth knowledge of normal child development is therefore essential.

During early treatment there is an emphasis on the development of spatial awareness and sequencing of movement as motor activities are learned through spatial memories. It is crucial to develop good quality gross motor activities as these precede the fine motor skills which are required for precise and detailed hand function.

**4. Fine motor skills**

Developmentally, large arm movements precede fine motor skills. Examples of such activities are action rhymes to music, Simon Says, bats and balls, etc. Using sticks with streamers to draw shapes, numbers and patterns in the air will give visual feedback and this method can be used prior to the teaching of cursive handwriting to establish the sequencing and rhythm. Developmental play progresses from large toys to small ones. Fine finger control can be encouraged with Duplo, farm animals, jigsaw puzzles, finger puppets etc.

**5. Language development**

The physiotherapist should work in close liaison with the speech and language therapist if a problem is suspected. It is important to pitch the instructions at a level which the child can understand. It is now thought that some behaviour problems can be caused if a too high language level is used as

the child may become frustrated. Some children may have difficulty coping with auditory and visual information at the same time.

Apart from auditory and visual memory problems, there may be short term memory deficits when the child cannot remember what has just been said.

Just as language can be used to teach motor activities, then motor activities can be used to teach language therapy, eg crawl under, sit in, stand on. Mathematical concepts can also be taught through gross motor activities, eg walk round a circle, square, triangle. In order to enhance the learning process, counting and measuring time, distance and speed as well as right/left orientation can be included in these activities.

**SUMMARY**

Physiotherapy has been linked traditionally to the orthopaedic management of children with spina bifida. There is still an important role for this, with attention given to the care of joint ranges, muscle strengthening, sensory awareness, gross and fine motor activities.

This is perhaps more of a medical model whereas it is my practice to link the programmes into the pre-school educational system and eventually into the National Curriculum. For those children with a Statement of Educational Need then the physiotherapy programme can become part of the Individual Education Plan (IEP) as determined by the Code of Practice.

Physiotherapy can be integrated into the home environment and school timetable so that the child does not have to be withdrawn for 'exercises.' Physiotherapy then becomes a way of life and, in my view, it is an educational issue rather more than a medical prescription. Physiotherapists should be seen as teachers of movement rather than 'givers of exercise.'

Finally, and most important of all, it should be FUN!

## Table-top Olympics

STUDENTS on a hospitality, leisure and tourism course at Peterborough Regional College organised an 'Olympics with a Difference' in aid of ASBAH.

Aiming to catch gold in the promotions and special events management section of their course, they got into the competitive spirit with a host of pub games and other table-top activities at the Crown Lodge Hotel, Outwell, near Wisbech, Cambridgeshire.

Entrants paid an entry fee for each game and the proceeds were handed over to Tom Logan, ASBAH's telesales manager.

## Wheelchair complaints

WIDESPREAD dissatisfaction with wheelchairs has been highlighted in a recent report.

The survey, conducted by Sheffield Hallam University and the Research Institute for Consumer Affairs, showed that wheelchair users were dissatisfied with the lack of support, comfort and mobility that many wheelchairs offered.

## Play leaflets

THE following resource leaflets are available from PLANET (Play Leisure Advice Network) - *People with Sensory Impairments, People with Profound Multiple Learning Disabilities, Multi-sensory Environments and Music Therapy.*

Contact: Jayne Gillard, PLANET, Cambridge House, Cambridge Grove, London W6 0LE. Tel: 0181-741 4119. Fax: 0181-741 4505.

## Ski bobs for hire

SKIERS with disabilities are usually limited to group activity weeks or special courses. Now learners and intermediates with previous training can rent at low cost American-built Yetti Mono Ski Bobs from the charity Sporting Activities for the Disabled.

The service enables individuals to carry on the sport independently with family and friends, without the need to buy expensive equipment. Sailing boats are also offered on a rental basis.

For more information, contact Mike Brown at Snow + Rock 01932-570070 or Peter Bailey 01372-275147.

## Four-wheel drive powerchair

GBL Wheelchair Warehouse has launched the new four-wheel drive Saracen powerchair. Originally designed for use in the Australian Outback, the chair is being developed further in the UK to enable disabled users to gain access to rough terrain.

For more details contact the Wheelchair Warehouse on 0181-569 8955.



# Your Voice

presents  
(Choice, Independence)

## THIS IS YOUR LIFE TOWARDS THE 21ST CENTURY

**THE TIME?** From the evening of Friday 24th to the afternoon of Saturday 26th October 1997.

# C.I.C.

**THE PLACE?** The Jane Hodge Hotel, near Cardiff, is an accessible hotel with a wide range of leisure and sports facilities for all guests, including an indoor heated swimming pool.

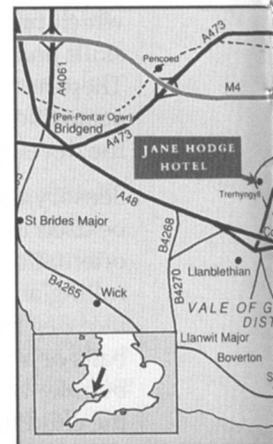
**THE REASON?** This event has been designed specifically for people with spina bifida and/or hydrocephalus. A wide range of activities will be held over the weekend with an emphasis on:

- Giving people the opportunity to try out new activities and learn new skills.
- Increasing personal awareness and development.
- Discussing important issues to us as people with spina bifida and/or hydrocephalus, and
- Learning how to get involved with YVIA or develop your own local group.

**THE COST?** Only £25.00 per disabled person. If parents or carers need to stay, a list of nearby bed and breakfast accommodation is available.

**FOR FURTHER DETAILS** and an application form, send in the form on this page to Teresa Cole by Friday 19th September 1997.

