

# Link

The magazine for people with  
Spina Bifida and/or Hydrocephalus

February/March 1999

Issue No 180 Price 80p



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## Euro-conference success

PEOPLE with SBAH from across Europe were able to compare notes on their lives, aspirations and frustrations at a conference organised by *Your Voice In ASBAH* (YVIA).

Although the delegates came from different cultures, common themes were found in their experience of discrimination and attitude.

Four people from Portugal and four from Eire joined a dozen British delegates for the groundbreaking event – made possible by a £26,000 grant from the European Commission to YVIA.

YVIA co-ordinator, Jon Burke, said: "The conference gave a lot of information and ideas about how disabled people can become involved in organisations and how organisations can involve disabled people in decision-making."

The other strand to the conference was to discuss the setting up of a Europe-wide register of disabled trainers by Mobility International.

Those present gave a lot of useful feedback on the idea of a register. The purpose of the register and the types of trainers that should be listed were clarified.

Another meeting is planned later this year, possibly in Portugal.

## New shunt will resist infection

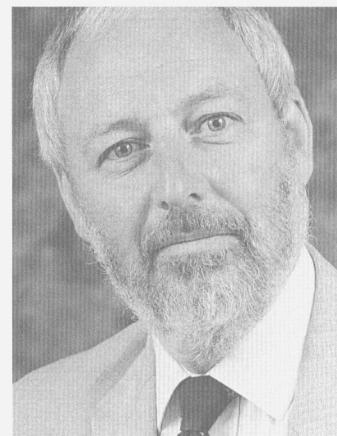
**RESEARCH funded by ASBAH could improve the quality of life of thousands of people who are being treated for hydrocephalus.**

For over 20 years, ASBAH has been supporting the search for a breakthrough in the control of a major complication in the use of the hydrocephalus shunt.

Post-operative infection has led to the failure of many shunt implants because bacteria originally found on the skin have colonised the shunt tubing, causing it to be blocked. Up to 4,000 shunt operations are carried out each year in the UK – many of them involving replacing infected shunts.

Although the shunt is still the best available treatment for hydrocephalus, problems of infection and blockage have bedevilled the shunt implant since its invention in the 1950s.

Now, ASBAH-funded research at the University of Nottingham looks like reducing the risk of this complication by up to 80 per cent. A new infection-resistant shunt, developed by our consultant in hydrocephalus, Dr Roger Bayston, has started to be used in operating theatres around the world.



Dr Roger Bayston

Dr Bayston, head of the university's Biomaterials-Related Infection Group, said: "As with all implantable devices, infection is a serious complication requiring surgical removal and further spells in hospital. In shunts, the infection rate varies from about five per cent in adults to between 10 and 15 per cent in babies."

The new shunt was put on the market in October by Codman Ltd, part of healthcare products giant Johnson & Johnson. It goes by the trade name of Bactiseal.

Dr Bayston said: "As the idea was a new concept, regulatory authorities

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Cover: Seven-year-old William McIlhatton celebrates with the rest of his pals, after hearing they have won a trip to Disney. Story on page 10. Photo reproduced with kind permission of Belfast Telegraph Newspapers Ltd.

# STAFF NEWS .... STAFF NEWS .... STAFF NEWS....



TAKING a bow – the new line-up of ASBAH's directors, following the retirements of Teresa Cole and former finance director and company secretary Derek Knightbridge.

Executive director Andrew Russell is pictured above with, from the left: new finance director and company secretary Brian Deffee;

new assistant director (policy and marketing) Linda Hams; Milly Rollinson, who has been promoted from services manager to assistant director (services); and Paul Dobson, promoted from assistant director (personnel) to director of personnel and IT. Paul now carries the additional rank of deputy executive director.

TERESA and Frank Cole plan to be even more of a double-act in the future. Teresa and her husband both retired from work in January and now their home near Huntingdon is alive to the sound of music as our former assistant director (services) brushes up her keynotes on the portable baby grand piano he bought her as a retirement cum birthday present.

On her leaving day, the couple turned the meeting room at ASBAH House into a French bistro and entertained staff lavishly. It was a familiar sight: Frank and Teresa together at ASBAH functions – always hospitable and cheerful, but leaving nothing to chance.

Now, they've put ASBAH behind them. Well, not quite. Teresa remains vice-president of the International Federation of Hydrocephalus and Spina Bifida (ifHSB) until well into the year 2000 and will carry on our work there. A couple of days after leaving us, she was making sure the paperwork was in order for an imminent ifHSB board meeting.



*Teresa Cole has retired from her role as assistant director (services)*

Frank has quit the agri-chemicals business full-time, and there's talk of him keeping his hand in with some consultancy. But from now on they'll be sharing even more time together: in the garden, going to France where a daughter, son-in-law and grandchildren live in Beaujolais country (just five minutes down the road, we're reliably informed, from one of the wineries), and helping daughter Marion over here decorate her flat.

But, first, sorting out the little things. The day after her retirement, Teresa said she went to the dentist believing that, if she was to get her teeth into anything new, they'd better be in good condition!

● JULIE Llewelyn, specialist adviser (medical) has left ASBAH to become a nurse adviser for a health-care company.

During her five years with us, Julie was based full-time at national centre, giving advice on continence management and other medical issues.

In her new job, with Wilkinson Healthcare, she will be doing similar work in the East of England.

Among her achievements while at ASBAH were getting the anal plug available on prescription; playing an important role in our annual survey of continence services and initiating a joint venture between ASBAH and Colorplast.

Julie said: "I have enjoyed my work with all the advisers out in the field, many of whom I will keep in contact with."



● NURSE, Paula Thompson, switches from East Region to national after being selected to step into Julie Llewelyn's shoes as full-time specialist adviser (medical).

East Region has begun looking for another part-time specialist adviser (medical).



● WELCOME back to Pat Waller, who returns to the job of adviser for Leicestershire and Northamptonshire. The new appointment follows Cathy Harrell's departure in November.

During her four years away from ASBAH, Pat has been a primary school teacher.

Pat's ASBAH phone number is 01933-674499.

## TV APPEAL CELEBRITY BECOMES ASBAH'S ROVING AMBASSADOR

**FROM TV star in Britain to shadowing a top civil servant in Europe – teenager David Proud saw 1998 out with style.**

David joined young disabled people from throughout Europe, invited to shadow European Commissioners at a special event held in Brussels in December to mark the European Day of Disabled People.

David (15), who goes to school in Whittlesey, near Peterborough, was named by ASBAH to be one of two disabled people representing the UK. Earlier in the year, he helped represent us on TV during the early-morning 'Get Up and Give' charity appeal.

Nursing a heavy cold, David shadowed Commissioner Padraig Flynn; took part in a shadow Commission meeting, which issued its own communiqué; and was invited into the European Parliament building to open a disability exhibition.

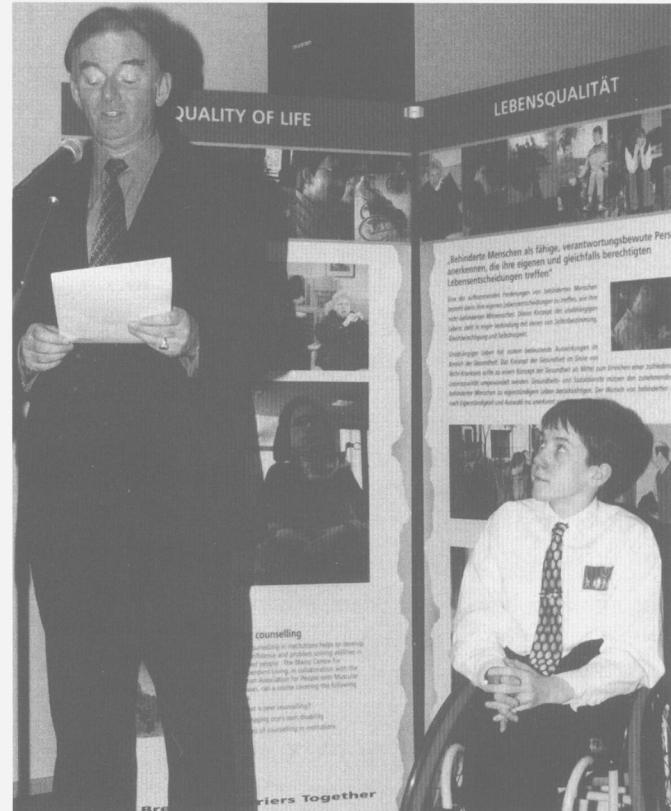
He and his mum, Wendy, enjoyed red carpet treatment after flying into Brussels from Stansted and staying at a top-class hotel.