# A W



**24 - 26 October 1997, Jane Hodge Hotel**

**in ASBAH  
C.I.C. '97  
(Prevention & Control)  
NEW LIFE – MOVING  
TOWARDS THE 21ST CENTURY**

Afternoon of Sunday

**1997**

is a purpose-built, fully equipped sports facilities available to

locally for adults with spina



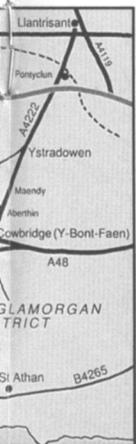
*You will be staying at the award-winning Jane Hodge Hotel, Trerhyngyll, near Cowbridge, South Glamorgan, Wales*

# WEEKEND AWAY WITH YVIA!

THE JANE Hodge Hotel, in the Vale of Glamorgan, is owned and managed by Grooms Holidays, part of a national charity which has been working with disabled people for 130 years.

The award-winning hotel is built on one level without any steps so that every part is completely accessible. Facilities include a warm swimming pool, spa bath, sauna, snooker, restaurant and bar, indoor sports and multi-gym, fully equipped with accessible weight training and exercise machines.

The hotel was recently highly commended in the Holiday Care Awards and has been upgraded from three to four crowns by the Wales Tourist Board.



**Jane Hodge Hotel, near Cardiff**

**Yes, I would like to be with YVIA at C.I.C. '97.**

**Name** \_\_\_\_\_

**Address** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**Phone** \_\_\_\_\_ (day)  
 \_\_\_\_\_ (eve)

**Please complete and return this form to: Teresa Cole, ASBAH, 42 Park Road, Peterborough PE1 2UQ, no later than 19th September 1997.**



# Getting into the media business

by Paul Darke

I should firstly say that almost everyone, who wishes to enter the media or film, fails – that is why there are so many critics. It is a tough, competitive business which takes no prisoners, spitting out its rejects with no mercy. But, there is hope. The main talents required are determination, dedication and skill (sadly, in that order); and being mediocre is no bar once a position is achieved or a single work gains prominence.

If you want it enough and can take constant rejection, you are the person for the job. Though it does help if you have youth, good looks, A-levels, a university degree and work experience on your side. The National Film School is, at this very moment, looking at how to get more disabled students on its courses/workshops (though fees are usual). So keep your eyes open and looking at relevant media information/training outlets, and watch out for any British Film Institute (BFI) initiatives (contact them and get on their mailing list, for example), or Arts Council of England schemes, such as the Disability Video Arts Project – usually advertised in *Disability Now* and *The Guardian* on Mondays (it is media jobs day and probably worth getting anyway).

If you want to make feature films, stick to film, rather than video or TV. Television side-tracks you and often insidiously exploits – the Disability Programmes Unit (DPU) will not do you any favours, for example, even if you reach its mediocre heights. Often a media organisation is looking for non-threatening trainees, so don't be too clever; it's a game that has to be played (I never was good at games!). Primarily, though, make

sure you are writing down ideas and treatments regularly and sending them off to places like BFI Production and BBC Drama, as well as Channel 4 and your local ITV regional station.

It is very difficult to get taken seriously unless you have a written script to at least first draft. So work on one, take it to professionals in your area for advice on re-writing once completed. There should be a writers' group in your area – details available from your regional arts board. A completed script shows dedication and commitment – something valued above all else (even talent), but do not take rejection to heart. If a script is rejected, ask why, and make corrections as requested.

Remember, most films/scripts are dreadful yet still get made and yours, given time, consideration and expert input by a script editor, could be as good (or bad) as anyone else's. Write from experience in the first instance, don't try to write about everything in one script and write it in the correct format, using a computer/type-

writer. The easier and more familiar something is to read, the more likely it is to be liked.

Read books on scripting, technique and direction (ring a film department lecturer at a chosen university for details), and watch a wide variety of films, not just popular ones – Swedish, Spanish (eg Pedro Almodovar's latest), and the avant garde (eg Steve Dwoskin's masterpiece *Trying To Kiss The Moon*, which is broadcast on Channel 4 later this year). Finally, keep your eye out for different films on television. Think about why they are good (or perceived to be), even if you do not like them (I often don't). But, above all, keep on *trying to kiss the moon*.

● Two separate bursaries for students with disabilities are available on two recognised one-year training courses – in Broadcast Journalism, and Newspaper, Photo and Magazine Journalism. **To find out about the 1998/9 bursaries, contact Steve Davis at RADAR on 0171-566 0127.**

● In the next *Link* Paul will review *Framed* – a new book on disability in the media, edited by Ann Poynton and to which Paul contributed.

## Becky – Barbie's fashionable friend

BECKY, the new addition to the Barbie doll family, has a fashionable and realistic wheelchair and she has bendable elbows and knees.

Whatever your feelings may be about Barbie and the world she portrays, the Play Leisure Advice Network (PLANET) welcomes the development of an affordable disabled doll which should be widely available.

Although Save the Children's research into disability toys raised concerns about the effectiveness of these toys when

used in isolation, Becky has a context – she is one of Barbie's friends and can join in all the activities associated with Barbie.

But Becky was launched in the United States in Toys 'R' Us stores and Toys 'R' Us, which has world exclusive rights to the doll, has no plans at present to bring Becky to the UK.

If you think Toys 'R' Us should introduce Becky in this country, please lobby your local store or phone 01628-414141 and give your views to the marketing manager.