Whittlesey's shadow Commissioner, sounding every inch the European statesman, commented: "The points I raised during our meeting were discussed in great detail and I was very pleased with my input into the final statement. There was a press conference where two of the shadow Commissioners read out the final statement to the world's press.

"The whole event was very exciting. I enjoyed putting my views across to the people who can make a difference and I consider it an honour to have been able to do so."

David was put forward to take part by Teresa Cole,

# David demonstrates star quality at European HQ



**David Proud helps Irish Commissioner Padraig Flynn open an exhibition in Brussels**

who has just retired as ASBAH's assistant director (services). Teresa remains heavily involved in European disability issues as vice-president of the International Federation for Hydrocephalus and Spina Bifida.

Teresa said: "David was an ambassador for ASBAH during two major events last year. He and his family performed brilliantly on both occasions."

# Officers & Staff

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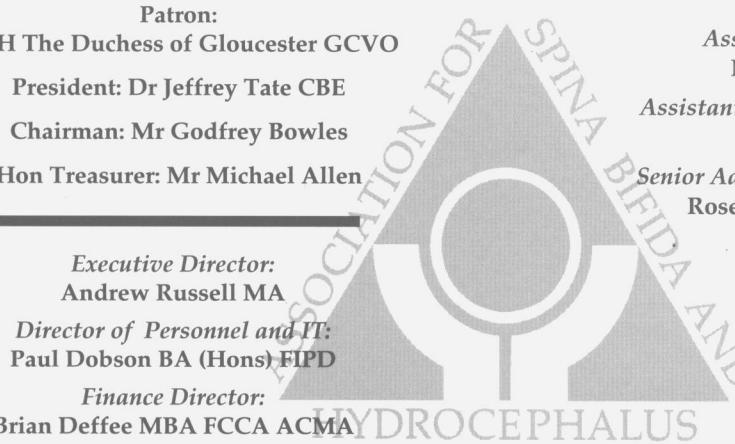
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# STAFF NEWS EXTRA .... STAFF NEWS EXTRA ....



Linda Knight



Caroline Ruijterman



Val Hardy



Shirley Large

● New national specialist adviser (mobility) is **Linda Knight**, who has done a lot of work on access in her previous professional role. With over 25 years' experience in occupational therapy, Linda has worked for both social services and health authorities in the Eastern Region.

She explains her latest career move with: "I hit 50 and thought it's time I did something else."

Linda works Mondays, Tuesdays and alternate Wednesdays, based at ASBAH national centre in Peterborough, tel: 01733-555988.

For the rest of the week, she will be writing reports for an agency to back-up compensation claims from people who are disabled by an accident. "I'm sure this will be intriguing as there will be no holds barred on the amount of money I can ask for, which will be totally different from when I was working for statutory authorities," she said.

● Two new part-time under-16s advisers are in post in Sussex following the sad passing of Sheila Wilkinson last year.

**Caroline Ruijterman** and **Val Hardy** are funded by Sussex ASBAH and national ASBAH.

Caroline covers West Sussex – her main hours are Mondays and Wednesdays from 12-5pm. Tel: 01903-871 443.

Caroline also now works as a practising counsellor although her original profession was social work. Not new to Sussex ASBAH, she also continues her job as a night care assistant at The Bungalows, Worthing, the group's independent living scheme.

Caroline lives at Patching and enjoys walking on the Sussex Downs. She is married to a Dutchman – hence her unusual surname – and has two teenage children.

Val Hardy is already a fairly experienced hand in Sussex. From 1987, she was full-time fieldworker for people aged 16+, going part-time when her first daughter was born and resigning in 1994 when her second daughter came along.

Since 1995, Val has been working for Sussex ASBAH on the 'buddy scheme' in which she tries to link up individuals with a friend. She also helps adult members to organise group social activities. She will be combining these roles with her new job covering East Sussex.

Val's main hours of work are Wednesdays and Thursdays from 9.30am–2.30pm. Tel: 01444-410 515.

● Answering your calls and welcoming visitors to ASBAH House in the afternoons is **Shirley Large**, who took over from Jill Whitmore.

Shirley is also doing a National Vocational Qualification (NVQ) Level 1 in office administration.

## New infection-resistant shunt, from page 3

around the world have taken a great interest in it and demanded extremely rigorous testing, probably more than for any other implantable device."

Johnson & Johnson hopes soon to launch the product in the USA, once final approval comes through from the federal Food and Drug Administration.

ASBAH executive director Andrew Russell commented: "This is an exciting development, which could improve the quality

of life for many thousands of people who rely on hydrocephalus shunts to stay healthy.

"Properly taken up, it could also save millions in healthcare budgets round the world as surgeons carry out many fewer shunt replacement operations."

Dr Bayston has worked for over 20 years on a number of world-leading research projects which have improved hydrocephalus shunt technology. He was ASBAH's Research Fellow for three years in the mid-70s.

## Taped publications

*Lift*, ASBAH's free magazine for people with sb/h, aged 14 years and upwards, is available on audio tape. If you prefer to receive *Lift* in this format, please contact Liz or Tony in the Publicity Department on 01733-555988.

ASBAH's Information Sheets 1 and 2 – *What is Spina Bifida?* and *What is Hydrocephalus?* – are also available on audio tape. Other ASBAH Information Sheets are taped, on request to our Information Dept, 01733-555988.

# Benefits proposals: "good for those who can work"

**ASBAH has welcomed the Government's proposals to reform the benefits system to encourage as many disabled people as possible to find work. But we have warned that the needs of the poorest in our community seem to have been overlooked.**

"There is no promise of any great improvement to the situation of the poorest disabled people and their families," said Linda Hams, ASBAH's assistant director (policy and marketing), who responded to the consultation.

"Income is not the only issue: access to the built environment, to good quality education and services, to affordable equipment of a high standard all impinge on finances and employability.

"Many ideas will be welcomed by disabled people who want to and can work, but there's little in the paper for people who need meaningful and dignified alternatives to work.

"On the other hand, we are pleased that the Government has made a statement to the effect that no-one should lose from these proposals."

The consultation paper – *A new contract for welfare: support for*

*disabled people* – includes the following ideas:

■ Reform Severe Disablement Allowance (SDA) so that people disabled below the age of 20 get extra help – an extra £25.60 a week more, after a year on benefit.

Exclude new claimants aged over 20 who have had more chance of working and qualifying for Incapacity Benefit (IB), and may also get non-means tested Disability Living Allowance (DLA).

ASBAH says: Excluding older claimants from SDA will be a major cut in entitlement which discriminates against women who've not had a work record, and will therefore not be eligible for IB.

■ Introduce a new Disability Income Guarantee for the under-60s on Income Support (IS) with the highest care needs. There will be a similar guarantee for severely disabled children in families on IS.

ASBAH says: Great if it works, but more details needed.

■ Extend for the first time the higher mobility rate of DLA – worth £35.85 a week – to three and four-year-olds.

ASBAH says: And about time.

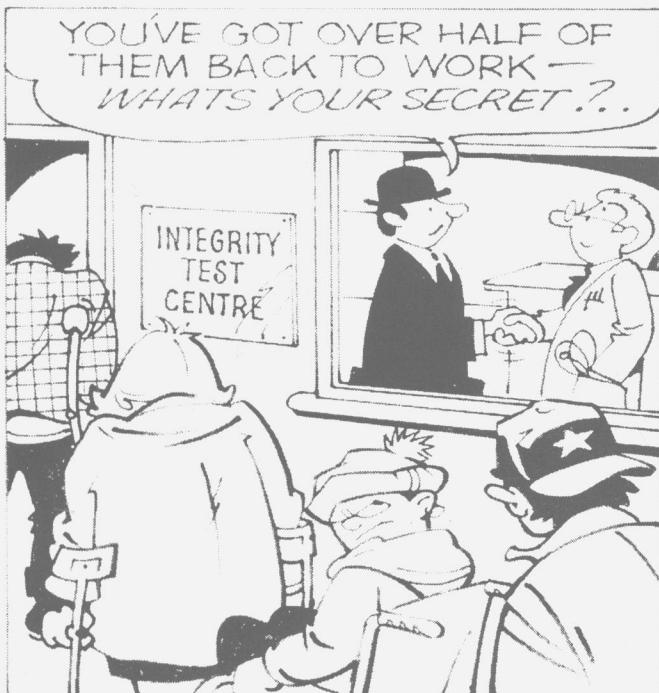
## MP to shadow ASBAH staff

A MEMBER of Parliament is to join ASBAH on an unpaid, two-day assignment in order to find out what makes us tick.