# HYDROCEPHALUS NETWORK NEWS

ASBAH, 42 Park Road, Peterborough PE1 2UQ

Tel: 01733 555988 Fax: 01733 555985

Internet Web Site: <http://www.asbah.demon.co.uk/>

Reg Charity Number 249338

Autumn '97

## Unravelling the causes of behaviour problems

A SYSTEMATIC way of attempting to explain behaviour problems associated with spina bifida and/or hydrocephalus was the subject of an ASBAH presentation to the Research Society for Hydrocephalus and Spina Bifida.

Leonie Holgate, a former ASBAH specialist adviser, and Rosemary Batchelor, co-ordinator, specialist advisers, made the presentation in Manchester in July.

The talk outlined three stages of a *Behaviour Triage*, which was devised by Leonie a few years ago to help ASBAH staff advise on and sort out behavioural disturbances.

The three stages are:

### 1 Could the behaviour problem be shunt-related?

Has the behaviour changed recently, in the past six months, or over a longer period? Does the behaviour fluctuate. If so, an appointment should be made to see the relevant neurosurgeon for a thorough check. In addition, a list should be made of the

changes and, if possible, an idea of when these changes started and/or occur.

### 2 Has the young person ever had any other brain damage, eg Dandy Walker cyst, tumour, severe epilepsy, cerebral palsy etc.

Have there always been problems with behaviour? Is the behaviour cyclical? If the answer is yes, an appointment should be made to see the paediatrician/neurologist, with a view to a referral to a behaviour psychologist and/or possible medication.

### 3 Could it be related to a lack of understanding of any learning difficulties in those dealing with the young person, resulting in insecurity, fear, etc?

Have the young person's circum-



Leonie Holgate

stances changed, eg new school, change of staff, imminent exams, problems with personal/emotional relationships? If the answer is yes, make contact with any parties involved, through an ASBAH adviser or specialist adviser, to improve understanding and suggest strategies for reducing the pressure/confusion in the young person. This may lead to an assessment or re-assessment by an educational psychologist and appropriate therapists and, occasionally, counselling, when available.

*FUNDAMENTAL to the successful treatment of children with cerebral palsy is the co-operation of parents in home handling. Handling the Young Child with Cerebral Palsy at Home has been expanded and updated to include a wealth of new information. It is written by Nancie R Finnie FCSP, formerly superintendent physiotherapist, Dept of Paediatrics, Charing Cross Hospital. Price £19.99. ISBN 0 7506 0579 0. Butterworth Heinemann.*

## **HYDROCEPHALUS NETWORK NEWS**

### **Contacts**

**Network Co-ordinator:**  
Rosemary Batchelor 01733-555988.

**Education (National):** Peter Walker 01733-555988.

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

**Medical/Contenance (National and Eastern Region):** Julie Llewelyn 01733-555988.

**Medical/Contenance (South East Region):** Caroline Berkley 0181-449 0475.

**Education (North):** Mike Dodd 01484-510202.

**Occupational Therapist, (Northern Region and START):** Rose Hinchliffe 01943-609468.

**Medical (North and North West):** Geraldine Binstead 01943-609468.

**Education (Northern Ireland):** Lorna Johnston 012477-72191.

**Medical/Contenance (Northern Ireland):** Marie McGonnell 016487-64748.

**Hydrocephalus (Northern Ireland):** Lorna Johnston 012477-72191.

**User-group forum project worker (Northern Ireland):** Helen Quinn 01265-51522.

**ASBAH's Honorary Consultant on Hydrocephalus:** Dr Roger Bayston MMedSci FRCPATH, contact through ASBAH's Services Dept at ASBAH House.

## **SPECIALIST ADVISER (EDUCATION) ...**

**PETER WALKER** is a former head teacher, who describes himself as a family man. He has five children – a doctor of immunology, a tax inspector, an ordained minister, a youth worker and a nursing sister – and seven grandchildren, therefore he is experienced and greatly in demand where children are concerned!

He is also a minister, having attended a theological college and served as a missionary for several years in Zaire, formerly the Belgian Congo.

He has a particular interest in the education of children with physical and learning difficulties and, in his role with ASBAH, he covers the whole of England and Wales, apart from Northern Region.

Due to his knowledge and experience in special needs, Peter was appointed a lay panel member of the Special Educational Needs Tribunal a few years ago. "This gives me experience in dealing with local educational authorities in relation to their Statements for our service users," he says.

He is also a member of the Independent Panel of Special Education Advisers; the National Association of Special Educational Needs, a Fellow of the College of Preceptors and a member of the Institute of Management.

Most of Peter's work involves informing parents about their rights and advising them about Statements of



Special Educational Needs, choice of school, provision within school, etc.

"If necessary, I also travel to attend meetings with parents concerning their child's reviews and negotiate with local education authorities," he says.

"I talk about educational issues concerning hydrocephalus, attend study days, visit schools for staff training and also inform other professionals about hydrocephalus and/or spina bifida."

He receives lots of calls from teachers and ancillary workers wanting advice on how to integrate and effectively teach a child with hydrocephalus in mainstream schools.

Peter also writes reports about the specific difficulties of individual children when local education authorities are undertaking statutory assessments.

His interests – on which he will be concentrating more when he retires next April – include gardening, DIY, car maintenance and, of course, his family.

# Mystery shunt infection is solved by parents attending Hydrocephalus Study Day

**W**E are parents of a son born 36 years ago with spina bifida and hydrocephalus. Although the hydrocephalus has left him with learning difficulties, he has no paralysis and has always walked.

Paul had the usual shunt problems and operations as a baby and toddler, so we knew the symptoms to watch out for.

By the time he was three his hydrocephalus was pronounced 'arrested' and his shunt redundant but left intact. We had some years free of problems until Paul reached teen-age, then he began to have seizures and eventually it became obvious that he needed a shunt again. The old one was left in place with the new one being inserted the other side with the tubing going to the heart (a VA shunt).

Again, we had many years shunt problem free and because Paul was now an adult he no longer had the yearly check-ups at the children's hospital, which left us feeling a bit out on a limb.

Fortunately, Sussex ASBAH saw that there was a need in this area and have been running a clinic with Dr McCarthy at Chailey Heritage for some years which has been a real Godsend to us.

**By Eileen Thompson, from near Crawley, Sussex**

Although we knew what to watch out for in a shunt blockage, we had never been told what the symptoms would be to indicate shunt infection. Had we known we may have saved ourselves the anguish which followed.

Roughly two years ago, Paul developed what appeared to be an abscess over his old chest scar. I won't go into details about all the mishaps that then happened between us, our GP and a local hospital. Suffice to say that Paul ended up at another hospital to have the shunt system removed and antibiotics to clear the infection.

Everything appeared fine for a few months but in February 1996, Paul began to develop what was later called chronic anaemia. He became ex-

## What's in the Aug/Sept Link

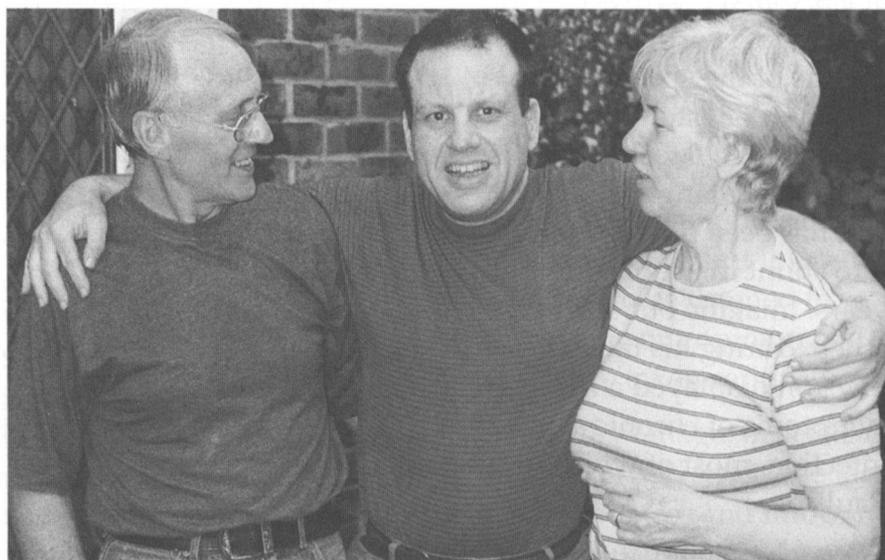
Awards for ASBAH young people . . . . . p5  
 Contenance campaign \_ p7  
 Carers Week . . . . . p10  
 Physiotherapy . . . p11-13  
 YVIA Conference \_ p14-15  
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*Link is ASBAH's main magazine. Subscription details from National Centre.*

tremely tired and pale and our GP did blood tests and after several courses of iron pills decided it was time for further investigation.

We waited several months to see a haematologist which, according to our GP, was quite within the time for 'urgent'! Meanwhile Paul had developed a very strange rash on his feet and legs.

*continued on page 4*



## *Mystery shunt infection* from page 3

He eventually saw the haematologist in September '96, seven months after our first visit to the GP. The outcome was that she decided it wasn't a blood problem and would refer Paul on to a renal specialist. The strange rash now had a name – Vasculitis.

So we waited once again. Paul's blood count was going down and down, and blood was appearing in his urine, but still there did not seem any sense of urgency.

In fairness to all the medical people involved, Paul had appeared to be well, apart from his fatigue and we now know that what was happening to him was quite rare. Nonetheless we felt he was seeing all the wrong people and time was being wasted, but we did not have the confidence to push our position. Also, Paul's blood tests had not shown any indication of infection.

Now we were waiting for an appointment to see a renal specialist. November came and we had booked our place at a SASBAH Hydrocephalus Study Day. Fortunately for us, one of the speakers was Dr Roger Bayston from Nottingham City Hospital. He is Hon Consultant to ASBAH and has been doing research into shunt infections for many years. Imagine our surprise when, during his talk, Dr Bayston displayed a list of symptoms of chronic shunt infection, most of which fitted Paul!

We spoke to him afterwards

and he immediately confirmed that it was indeed classic VA shunt infection symptoms. Well, our feelings were a mixture of relief and consternation. At last, here was someone who knew what was wrong with Paul, but how much damage had been done by neglecting it for so long?

Dr Bayston was very kind and informative and offered to write to relevant people for us.

When we got home we phoned our GP to find that a relief doctor was there. After putting her in the picture, we asked for Paul to be referred to an appropriate doctor. To our surprise, she refused and insisted we still wait for the renal appointment. For once in our lives we insisted and stood our ground and she reluctantly agreed to write.

Another month passed – why we let it drag on again, I do not know – and we had heard nothing so we phoned the hospital. They had no record of any letter about Paul. I phoned our surgery – they also had no record of a letter being sent. By this time we were beginning to think the whole world was against us. Why would nobody do anything for us?

Once more we sought Dr Bayston and Dr McCarthy's advice and ended up phoning the neurological hospital. They immediately said they would see Paul and he was eventually admitted at the end of December and had the shunt removed. This was not without difficulty because the plastic tube had become

brittle over the years and a small piece was left behind, so Paul was transferred to St George's at Tooting and a cardiac team was able to remove it, then he went back to our usual hospital.