Peterborough MP, Helen Brinton, will shadow members of staff later in the year under a scheme organised by the National Council for Voluntary Organisations, where backbench MPs are invited to pair themselves with charities. Not only will she be finding out how we work in a highly competitive fundraising environment, but she will learn more about the wide range of issues which affect severely disabled people.

The MP has already co-operated with ASBAH when she tabled a widely-supported Commons backbench motion calling for the mandatory fortification of flour with folic acid.

*Cartoonist David Swift takes a sideswipe at the "All Work Test" for Incapacity Benefit, which includes a score for inability to carry a 5lb bag of potatoes in either hand.*



## BIP update

IT SEEMS that the Benefits Integrity Project (BIP) will continue until a replacement method of regular reviews of Disability Living Allowance cases is initiated.

A further exemption has come to the attention of Mary Malcolm, ASBAH's national benefits adviser and co-ordinator of our Eastern Region. If you received a **life award** of Attendance Allowance and Mobility Allowance **before** conversion to DLA, you should **not** be contacted under BIP.

You are also exempt from BIP if you:

- Are getting the lower rate of either of the components; or
- Are getting just one of the components at any rate; or
- Have claimed DLA in the last 12 months; or
- Are under 16; or
- Are quadriplegic; or
- Are deaf and blind; or
- Are a double amputee; or
- Are terminally ill; or
- Are severely mentally impaired; or
- Are paraplegic; or
- Are aged 65 or over.

From 23 September 1998, you are exempt, and should not be contacted under BIP, if your main disabling condition is: cystic fibrosis; dementia; Motor Neurone Disease; Multiple Allergy Syndrome; Hyperkinetic Syndrome; Total Parenteral Nutrition or Haemodialysis **and** you get both the higher rate mobility component and higher rate care component.

From 16 November 1998, you are exempt from BIP if your DLA award was made before April 1992, **or** your main disabling condition is: Parkinson's Disease; Multiple Sclerosis; neurological disease; learning difficulties **and** you receive both the higher rate mobility component and higher rate care component.

- **If you are contacted under BIP, it's important that you take advice before filling out the form as you may be exempt.**

## LINK LOOKS AT ASBAH'S SIXTH FAMILY WEEKEND

ASBAH Family Weekends are increasing in popularity. We were so swamped with applicants for the last one that, unfortunately, we had to turn down 14 families. All asked to be put on the waiting list for next time!

We took 15 children with spina bifida and / or hydrocephalus, aged from 10 months to six years old – along with parents and brothers and sisters – to the Pioneer Centre, Cleobury Mortimer, near Kidderminster, Worcestershire.

Two local families came for the day on the Saturday as we ran out of accommodation and they were eager to come and listen to the lectures and meet other families.

We took 16 ASBAH staff including three from our Telesales team (a new venture for them!) and four volunteers. We also took an aromatherapist and a reflexologist.

The children were divided into four groups according to age, each group with its designated group leaders.

While the children had their own programmes, the parents had lectures and discussion groups.

In the evenings, we ran a baby sitting rota – and a mini bus service to

# Llamas, lions

by Rosemary Batchelor  
Senior Adviser Health & Policy Issues, ASBAH

the local pub. One single mum had never been out in the evening since her son was born five and a half years ago.

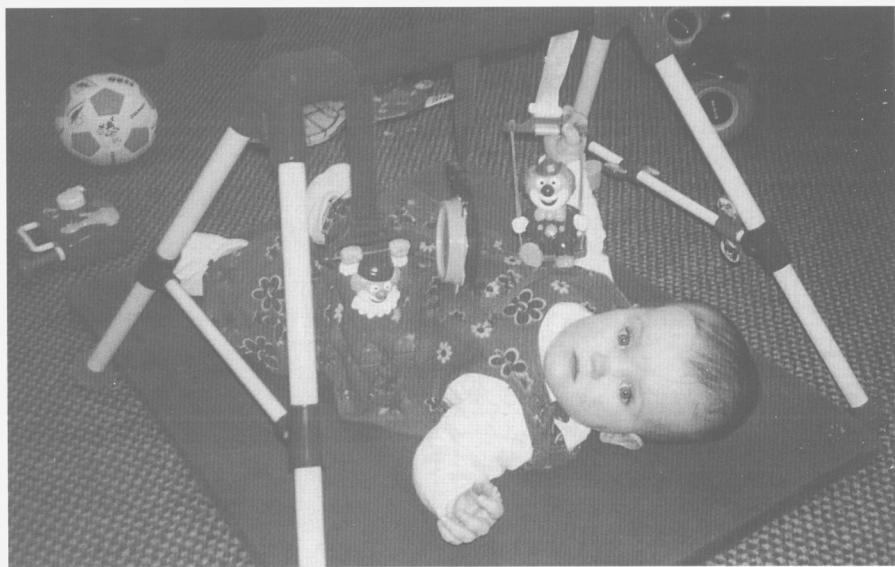
The Friday night found the parents eager for their night out and most of the children still up and ready to be entertained. We had an action-packed evening – chess competitions and draughts, videos, puzzles and storytelling. The children behaved impeccably and, as we chased the last one reluctantly to bed at 11pm, all agreed 'it was brilliant'!

The next morning dawned wet and dismal, but did nothing to dampen the spirits of the 2-4 year-olds' group who were off to the local Safari Park.

The babies went into the creche and the 5-7s were set to paint.

The oldest group of children, all siblings, had the opportunity to share their feelings about their disabled brothers and sisters, and about the effects the disabilities had on them and their lives.

This group bonded well together



Fourteen-month-old Greta gets to grips with the baby gym

# & learning through sharing

through playing the ancient Indian game of Moksha Chitram with their group leaders. Judging from the laughter from their base room, it was also good fun!

The work done with this group evoked a lot of interest and discussion with the parents and led to requests for more of the same!

At lunch time, the Safari Park group returned full of stories of monkeys and lions spotted through the teeming rain.

After lunch, it was the turn of the older two groups to brave the rain and visit the Safari Park. Surely one of the highlights of the trip must have been the excitement of seeing the flooded River Severn where the water was up to the tops of the trees in the fields!

The animals at the Safari Park were wet but inquisitive and the llamas were a particular favourite. We had a quick stop for drinks and spending pocket money then a dash through the showers and back to the Pioneer Centre.

Again, on Saturday evening we babysat and the (by now fierce!) chess and draughts competitions continued. Luckily, all but the older children were exhausted and in bed.

On Sunday, we had face painting and – briefly! – the sun came out, so our male staff took the older children out to play football.

The babies went out in-between showers and we were even able to run a nature hunt. Some of the 'finds' were very innovative and smacked of cheating!

Several of the children made firm friendships and attached themselves to their 'new' families for mealtimes and for quiet time round the TV.

Two little boys with severe behaviour problems at home learnt how to play without continuous fighting – and enjoyed it! And they appreciated the male volunteers who were

always ready for football or general rough and tumble games!

Many parents of disabled children are anxious about letting them join in the physical activities that their able bodied peers enjoy: children with spina bifida and/or hydrocephalus can take part in most games, albeit with care in some cases.

We find that, at Family Weekends, most parents are more relaxed about their children joining in with their able-bodied siblings as they are confident that ASBAH staff are 'used to' spina bifida and hydrocephalus, and feel that the children will, therefore, come to no harm. So far, their confidence has been justified!

Children with disabilities and their siblings are often socially isolated and afraid of the future. The siblings need to know that they are not alone and need opportunities to share their feelings in a controlled situation. Our special siblings' group went a long way to achieving this and some very interesting views and ideas



*Nathan, aged two, enjoys the fun*

were expressed. Amongst these was a general view that their grandparents need the help and information that parents have.

Disabled children benefit from having a chance to be with others with similar disabilities. Again, this is a sharing of ideas and coping mechanisms and hopes.

Our parents' evaluation sheets reflected their enthusiasm for such courses as these: we are grateful to Children In Need for making this financially possible.



*Telesales Dept volunteers:  
Asif Shaheed with 19-month-old  
Ashley; Brigitte Sargeant with  
14-month-old Alice and Martyn  
Cooke with four-year-old Daniel*



### Massive token collection wins pupils Disney prize

TWENTY-four pupils, nine of whom have spina bifida and/or hydrocephalus, are off to meet Mickey Mouse and enjoy all the fun of Disney after winning a fantastic competition.