Paul had a drainage tube for about four days and a new VP shunt was inserted (going into the tummy). We were told that Paul had shunt nephritis. We were quite surprised that he was not given any antibiotics but, when we inquired, we were told it was because they could not grow any cultures from his blood. We have since learned from Dr Bayston that this is not unusual and, of course, does not mean that there is no infection present.

Anyway, things seemed to be going OK. Paul's kidneys were recovering well and all his symptoms had disappeared, so he was able to come home again.

By February, we noticed the dreaded rash appearing on Paul's feet and legs again. We immediately contacted the hospital, and his surgeon suggested that a piece of the VA shunt must have been left behind because, had the new shunt been infected, it would have presented different symptoms. So we took Paul the next day for X-rays. Sure enough, there was a piece of tube roughly 4" long in the chest area. So it was back to St George's to see the cardiac consultant again. We were very hopeful and thought 'Great, remove the piece and all will be well,' but the consultant decided it was not the

*continued on page 5*

## Mystery shunt infection from page 4

source of the problem as it appeared to be a piece of tube left in from years ago. He felt it would be far too dangerous to try to operate as it would mean removal of part of the lung.

So, back to Paul's surgeon at our usual hospital. It seemed now it was going to be treated as a renal problem. We were unconvinced and felt, after speaking with Dr Bayston again, that his new shunt was the culprit.

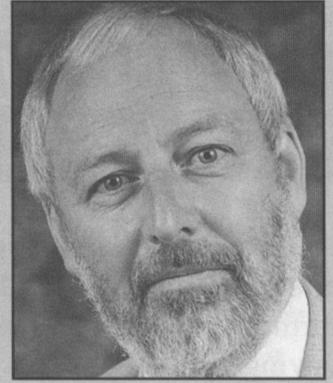
However, it was decided that Paul should be admitted to the renal ward at St George's for three days' tests, which would include a kidney biopsy and heart soundings.

The three days turned into three weeks and to top it all, whilst Paul was there, he developed a headache which we were sure was related to shunt blockage.

The renal staff were unaware of the symptoms and we had quite a time convincing them until nearly a week later, he was so poorly he could not walk and they were forced to contact our usual hospital. As it was a bank holiday and ambulances were scarce we agreed to take Paul ourselves, having to put him in a wheelchair to get to the car.

Paul had an operation that night and a couple of days later we took him back to St George's. Writing about it brings back all the stress and anxiety we felt. Paul was a hero throughout, never complaining about all the needles

**Dr Roger Bayston, ASBAH's hon consultant in hydrocephalus, says:** "Shunt nephritis develops when a VA shunt infection goes undetected for anything over a year or so. The body tries unsuccessfully to get rid of the infection by producing enormous amounts of antibody, and eventually this damages tissues such as the blood vessels in the skin (causing the rash), the kidneys (shunt nephritis), and sometimes the joints. Anaemia always develops and cannot be treated by the usual methods. The symptoms which Paul had are typical of shunt nephritis, and the only successful treatment is shunt removal and antibiotics according to the BSAC protocol. Diagnosis of VA shunt infection used to be very difficult, and we used to see a lot of nephritis, but since our use of the special blood test we can diagnose it quite easily and if done early the nephritis will be prevented."



and procedures he had to endure.

Paul's biopsy showed some kidney damage and he is now taking pills for high blood pressure. His kidney function is fairly good. The results of all the other tests were normal.

He was at long last put on antibiotics for one month and we are very pleased to say that Paul is in good shape at present and back at his day centre, enjoying being with his friends again. We hardly dare hope that all will be well from now on.

I should say at this point that we were able to send a sample of Paul's blood to Dr Bayston and he identified a Staphylococcus epidermis infection. Although Paul's doctors had said they could not grow anything, one or two admitted they did find Staphylococcus epidermis but

felt it was simply contamination when the samples were taken!

Dr Bayston's input has been invaluable to us and we are so thankful that we went to the study day. What a good thing that ASBAH is supporting his research – I know that funds are badly needed to keep the research going. The same goes for the SASBAH clinic at Chailey and we are very grateful for Dr McCarthy's expertise.

We do not want to be hard on GPs, nursing staff, etc who obviously cannot know everything, especially outside their own fields. But it would be so nice to be listened to and to have our opinion and experience taken seriously.

The value of magazines like *Link* and *HN News* is the fact that experiences and information can be aired and shared.

# True story

IN October 1994, two weeks after celebrating my 30th birthday, I was diagnosed as having hydrocephalus.

I had an emergency operation at Maudsley Hospital to have a shunt inserted. The doctors could not understand how my hydrocephalus had come on, especially as no tumours were evident. They are still not sure to this day.

They think the most likely explanation is the Toxoplasmosis I had when I was 19. I was very ill and had a severe reaction to the antibiotics they gave me.

After my last operation the doctors checked through my records and found that, at the time, I also had a case of meningitis which probably shifted the lining of my brain, thus narrowing one of my blood vessels. This steadily narrowed over the years, causing hydrocephalus to develop. The doctors said it was amazing I was able to function with so much excess fluid in my brain and that I have a very high pain threshold.

In May 1996 I noticed that three days in a row I woke up with a bad headache. Realising that something was wrong, I went to my doctor who very promptly arranged for me to go to Kings College Hospital for a scan. When I arrived the doctors told me that they would like to keep



**by Earlin Alexander  
from Catford, London**

me in for a few days observation.

A week and two scans later I was still there. I was still experiencing the headaches but the scans were normal. The doctors told me that there was nothing wrong because if the shunt was blocked my condition would have deteriorated and I would be displaying more symptoms than a headache.

I was told I was using valuable bed space and to go home. I was very distressed as deep down I knew something was wrong. The nurses were very supportive and knew my history, having nursed me through my first operation.

They remembered that I was an unusual case as I displayed no real symptoms, so the sister arranged for a neurologist doctor to see me. He was sympathetic and interested to find out how I developed hydrocephalus and suggested

that he carry out further tests on me at Maudsley Hospital.

Over the next week I had every sort of test imaginable carried out on me. I was still having headaches and had another scan. Again, the result was normal. The doctor said that all the tests were negative and that I would have to go home after the final test, a lumbar puncture.

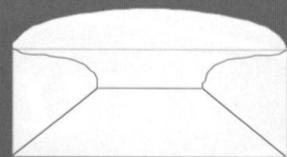
The lumbar puncture was carried out at 9am. By 4pm I was unconscious. I then drifted in and out of consciousness over the next 48 hours.

When I came to, I was in intensive care being prepared for an operation to replace the shunt. I was told that my shunt was not working properly but, every time a scan had been carried out, the shunt seemed to work. This was only picked up by the doctors because the fluid removed for the lumbar puncture had unsettled an already unreliable shunt, hence the unconsciousness.

Since the operation I have had no low pressure headaches and everything has gone back to normal.

The doctor who told me I was using valuable bed space came to see me just before I was discharged. He commented on how strange it was that I had displayed no symptoms. I replied that not everyone could be based on a 'text book' diagnosis and that doctors should listen to patients more.

I hope that is one doctor who won't be so dismissive of patients' views again.



I WOULD like to hear from parents who have a child with a brain tumour plus hydrocephalus. My two-year-old son was born with a brain tumour which shrunk of its own accord, so he has a better future to look forward to.

*Miss S Vaughan  
70 Buxton Crescent  
Turfhill, Rochdale  
Lancs OL16 4TU*

I HAVE a seven and a half-year-old daughter Emily who has hydrocephalus and severe learning difficulties.

I would very much like to contact other parents of children with severe learning difficulties who are about the same age as Emily or a bit older, to get an idea of what we should expect.

Emily is now at a special school after moving from a mainstream school more than 12 months ago. She is in a smaller sized class and doing a lot better.

*Karen Royle  
1 Mithril Close  
Widnes  
Cheshire WA8 3FH  
Tel: 0151-424 1788*

## Young people with experience of foster care needed

THE National Foster Care Association (NFCA) wants disabled young people, who are or have been in foster care, to help improve future care planning.

In a new project, funded by the National Lottery, NFCA will carry out a pilot study with three local authorities (Camden, Islington and East Sussex) to identify the support needed by disabled young people to enable them to make the transition to adult living. The study will also investigate the levels of support provided by and offered to foster carers looking after disabled young people.

Disabled persons project worker Simone Aspis said: "Ten per cent of foster carers in an NFCA survey raised concerns about the care they

## Stay safe in the sun

HERE are some fashionable and practical ideas for people who enjoy being out in the sun but want to protect themselves.

Legionnaire-style sun hats for children and adults, with peaked front and flaps over the ears and neck, are available from the Health Education Authority (HEA).

The hats are made out of a fabric which blocks out at least 97% of the harmful rays of the sun and the price is £9.50 for all sizes.

Also featured in the HEA catalogue are one and two-piece sun suits, hooded tops,

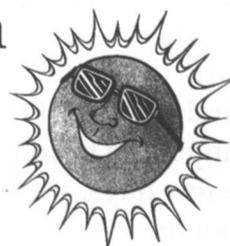
long shorts and t-shirts with higher necks and

longer arms, to help children and adult's 'cover up' on the beach or in the garden.

There is also a choice of four styles of children's sunglasses giving 100% ultraviolet protection, at £3.95 each.

A tent-like structure for the beach - 'the pod' - gives babies and toddlers total protection from sun, heat, wind and rain. It costs £39.95.

*The HEA brochure Sun Know How '97 can be obtained on 01225-867711.*



were able to provide for disabled young people. Care planning for disabled young people reaching the age of 18 was variously described as confused, confusing and, in some cases, inadequate."

Ms Aspis hopes to draw on the experiences of young

people and their foster carers in the three local authority areas in order to define future good practice.

*Anyone who can help should contact Simone at the National Foster Care Association on 0171-828 6266.*

# True story

IN May 1996, Kirsty was complaining of headaches and she was having lots of fits. At our local hospital, they just wanted to monitor Kirsty but, by the end of the day, she was screaming with headaches and hated the light.

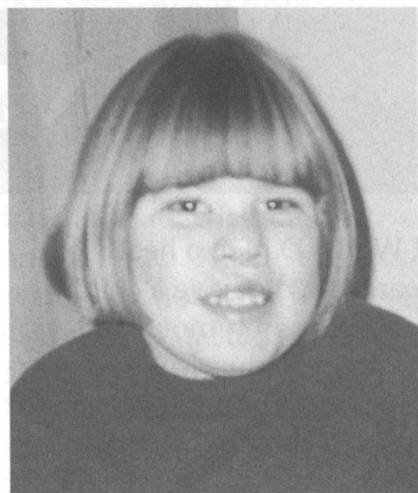
As they were going to do nothing, we decided to take Kirsty to Kings College Hospital in London. They fixed our daughter up to a monitor to see if there was any pressure there, but she was fine and she didn't complain of any more headaches. So, after a few days, we brought her home.

Everything was fine until October when she complained of headaches again. Again, all our local hospital wanted to do was monitor Kirsty, so we took her to another hospital for an x-ray which showed her shunt was broken in half in the neck. The doctor was unconcerned and told us to take Kirsty to Kings College

**by Nicola Manley  
from Shepherdswell,  
near Dover**

Hospital in our own car. We were glad to get out of that hospital and decided these hospitals were a waste of time and we should have gone straight to London, but then we thought we should have faith in these hospitals as they deal with Kirsty and should realise problems when they arise.