Parents, staff, relatives, friends, shops, factories, church groups, taxi, bus and delivery drivers, as well as more than a dozen other schools, combined efforts to ensure that Beechgrove Special School – one of the smallest schools in Northern Ireland – scooped first prize.

Weeks of frantic cutting and sticking newspaper tokens on a massive scale for *The Belfast Telegraph's Class of '99* competition paid off, with 532,090 tokens being collected – giving Beechgrove School in Ballymena the winning ratio of 22,170 tokens per child.

Seven-year-old William McIlhatton, who has spina bifida, and the other pupils pictured on the front of *Link* cheered with delight at the news.

The lucky winners, and 22 adults, will stay in top accommodation in Orlando with all meals and passes to theme parks included in their prize.

During their week away, the *Class of '99* will visit Disney's new Animal Kingdom and plunge into movie-land at Universal Studios.

### Latex allergy group

THE LATEX Allergy Support Group, formed a year ago, has 200 members and operates a helpline.

Membership is £10 a year with a quarterly newsletter. A series of fact-sheets and an 'international document' giving guidance to professionals in French, German, Spanish and Italian, which can be used when travelling abroad, are also available.

**Latex Allergy Support Group,**  
PO Box 36, Cheltenham, Glos  
GL52 4WY. National helpline:  
07071-225838, open 7-10pm daily.



*The path is laid from its beginning at the Wharfedale flats ....*

## The secret garden's no secret any more!

BY TONY BRITTON

AN ORNAMENTAL garden planted on the crest of a hill, with panoramic views over the valley towards ASBAH trustee Michael Booth's house perched in the distance, is part of the outdoor heritage of Five Oaks.

For most of the residents in the pair of ASBAH-managed houses which make up the Five Oaks Housing Scheme, however, the half-acre treasure has remained one of their best kept secrets. Mounds and walls kept out visitors and all but the most intrepid wheelchair-users.

But the secret garden, in Ben Rhydding, West Yorkshire, has now had its cover blown – thanks to a ground-breaking partnership between housing support staff there and The Prince's Trust Volunteers.

Three weeks' work by a dozen

volunteers, often in driving wind and rain, led to the creation of a footpath from the car park beside the Wharfedale flats right into the garden itself.

"They had to excavate through a large mound of earth to open up the garden and then lay tonnes of hardcore and topping, which set almost like concrete but is twice as resistant to extremes of weather," said Five Oaks housing support worker Mark Best.

"We've been left with a beautiful 25-yard long path, the recommended 1.2 metres in width for wheelchair-users and a gradient of only a couple of inches from beginning to end. It's not dead straight, it's got this curved shape to keep it interesting. And there were added bonuses – all the debris was removed at the end and we didn't pay a penny for the work!"



*.... through to the garden shed ....*

Andy Grunstein, team leader with the Prince's Trust Volunteers based at the City of Bradford YMCA, said the footpath project was initially suggested by assistant housing support worker Simon Forshaw and was selected – for its originality and imagination – from a shortlist of three.

The foundation hardcore – limestone dust topping which set solid when mixed with water – heavy-duty boarding, plant hire and tools like rollers and tampers were all supplied free by local companies.

Andy added: "We got good support from local firms and it finished up really well. There was much more material to excavate than we first thought, the weather was awful and, because of the remoteness of the site, most of us had to come in from quite a way off – so it was hard work."

Main suppliers who gave materials or loaned tools were: Manningham Timber & Plywood, Berry & Marshall Quarry, Tarmac Roadstone Ltd, Skipton Hire Centre, Sainsbury's Homebase and The Countryside Service (advice and help).



*..... and into the garden itself. Pictured are Nikki Gibson (foreground), with Carolyn Wood, Steve Cooper, Mark Best and Simon Forshaw.*

## Housing advice

SHELTERLINE is a free 24-hour national telephone helpline.

It is for people with any sort of housing-related problem. This includes help if you are:

- homeless or threatened with losing your home.
- having problems paying your rent or mortgage.
- having problems getting repairs done.
- trying to get rehoused.
- experiencing harassment or violence in your home.
- unhappy about decisions on housing benefits or rehousing.
- living in crowded or unsuitable housing.

When you call Shelterline, they will: try to deal with any emergency; clarify the problem and give you possible solutions; tell you what you can do next; explain where you can go for further help and advice; send out any further information to help you.

All calls are treated in confidence. Shelterline can give advice via minicom and text phone and use a special translation service for anyone who needs it.

*Shelterline's freephone number is: 0808-800 4444.*

## Trisomy 13 & 18

A NEW booklet explores the issues confronting parents after a prenatal diagnosis of Trisomy 13 or 18, and includes sections about chromosome abnormalities, what is involved if termination is chosen and how to plan when the pregnancy continues.

*Your Unborn Baby* has been published by the Support Organisation for Trisomy 13/18 and related disorders (SOFT).

*Copies from: Rosemary Davies, 7 Orwell Road, Petersfield, Hampshire GU31 4LQ. Tel: 01730-261258.*

**B**obbie Knighton felt super-fit during her third pregnancy. She ate a good diet, gave up alcohol and conscientiously attended all her antenatal check-ups. Her blood test at 18 weeks was normal, and baby was active.

So, when she went for her routine ultrasound scan at 20 weeks, she was in a positive mood. Her daughter Georgina, now four, was particularly excited at the prospect of having a little brother or sister.

During the scan, however, the radiographer fell silent and took an exceptionally long time, checking every measurement. She then told Bobbie and her husband that something was seriously wrong with the baby, and that she would have to fetch the consultant.

Within 15 minutes, the Knights, who live in Baldock, Hertfordshire, were given the news that their child – a girl – had severe spina bifida, a defect in which part of the spinal column fails to develop completely, leaving the spinal cord exposed. The baby also has a misshapen head, which suggested that she was suffering from hydrocephalus (water on the brain).

Mrs Knighton went into hospital the next day for a termination. "The labour lasted almost 24 hours and was much worse than my previous labours," she says, "because my body was not ready to deliver the baby. Mother Nature was telling me to hold on."

"The experience was horrific. Part of me died that day. We named the baby Ellen, and we both held her. We had a service for her and planted a rose tree in her memory."

"We have delayed having any more children because we were frightened of having another child out of grief."

One of the tragedies of this case is that it probably could have been prevented. Scientists discovered as long ago as 1991 – five years before Mrs Knighton's pregnancy – that, if mothers increased their intake of folic acid (a vitamin occurring in liver, green leafy vegetables and certain other foods) around the time of conception, their risk of having a baby affected by spina bifida could be reduced by two-thirds.

Yet today, more than seven years later, the spectre of spina bifida is still haunting many pregnancies. More than 1,000 women a year in the UK discover that they are carrying a baby affected by a neural tube defect (mainly spina bifida and hydrocephalus) and about 850 of them go through a traumatic and painful termination.

An obvious solution to the problem was put forward in the

government, however, to opt for a less intensive policy. It mounted a campaign to persuade women to increase their intake of folic acid.

That campaign has had an end and, despite an international pressure from the World Health Organization, has not yet had the desired effect. It cost money and there is no evidence that it has significantly reduced the number of affected babies.

The reason is simple: most women at risk of having a baby with spina bifida eat a diet lacking in folic acid. And the women who are at risk have heard of the campaign. Also, half of all pregnancies are unplanned, so many women do not start taking a supplement such as iron or folic acid until after a positive pregnancy test, by which time it is too late.

## Why we need to fortify flour with folic acid

**Adding folic acid to flour could have prevented the tragic birth of Ellen. Annabel Fenwick's article, first published in *The Independent*, highlights the need for fortification.**

In *British Medical Journal* in 1995 by Nicholas Wald, professor of environmental and preventive medicine at St Bartholomew's Hospital, London, who suggested that flour manufacturers should be required to fortify flour with folic acid to ensure that all women of child-bearing age consume a high enough dose to reduce the risk.

Flour is already fortified with calcium, iron, niacin and thiamine, so adding one more vitamin would not be such a big step. The then-Conservative

Government to require flour manufacturers to add folic acid to prevent neural tube defects. Even well-educated women like Mrs Knighton often delay taking it until two months into pregnancy.

"The current strategy of encouraging women to take folic acid supplements does not reach all women who become pregnant accidentally," said Tony Blair's spokesman for the Department of Health.

"There is enough evidence to support the safety of folic acid," said a spokesman for the Government to put folic acid into flour.

however, decided interventionist started a publicity campaign to persuade women to take folic acid.

has now come to despite having won a prize from the Organisation, it has not yet reached the desired figure of more than £2.3m in evidence that it may have reduced the rate of neural tube defects in pregnancies.

simple: the women most likely to have a baby with spina bifida are those who are taking folic acid in natural form. These are the same women who are least likely to take part in the campaign. Neural tube defects are most common in women who do not take folic acid as a supplement, or folic acid, until after they have had a pregnancy test, because it is too late to



Bobbie Knighton and her children, Charles, six, and Georgina, four. Her third baby had spina bifida, caused by folic acid deficiency during pregnancy. Photo: The Independent (photographer, Keith Dobney).

# We need power

to reduce birth defects. So why doesn't the government investigate? This article first appeared in The Independent in December 1998.

defects. Unfortunatly, women like Bobbie often do not start taking folic acid until two months into their pregnancy.

A strategy of encouraging women to take supplements before they reach those who are planning to become pregnant, said Tony Britton, chairman of ASBAH.

ough known about folic acid for the last 20 years, millers require millers to add folic acid into flour, just

as the Food and Drug Administration in the US has done since January."

That is a view with which many specialists concur. Dr Richard Smith, editor of the *BMJ*, recommended the same thing in his Edwin Chadwick lecture on public health last month and Dr Patricia Troop, director of public health for the Anglia and Oxford Region, believes that a majority of regional public health directors also favour it. Professor Richard Smithells, a retired professor of paediatrics at Leeds

University, who was the first person to prove a connection between maternal folic acid intake and neural tube defects, back in 1965, also wants to see folic acid routinely added to flour.

So why hasn't it happened?

In the early Nineties, the philosophy of the government was to blame. It adopted an approach of raising awareness and encouraging dietary supplements instead. But in 1997 the incoming Labour government appointed the first-ever minister of public health, and things looked likely to change.

Professor Sir John Grimley Evans, who chairs the government's sub-group on folic acid, and is a member of the Committee on the Medical Aspects of Food (Coma), says there are two important reasons why the decision to fortify flour has been delayed.

"First, there is concern about the interaction between folic acid and pernicious anaemia, a condition

caused by a deficiency of vitamin B12, which can lead to neural damage. If people who are developing pernicious anaemia take too much folic acid, it can mask anaemia, but lead to neurological damage before its true cause – vitamin B12 deficiency – is discovered."

Professor Wald believes that this problem can be overcome by teaching doctors to diagnose pernicious anaemia with greater clinical precision, while other experts believe the proposed level of folic acid enrichment would not be enough to cause problems.

The Government's sub-group on folic acid is expected to clear up doubts in this area shortly.

Unfortunately, the issue has more recently been clouded by research into other effects of folic acid. Scientists have discovered new evidence suggesting that, if adults increase their

*continued on page 14*

## TRAVEL NEWS

CHEAPER ferry fares for disabled people are available for those wishing to travel from Portsmouth and Lymington to the Isle of Wight.

Wightlink has introduced a free disabled person's card for both car and foot passengers. Any Orange Badge holder is entitled to the card, normally sent out within 14 days of them receiving your application.

Derek Sprake, secretary of Isle of Wight ASBAH, who told *Link* about the card, also points out that travellers can also make considerable savings by travelling at night.

He added: "Similar savings may be available on other holiday routes around the British Isles, but they are not usually made obvious in their leaflets."

● Phone Wightlink's sales and reservations office on 0990-827744 for a Disabled Persons Pack.

THE BRITISH Tourist Office has opened a new 'one stop travel shop' Visitor Centre in Regent Street, London, which provides easy access to a comprehensive travel and accommodation service.

Entry to the centre is at street level with automatic doors and all of the ground floor is at one level. The British Tourist Authority, England, Wales, Scotland and Ireland all have information desks at wheelchair height on the ground floor.

## ASDA first on folic acid

ASDA has become the first supermarket retailer in Britain to add folic acid to bread baked fresh every day in their in-store bakeries. The company bakes over one million loaves and rolls every day in its 223 stores.

The move will have no effect on the taste or price of ASDA's bread but, by increasing the amount of folic acid in the diet of its customers, will help prevent spina bifida in pregnancy.

ASBAH executive director Andrew Russell welcomed the move. "Folic acid still remains one

of this country's most underestimated health products," he said.

"Although its power in helping to reduce the number of spina bifida pregnancies has been known about for almost eight years, there are still many women who do not take a daily supplement before they conceive through to the end of the third month of pregnancy."

About 1,000 pregnancies a year are still affected by spina bifida in the UK, with nine out of 10 mothers choosing termination after discovering their baby has a disability after having prenatal scans.

## Science writing awards

YOUNG scientists between the ages of 16 and 28 are invited to enter a writing competition, with the chance to win a trip to the USA and cash prizes.

*The Daily Telegraph* BSAF Young Science Writer Awards seek to encourage young science writers to test their journalistic abilities by writing a 700-word article on a science subject that they are interested in, which will entertain and inform readers.

Full details from: *The Daily Telegraph* BASF Young Science hot-line on 0171-704 5314, or on the Internet <http://www.science-writer.co.uk>

## Picnic for 'outsiders'

OUTSIDERS, a club for people who feel isolated or rejected, celebrates its 20th anniversary this year.

The club aims to help members gain confidence and have more chances to form relationships and find love.

Anyone interested in joining or seeing how the club has evolved, is invited to a Sensuality Day on Tuesday 8 June from 1.30-5pm at The Royal Botanical Gardens at Kew, London, in the new area devoted to the senses, just south of the bakery near the Brentford Gate car park. There will be massage and a sensual picnic. Entrance is free to people with disabilities.

## Why we need flour power

continued from page 13

intake of folic acid, they may reduce their risk of cardiovascular disease. The Government's experts on folic acid are now wondering whether this matter should be clarified before making any recommendation on fortifying food.

"There has not been a controlled trial to show that giving folic acid reduces cardiovascular disease," commented Professor Sir John Grimley Evans.

"If flour were fortified with folic

acid, it would be impossible to conduct such a trial in the UK, or to discover the ideal amount of folic acid to give," he explained, "because everyone would be consuming more in their diet."

Sir John admitted that a trial to clarify the effects of folic acid on cardiovascular disease could take 10-15 years to complete. "There are obviously some people to whom neural tube defects are the only things that matter," he pointed out. "But we have to take to heart all the implications of fortifying food."

While academics puzzle over the new dilemma of folic acid and cardiovascular disease, more than 150 mothers a year will continue to give birth to babies with spina bifida and another 850 will go through the painful trauma of a late termination of a wanted baby.

Helen Brinton, MP for Peterborough, who has been campaigning on the issue, said: "It is really outrageous that the last government dragged its heels on this. How long will women have to wait?"

YOUNG disabled members saved a local ASBAH after the previous executive committee decided to wind up the group due to lack of interest.

Just before the group's last annual general meeting, younger members decided they wanted to continue and their proposal was sent out with a notice of the meeting.

There was a good turn out at the meeting for North Hants, South Berks and West Surrey ASBAH, and the motion to close the association was lost.

Five disabled members, Vicky Beken, Samantha Phillips, Melinda Exley, Helen Bryant and Rachel Hatch, the first two of whom had been part of the committee before, were voted in to office.

New chairman Vicky Beken said: "Samantha and I definitely didn't want the association to close so we got as many people as we could to attend the annual meeting. Nobody wanted to be chairman so, as I definitely want it to continue, I took on the job."

"Disabled people aren't running the association but we are now in the majority on the committee."

Parents who no longer wanted to do committee work agreed to support the newcomers, with former chairman Gill Beken becoming the committee's administrator, though not attending meetings, and long-standing committee members Sue

## Young ASBAH members save the day



Vicky Beken (centre) and Samantha Phillips (right) saved their local ASBAH by whipping up support among young disabled members to sit on the committee. Mary Bellairs (left) is a long-standing committee member

Washington and Mary Bellairs continuing in their roles. Two other former committee members attend meetings now and then.

Mrs Beken said: "We've suggested they take it slowly. This year, the aim is to try and build bridges and get ideas.

"Vicky, the chairman, wants to contact social services or the housing associations to see if a handyman can be funded, to change a light bulb or fix a washing machine – allowing them complete independence from parents.

"They are also looking to encourage

young families, particularly with children with hydrocephalus, to join by working with the ASBAH advisers.

"They are looking at new ways of raising funds and are interested in linking up with other disability groups to lobby on transport issues."