We got to Kings at 6pm and they said it was disgusting that we had come up on our own - we should have come by ambulance. At midnight they operated and said the operation would only take an hour, but it ended up taking three hours. They found Kirsty's shunt had fallen to pieces. The doctor said it was like hard putty and he had not seen anything like it before. Kirsty's last shunt was put in nine years ago when



*Kirsty*

she was three weeks old, so it had lasted a long time.

Kirsty recovered quickly and was soon back at school.

However, a check-up in May this year revealed that the new shunt was failing to drain on the left side, so another one had to be put in. So now Kirsty has three shunts, but she is still having lots of fits and headaches, which are once again keeping her away from school.

When Kirsty has headaches and really does not feel well, we know that something is wrong as she does not moan for nothing. We just wish the doctors would take it all a bit more seriously.

It was nice to read the letter from Mandy Tindal from Gosport, Hants, as it seems that she had the same sort of response we had.

*If you have a true story you would like to share, send it to: Rosemary Batchelor, Co-ordinator, Specialist Advisers, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.*

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

Service user's name \_\_\_\_\_

Parent's name (IF APPLICABLE) \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_ Tel: \_\_\_\_\_

I enclose a cheque/postal order payable to 'ASBAH.'

All payments should be made in Sterling.

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

I recently went on a short trip to Paris. This was one of those 'collect ten million tokens and get a free trip' jobs you see in most newspapers. For days, all round the country my family was busy shredding newspapers. That, for me, was the easy part. Although a free trip can't be bad, I didn't relish the thought of physically getting about a strange city. To make life easier for myself (and consequently the family) some research was needed.

What I really wanted to do was rent a Shopmobility-style electric scooter in Paris and buzz around the city centre. However, France is sadly behind the times and seems to lack such a service. (Any budding business types want to change that?)

I went through a number of well-meaning but unavailing people looking for information, until I got to RADAR. They recommended the book *Access to Paris* and very kindly sent me the scooter-related pages. I set off to find the rest of it.

I've complained often and long about British book shops' treatment of the disabled. Entire shelves can be stacked with *The Love Life Of The Mongolian Wombat* (or some such) and there's not a single book about travel for the disabled in the whole store. I'm not talking about some hole in the wall shop, but a multi-floor site

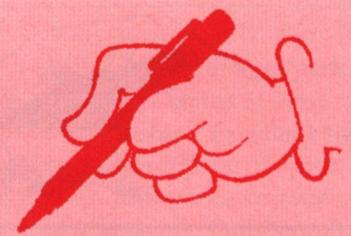
catering for more students than you can throw a grant at! I'm determined to write to book shops requesting more stuff for disabled people. If you agree, write to me via *Link*!

As a link to Europe, using the Eurostar is much easier than ferries. (No sickness!) We used a 'normal' train to London, abandoned the grindingly slow rail-bus for a taxi and arrived at Waterloo, where a wheelchair was waiting for me. I am always relieved to find only one wheelchair and not two – one for Mr Fulford and one for Mr Brown.

There are down and up sides to a wheelchair. The down side is, if someone is pushing you, you have less chance at the duty free – if you don't speak up! The up side is you get to push through the crowd and save your legs. And you get on the train first.

The Eurostar train was unnaturally comfortable, clean and wickedly fast (on the French side). Entering the tunnel was a notable moment, even if it was visually rather dull. The tunnel is, after all, just dark. We were soon out the other side and speeding through a blurred France.

Although all the staff and signs were bilingual, I couldn't help noticing that French announcements came first on the other side of the tunnel.



## Dave's diary

Arriving in Paris we caught a taxi to the hotel. We abandoned the Paris rail system as too much like hard work. Similarly, the only places the book said might rent scooters were impossibly far from the city centre. We ended up using a combination of taxis, buses and boats to get about and see some very impressive buildings. The other great thing about Paris was the number of establishments providing food and drink. We did surprisingly well in those 48 hours.

**David Fulford-Brown**

## DATES FOR YOUR DIARY

### 7-8 August

Independent Living Exhibition, Sandown Park, Esher, Surrey. Admission free if tickets ordered in advance, tel: 01275-836465.

### August 18-19, 20-21, 22-23

ASBAH Northern Ireland Region, three two-day mobility courses in Armagh (Aug 18-19), Coleraine (Aug 20-21) and Belfast (22-23), with Tim Leech, ASBAH specialist adviser (mobility). For a free place, contact Regional office, tel: 01265-51522.

### 28-31 August

IFHSB International Congress, Gustav-Stresemann-Institut, Bonn, Germany. Fee DM 700 for bookings before 30 April, 10% surcharge afterwards. Details: Walter Bass, Germanenstr 59, D-53859 Niederkassel, Germany, tel: +49-231-834777, fax +49-231-833911.

### Monday 8 September

ASBAH support group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. Valerie Bottoms, tel: 01582-605749.

### September-November

ASBAH North Ireland Region, repeat of 'Lifeskills – a survivor's course', as an evening class. Details: Regional office, tel: 01265-51522.

### Monday 22 September

Disability Equality Training Course, introductory course led by Barbara Lisicki, Greater London Association of Disabled People, 9.30am-5pm, at 336 Brixton Road, London SW9 7AA. Brenda Ellis, tel: 0171 346 5805.



# Letters

 **HAVING** lost a daughter to spina bifida and hydrocephalus 10 years ago, I am currently conducting research into how people's lives are affected by neural tube defects.