Meetings are held every two months at members' homes, mainly at Vicky and Samantha's flat which is quite central. The local association pays the taxi fares of those committee members who do not drive so they are not out of pocket.

## Demand for user-focused NHS wins support

A CONSORTIUM of charities – working for a user-focused, empowering NHS – gained cross-party support for its Early Day Motion for the setting up of a body responsible for services for disabled people.

*emPOWER* believes that only a Disablement Services Authority will address the significant and expensive variations in NHS disablement service delivery.

The consortium was delighted when Health Minister John

Hutton committed himself to working with *emPOWER*.

Sam Gallop OBE, chairman of the *emPOWER* steering group, said: "We are overwhelmed by MPs' support.

"The All-Party Parliamentary Disablement Group's endorsement of *emPOWER*'s Millennium Agenda for Independence shows that MPs understand the urgent need for a Disablement Services Authority. Meeting real need raises standards and releases resources."

Roger Berry MP, Secretary of the influential All-Party Disablement Group and host of *emPOWER*'s House of Commons reception, said: "Empowering disabled people to access greater independence and, where possible, employment makes economic sense. The New Deal and Welfare to Work depend on high quality disablement services. A Disablement Services Authority, giving national focus and improving cost efficiency, is an essential part of that equation."

## DIARY DATES ... DIARY DATES ... DIARY DATES ...

### Saturday 6 March

ASBAH Northern Ireland Region, wheelie kids and speedy wheelers meet at McKinnery Hall, Musgrave Park Hospital, Belfast. Funded by the EU Special Support Programme for Peace and Reconciliation. Details: Linda Maxwell, tel: 01232-761814.

### Saturday 6 March

British Wheelchair Sports Foundation, Primary Sports Camp, open to any child with a physical disability aged between six and 11, Stoke Mandeville. Charlie Bethel, BWSF, tel: 01296-395995.

### 12 – 14 March

Aim High, Be Positive!, activities and workshop weekend organised by national ASBAH at Plas Menai, Portdinorwic, North Wales. Cost £30 per participant, plus £25 donation by local Association. £15 deposit required). Application forms, returnable by 1 March, from Mrs Jill Bartlett, ASBAH, 4 Ta'ir Felin, Felinheli, Gwynedd, LL56 4JF.

### Saturday 13 March

ASBAH Study Day. Topics include pre-natal diagnosis and involvement of the paediatric neurosurgeon; genetic counselling; continence management in spina bifida; surgical intervention; intermittent catheterisation; pregnancy and parenting; disabled people and sport. Park Dean School, Oldham, Greater Manchester 9am – 4.30pm. Cost £6 per person. Bookings taken until Friday 5 March. Details: Jean Black, ASBAH Adviser, The Newbridge Centre, Cromer Street, Stockport SK1 2NY.

### 15 – 19 March

ASBAH's Challenge, an adventure and learning course for young people with SBAH, aged 11-17, supported by the BBC Children in Need Appeal, at Churchtown Farm, Lanlivery, Cornwall. Cost: £50 per participant. Details: Lynn Thomas, 01733-555988.

### Saturday 27 March

ASBAH Northern Ireland Region,

After School – What Next? Information day for 15+ year olds and their parents. Venue to be arranged. Funded by the EU Special Support Programme for Peace and Reconciliation. Details: Linda Maxwell, tel: 01232-761814.

### May

ASBAH Northern Ireland Region residential weekend for 15-19-year-olds, organised in partnership with Northern Ireland ASBAH. Venue and programme to be finalised. Details: Linda Maxwell, tel: 01232-761814.

### Saturday 15 May

Delyn and Deeside Disabled Sports Club, 10th Annual Games, Deeside Leisure Centre, 10am–4pm. Friends and spectators welcome.

### 6 – 9 May

International Symposium on Spina Bifida, Verona, Italy. Details on: [www.renbeltravel.it/errebicongressi/issb99](http://www.renbeltravel.it/errebicongressi/issb99)

### 26 June – 4 July

Youth in Action, a leadership training course in Integrated Youth Work, module 2, Ballinran, Northern Ireland (with financial support from the Youth for Europe Programme, European Commission), for people aged between 16 and 25. Susan O'Flaherty, projects officer, Mobility International, 18 Boulevard Baudouin, 1000 Brussels, Belgium, tel: +32 2 201 56 08, fax: +32 2 201 57 63, email: [mobint@arcadis.be](mailto:mobint@arcadis.be)

### 17 – 24 July

Share Music Course, Stackpole Centre, Pembroke, South Wales. Brochure for this and other courses for 1999 from: Dr Michael Swallow, 15 Deramore Drive, Belfast BT9 5JQ, tel/fax: 01232-669042.

### 23 – 26 September

11th International Conference on Hydrocephalus and Spina Bifida, organised by the ifHSB, Perth, Western Australia. Secretariat, P O Box 568, Kalamunda, Western Australia 6076, tel: +61 08 9257 2088, fax: +61 08 9257 2099, email: [petrconf@iinet.net.au](mailto:petrconf@iinet.net.au)

# How to

MANY people with spina bifida will, at some time or another, develop a pressure sore. This is usually no-one's fault and there are many things that can be done to prevent them but, to do this, it is important to understand what causes them.

### CAUSES

**Poor circulation** below the waist means that the cells don't get adequate supplies of oxygen and nutrients to keep them healthy. Nor do they get rid of all their waste products.

A system of the body called the lymphatic system works together with the circulation to remove fluid and waste products. This also does not work as efficiently in people with spina bifida as it should, so there can be a build-up of fluid in the legs. This is called oedema. All these things together mean that pressure sores can develop very rapidly and then be very slow to heal.

**Neurological** (nerve) problems associated with spina bifida and the resulting loss of feeling means that little or no discomfort is felt and therefore there is no trigger telling you to move and reduce the pressure on a particular part of the body.

**Incontinence** will cause the skin to become even more prone to damage as both urine and faeces contain substances that break down the skin and cause it to become infected.

### PREVENTION (reducing the risk)

**Change your position** Every 20 minutes lift your bottom off the chair and change the position of your legs. This allows the blood to flow normally for a few seconds (that's all it needs!). If it is too difficult to lift your bottom, then try a change of position; leaning forwards or to one side then the other.

# avoid pressure sores

## **Regular inspection of the skin**

Ideally the whole body should be inspected night and morning for signs of any redness or changes in the skin. If you find a red patch and it disappears quickly after you have eased the pressure in that area, there is no cause for alarm. But if the red colour remains, this could be the first sign of a sore developing. A close eye should be kept on this area and no further pressure should be put on it. A long-handled mirror is very useful for inspecting the back and bottom!

**Diet** A good balanced diet is essential for both the prevention and healing of pressure sores. An adequate intake of fluids helps to keep the skin supple and hydrated. Complex carbohydrates (bread, rice, pasta) will keep the muscles healthy. Iron-rich food such as spinach, will help the blood carry the oxygen around the body to the cells. Vitamin C and zinc (a mineral) both help wound healing, as does an adequate supply of protein (found in meat, fish and dairy products).

**Wear suitable clothing** Avoid clothes that are too tight or have hard seams, zips or buttons that might cause pressure. Good fitting shoes, with the feet put in properly, are essential. Take care when transferring from your wheelchair not to knock or drag the body. Barrier creams such as Sudocrem, Conotrane or Zinc and Castor Oil Cream, can be useful protection for the skin against incontinence but the most important protection is to clean up and change as soon as an 'accident' has happened.

**Hospital admissions** If you have to go into hospital and will be spending more time than usual in bed, ring the ward and tell them before you go that you will need a pressure-relieving mattress. Operating theatres also need to be aware of your needs before you have an operation. A visit before admission will be useful to you and to the staff.

If you have to visit the Accident &

**By Caroline Berkley  
ASBAH Specialist Adviser  
(Medical/Continence)  
South East Region**



Emergency Department, do remind them as soon as possible of your high risk of developing sores. The staff should then make sure that you are not left on a hand trolley or in a wheelchair without help to move around every 20 minutes or so.

## **TREATMENT**

If a sore develops, it should be assessed as soon as possible by a specialist nurse or doctor who will 'grade' it and start the most appropriate treatment.

There are many different products available for treating pressure sores and it would be impossible to list them all here. However, this is a rough guide:

If the skin is red but not broken, a second 'skin' may be used, such as Op Site or Tegaderm, to help prevent any further breakdown.

If the skin is broken but not infected or bleeding, something such as Comfeel, Granuflex or Allevyn would be applied. These dressings should **not** be changed every day unless they have become detached.