The first area of my research deals with counselling to families, other than genetics counselling, who have suffered the loss of a child – either through the mother having to undergo a termination or where the child passed away in early infancy. Were you offered counselling? If so, what form did it take? Did you feel the counselling helped or, did you feel that there was something missing?

The second area of my research deals with the emotional problems experienced by males born with external genetic deformities in forming relationships.

If you feel able to contribute to this important area of research then you are invited to write (anonymously if you prefer) to me at the address below. I thank you in anticipation of your assistance.

*Stephen Weiss-Geiger  
The Faculty of Humanities  
Nottingham Trent University  
Clifton Campus, Clifton Lane  
Clifton  
Nottingham NG11*

 **I AM** an occupational therapy student researching services received by parents who are wheelchair users. This research study forms part of my degree course. Please can any *Link* readers help?

I would like to interview parents of children under five who have had contact with a Social Services occupational therapist (OT). People who live in the South

Midlands, Home Counties or London areas would be the most easily accessible for me, and I would welcome contact from fathers as well as mothers.

For further information, please ring Diane Stevens on 01442-392309 (give me your number and I will call you back to keep the cost to a minimum). Thank you.

*Diane Stevens  
Hemel Hempstead*

 Please send your letters to: **Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.** The Editor reserves the right to edit letters for publication.

 **MY** daughter Amy was featured on the cover of *Link* a few months ago.

Do any readers with spina bifida and/or hydrocephalus have relatives in the Royal Navy who were present at the testing of the 'H' bombs and 'A' bombs on Christmas Island and Monte Bello in approx 1957-1958.

If you can help, please contact me at the address below. Everyone's help will be greatly appreciated.

*Mrs Helen Boler  
157 Woodseats Road  
Woodseats  
Sheffield S8 0PL*

 **I LIVE** in Louisiana and lost a daughter to anencephaly in 1995.

I am trying to start a Memorial Page for children on the Internet and would like parents who have lost children to a disease to contact me. My e-mail address is: [www.geocities.com/SouthBeach/Lights/4198](http://www.geocities.com/SouthBeach/Lights/4198)

There is a form to fill out and I will do the rest. Please e-mail me with any suggestions. Your help will be appreciated.

*Tammy*

## DIARY DATES EXTRA

### 25-26 September

Independent Living Exhibition, Doncaster Exhibition Centre. Admission free if tickets ordered in advance, tel: 01275-836465.

### Saturday 27 September

'Getting the Best For Your Child' - ASBAH study half-day for parents with children under-five at the Glaxo Centre, Liverpool. 9.30am-1pm. Speaker: Paul May, consultant paediatric neurosurgeon, Alder Hey Children's Hospital. *Details:*

*Angela Lansley 0151-733 8392 or Elizabeth Miers 01490-450360.*

### Monday 13 October

ASBAH support group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, tel: 01582-605749.*

### Thursday 23 October

'Spina Bifida & Hydrocephalus - An Holistic Approach', study day organised by ASBAH Eastern Region, The Lincoln Suite, The Lawn, Union Road, Lincoln,

9.30am-4.05pm. Speakers: Professor Kypros Nicolaidis; hon consultant paediatric neurosurgeon Michael Vloeberghs; consultant paediatric surgeon and urologist Christopher Rance; ASBAH specialist adviser (medical) Julie Llewelyn. £15 service-users and family members, £30 professionals. *Booking forms (returnable by 23 September) from: Rebecca Sewell, ASBAH East, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988.*

## HOLIDAY ACCOMMODATION

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

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

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

### FOR SALE

'Lark 4', four-wheel scooter in excellent condition, with battery charger, purchased in March 1997 for £2,300 but no longer required. £1,900 ono. Stored in garage at Didcot, Oxfordshire. Mrs Lesley Young, 131 Walterbush Road, Chipping Norton, Oxon OX7 5DQ.

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

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

**WESTGATE ON SEA, KENT** – Sandy bays and wheelchair access. Semi detached bungalow sleeps eight plus cot. Colour TV, kitchen and shower room for wheelchair use. Lovely garden and summer house. Parking 3 cars. NO steps. Cheap autumn and winter breaks. *Greenwich ASBAH, Doug Endersby 0181-293 4598.*

**NAISH HOLIDAY VILLAGE, NEW MILTON** – Cliff-top park with "excellent" status at New Milton, Hampshire. Excellent site facilities within 100 yards, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible log cabin accommodation. Sleeps six, well-furnished. Free club membership.

**GRANGE COURT HOLIDAY VILLAGE** – Park with "good" status at Goodrington Sands, Devon. Excellent site facilities within short walk, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible mobile home. Sleeps 4-6, well appointed. Free club membership. (Purchased with funds from the National Lottery).

**MILLENDREATH HOLIDAY VILLAGE** – Excellent seaside site with good facilities, just outside Looe in Cornwall. Restaurant, clubhouse, indoor pool. Fully-equipped, and fully wheelchair accessible, two-bedroom chalet accommodation. Sleeps 6 – well-furnished and comfortable. Free club membership.

*Details: Mr P Cash, tel: 01425-672055 – Bournemouth Spina Bifida Association, registered charity number 261914.*

# LINK Rates

Link ISSN 1360-323X

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Published by ASBAH,

ASBAH House,

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Peterborough PE1 2UQ

Telephone: 01733 555988.

E-mail: [lcawthorne@asbah.demon.co.uk](mailto:lcawthorne@asbah.demon.co.uk).

### LINK SUBSCRIPTION 6 EDITIONS – 12 MONTHS

UK ..... £4.80

Europe and Overseas Surface Mail ..... £7.50

Air Mail ..... £15.00

All payments should be made in Sterling.

Classified Rates: £3.50 for 30 words max;

£4.75 for 30-45 words;

£6.00 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.

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