For deep sores, a gel such as Intra-site or Granugel, may be used. These are very good for the sore but can ooze so the top dressing may need changing every day (sometimes twice a day). These gels can also be used for infected wounds.

The above are just some examples of the many products on the market and when they might be used. It is not meant to be a definitive guide and ASBAH does not endorse the use of any of the named products over any not listed.

The best treatment of all is relief of pressure from the affected area. Special cushions and mattresses are available and the community team (occupational therapist or nurse) is responsible for assessing and arranging provision of these.

If there are recurrent sores, it may be that a further assessment of pressure relief aids, equipment, etc – that is, wheelchair and lifestyle – needs to be made.

## **Pressure sore prevention – remember:**

- 1. Lift your bottom from your chair every 20 minutes.**
- 2. Change the position of your legs at the same time.**
- 3. Check your skin all over at least once a day (twice is better).**
- 4. If you are wet or soiled, the quicker you clean up and change, the better.**
- 5. Take care when transferring from your wheelchair.**
- 6. Eat a good balanced diet including a variety of fruit and veg, and drink plenty of clear fluids.**



LONDON  
MARATHON  
18 APRIL 1999



Runner Matthew Shapcott, pictured with his mum Kim

**A LONDON teenager is aiming high – both in his plan to run the ‘big one’ but also in his goal to raise £1,000 for ASBAH.**

Eighteen-year-old Matthew Shapcott, from Bermondsey, loves sport and has wanted to enter the Flora London Marathon for years.

Watching runners go along Brunel Road, close to his grandparents' home in SE16, has been a big family event, something like Christmas, ever since he was a boy.

Now he has a place and is steadily building up his running distance, regularly training on the road and in the gym.

"I've run mini marathons before but nothing like this. You can't get a bigger challenge than the London Marathon," he said.

"At first, I wanted to do the marathon for me, but then I thought I would do it for a charity as well."

His mum, Kim, who has spina bifida, has been helped by ASBAH

and given support by SE London adviser Rachel Nicholls.

Mrs Shapcott said: "Matthew didn't regard me as disabled as he had never seen me ill, so he didn't think of ASBAH at first.

"We sat down and went through a few charities and I thought of ASBAH straight away, but I wanted it to be his choice.

"Then, last December, I went into hospital and it was a big challenge for him. It was then that he said he would raise money for ASBAH."

Mrs Shapcott is very proud of her son, who is also a student.

"As long as he finishes and has no injuries, I don't mind. Running the London Marathon is a big ambition – it's brilliant," she said.

Despite a calf injury in January, Matthew was continuing to build up the miles until he is fit to do the full 26 miles on Sunday 18 April.

Matthew also plays for two local football teams, is a black belt in karate and enjoys squash, tennis, swimming, table tennis, snooker and pool at the pub.



## Still cycling at 70

SEVENTY-year-old Mary Woolman, who has spina bifida occulta, managed to double her expected distance when she took part in a sponsored bike ride.

Wind and rain on the journey home failed to dampen spirits and Mary and her escort clocked-up 22 miles in their tour of 10 churches in and around in Sheringham in Norfolk.

Mrs Woolman has been riding a bike for most of her life. Her biggest frustration these days is clumsiness about the home.

She decided to take up the challenge to ride further than she had done for many years – on a three-gear Shopper – in support of North Norfolk Churches Bike Ride and raised £239.

## New job for Paul

FORMER Link columnist Paul Darke has a new job with Leonard Cheshire to help empower its service-users.

Paul will be helping to put together a database and information package which will contain details of independent advocacy for all staff and service-users.

Many of the services and accommodation run by Leonard Cheshire are used by people with spina bifida and/or hydrocephalus.

At the end of last year, ASBAH and Leonard Cheshire signed a partnership agreement pledging to work together for people with spina bifida and/or hydrocephalus.

Paul's previous job was co-ordinator of West Midlands Disability Arts Forum.

# Double triumph in gold award

A YOUNG woman has achieved the double triumph of gaining the gold Duke of Edinburgh Award and helping someone else to accomplish it.

Twenty-six-year-old Karen Robinson received her certificate at St James' Palace, London, last spring, but then spent several weeks giving literary assistance to a friend who was researching and writing a project for her own award.

Now Lisa Sadler, who has learning difficulties, has heard that she has won the gold award and is looking forward to her palace presentation.

Karen, who worked through bronze, silver and gold awards in seven years, said: "I would definitely recommend the award scheme to anybody who enjoys having a go at something. It's the best challenge I've ever done and I thoroughly enjoyed it."

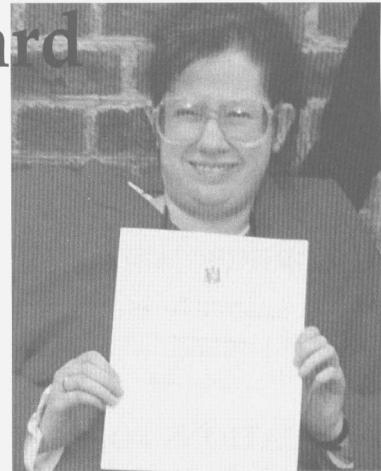
Karen's own gold award consisted of an exploration of the Goyt

Valley, south Derbyshire, looking at access for people with mobility problems, with three nights under canvas; a residential at the Kielder Forest Outward Bound Centre; helping at a girl guides' group; learning to play the synthesizer keyboard and archery.

Her award group leader eventually got permission for two group members, including Karen, to use electric scooters rather than manual wheelchairs for some of the activities.

Karen, a Sheffield ASBAH member, said: "I am sad that my involvement with the scheme has come to an end although it encouraged me to get back into one or two things like the synthesizer keyboard and girl guides.

"As long as you start something you enjoy through the scheme, it can set you up for a job for life. You don't have to stop once you finish the award, you can continue and aim for higher things."



*Karen Robinson outside St James's Palace, London, where she received her Duke of Edinburgh Award Gold Award Certificate*

Karen, whose father is ASBAH Executive Committee member Tim Robinson, is currently studying Maths and English at Norton College in Sheffield.

● Details on the scheme from: Duke of Edinburgh's Award, Gulliver House, Madeira Walk, Windsor, Berkshire SL4 1EU. Tel: 01753- 810753. email: AwardHQ@dea.sonnet.co.uk

**If you want an event or study day, we may be organising it**

## ASBAH's fast forward into 1999

SO that you can see what's coming up as an ASBAH study day or event, *Link* brings you an advance look at what is being proposed with this forward planning diary.

Full details of these events are yet to be confirmed, but this forward planner lets you know the subjects of study days and special events well in advance.

A good way of finding out all the details, nearer the time, of an event you are interested in, is to look at *Link*'s regular *Diary Dates* section. Or you can contact the organisers, again nearer the time the event is scheduled to take place.

Study days planned as this issue of *Link* went to press were:

### 24 April

**Hydrocephalus, Bristol.**  
Julie Knight, tel: 0117-924 5077.

### May

**Hydrocephalus, SW Yorkshire.**  
Organised by Northern Region.

### May

**Residential Weekend for 15-19-year-olds.**

Organised by Northern Ireland Region in partnership with Northern Ireland ASBAH.  
Linda Maxwell, tel: 01232-761814.

### June

**Education, Nottingham.**  
Organised by East Region.

### June/July

**Sports Taster Day.**  
Organised by South East Region.

### 20-22 August

**Children with profound disabilities, Northampton.**  
Organised by national ASBAH.

### Sept/Oct

**Autumn Experience, Ilkley, North Yorkshire.**  
Organised by Northern Region.

### October

**Hydrocephalus, Humberside**  
Organised by Northern Region.

● For study days and weekends in March, see *Diary Dates* on page 16 of this issue of *Link*.



# PUBLICATIONS ORDER FORM

CUT OUT  
OR  
PHOTOCOPY  
THIS PAGE

## SUBSCRIPTION MAGAZINE

Link – bi-monthly magazine of ASBAH	£ Price (inc p & p)	Quantity ordered	Total Price
	UK 4.80		
1 year subscription (6 issues)	Airmail 15.00		
	Europe/Surface Mail 7.50		

## PUBLICATIONS FOR SALE

Spina Bifida and Pregnancy, a booklet for women with spina bifida and/or hydrocephalus (ASBAH)	UK 1.00 Overseas 2.00		
Children with Spina Bifida and/or Hydrocephalus at School – Edited by ASBAH	2.75		
Hydrocephalus Information Pack (for new parents, parents, teachers and employers) – Ed by ASBAH	3.50		
The Statementing Process for Children with Special Educational Needs (ASBAH)	1.75		
The Learner Driver with Spina Bifida and Hydrocephalus by Barbara Simms and Warren Nichols	1.75		
Love and Loss: conversation with parents of babies with spina bifida managed without surgery, MacKeith Press	5.00		
One Step at a Time, a view of integration at one school, by Margaret Slade, Maysdale Press	3.95		

## INFORMATION SHEETS – single copies free with self-addressed envelope and two stamps

(tick those required)

- What is Spina Bifida?
- What is Hydrocephalus?
- Ante-Natal Screening
- Genetic Counselling
- Vitamin Supplementation in the Prevention of Neural Tube Defects
- Vaccinations and Spina Bifida and/or Hydrocephalus
- A Guide to Educational Statementing
- Just what is ASBAH?
- Continence Management
- Spina Bifida Occulta

## YOUNG PEOPLE'S LEAFLETS

(for adolescents with spina bifida and/or hydrocephalus). Single copies free with self-addressed envelope and two stamps

- ★ Bullying
- ★ Making Friends
- ★ Self Image
- ★ Continence
- ★ Personal Hygiene
- ★ Healthy Living
- ★ Coping Under Pressure
- ★ Let's Talk about Sex
- ★ More Talk about Sex

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**I**'M BACK! And I'm knackered! So much for Xmas being a time of rest. Mine was the usual round of cleaning, tidying, drinking, eating and last minute shopping. If I could have a Christmas wish this year I'd ask for an end to Xmas shopping.

Each year, I promise myself I won't get involved in the madness that is Christmas shopping. Each year, I end up trying to read the confused mess that my shopping list has become as I scuttle round thousands of shops, being trod under foot and elbowed in the ribs by old ladies. I must be mad. I wish I could organise all this stuff a few months ahead. I could shop while the shops were quiet. Or, better still, avoid the shops altogether and go shopping by phone or over the Net. Of course, then I'd have to be organised, wouldn't I? So it'll never happen! And I'd need a new computer.

A big Christmas wish is for a new computer. Mine was made about a decade ago and struggles when I type these columns, never mind wanting to surf the Net (*man!*). So I need a new one. There are a number of charities that will give you something towards a computer, if you ask them (the Leonard Cheshire Foundation was advertising something about computers in *Link*, just before Christmas). But I am probably undeserving, haven't the patience to wait and (for once in my life) have the cash in my sweaty hands. So I'm busy trying pick a computer.

With my luck, whatever I buy and wherever I buy it from, my computer will probably get taken out by the Millennium Bug. I wish people could make up their minds about this. One minute all the computers will go down on January 1st. The next everything is fine. The problem is that the people who tell us everything is fine are sometimes the same ones telling us we should stockpile food and water!

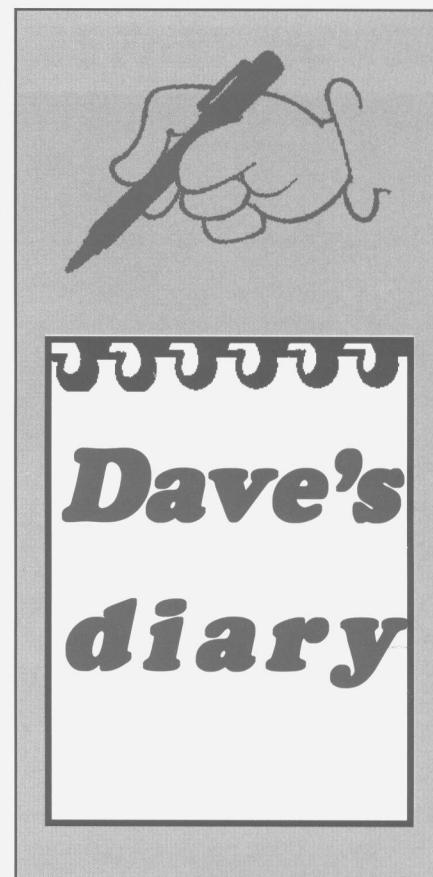
My biggest New Year is for everyone to stop being miserable and cheer up! Everyone has predictions of doom and gloom around this time. Nostradamus even said the world was going to end in 1999. And you don't get much gloomier

than that. I don't think so. My prediction is that things will get better. There are some rays of hope.

I recently read in *The Sunday Times* of an operation where a baby with SB had its spine closed up while it was still inside its mother. The operation seemed to limit the damage done and the baby seemed to be born less disabled than it could have been. Whatever the full story, I think this has great promise and surgery is certainly better than the old choice mothers had of abort it or live with it. I hope that, in the future, those trying to clone things will realise that Wales is actually full of sheep and that they should really try cloning something useful like blood cells or even (please God), nerve cells!

There may be hope for the media too: Also in *The Sunday Times* was a story showing a disabled girl as a human being, rather than as some angel or like Scrooge's tragic and terminal Tiny Tim (read *A Christmas Carol* if you really want to know). Any Christmas without seeing Tiny Tim on the telly is a good one.

The BBC slipped in an updated version, called *Scrooged* but I switched over. My favourite film this Christmas was *Ghostbusters*. Looking in the mirror, I have to say that after all the turkey and such like I look far more like the blob ghost from *Ghostbusters*, than I do skinny old Tiny Tim.



Right now, my most appropriate Christmas (or New Year) film would be *The Blob*! My wish film for Christmas Future must surely be: *Tiny Tim: The Revenge* (he's back and he's got Scrooge in his sights!), with Arnold Schwarzenegger as Tiny Tim! I wish!

Finally, I wish you a better New Year.

*David Fulford-Brown  
david.fulford-brown@virgin.net*

## Twins and multiple births special needs group

A NATIONWIDE group exists for parents of twins, triplets and more, when one or more of the multiple children have special needs.

The Special Needs Group is run by TAMBA – the Twins and Multiple Births Association.

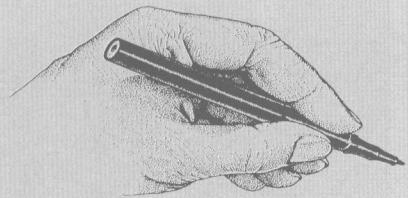
The group offers three newsletters a year, contact for mutual support, family days out and a resource and information service.

Lorraine Wallace, of the group, said: "Families with children with special needs need the support and encouragement of families in

similar situations. We so often feel 'we are the only ones' but to talk to someone who's 'been there and done that' can be very reassuring and with the added stresses and strains of multiple children, we believe our group is unique."

Membership rates are: one parent families free; individual/family (eight months) £12; individual/family (12 months) £15 – plus £5 to join the Special Needs Group.

*TAMBA Membership, PO Box 30, Little Sutton, South Wirral L66 1TH. Tel: 0870-121 4000. Fax: 0870-121 4001 (calls charged at national rate).*



# Letters



HERE are some pointers for anyone contemplating taking a wheelchair to Orlando, USA:

1. Take your Orange Badge with you to the licensing department in South Vernon Street, Kissimmee, opposite the Court House. For \$15 you will receive a Visitor's Disabled Permit allowing you to park at any of the many disabled places which you will find in any parking area. This is particularly useful at the theme parks and will guarantee easy access, close to the entry gates.

Although some officials may accept the Orange Badge, it is not officially recognised in Florida, so it is safer to have the correct permit.

2. Holders of the Orange Badge are allowed to park in the short-term

car parks at Gatwick Airport at long-term rates, and it is even cheaper if you book ahead and pre-pay your parking. As you will require your Orange Badge on your trip, they are satisfied if a photocopy of the badge is left on display along with the orange time indicator.

This applies to anyone flying to any destination from Gatwick.

3. Beware of Travelodge. Their rooms which are suitable for wheelchairs can only accommodate two people, so an average family would have to pay almost £100 for a single night, and that is just for the room. If you require to stay overnight it would be worth shopping around for a decent hotel that will offer you free parking for a couple of weeks.

There are plenty of them around Gatwick.

4. Don't be concerned about your wheelchair on the journey. The airline will ensure it is there waiting for you on arrival. They will also ensure you are given priority at immigration and, although you will probably be last off the plane, you will be on your way to your hotel when most of the other passengers are wearily waiting to be allowed into America.



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## FOR SALE

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*Tel: 01702-555822 (Benfleet, Essex).*

**PONY II** Ortho-Kinetic child's battery-powered, indoor/outdoor trike. Hand throttle control – Forward/Reverse, speed limiter, pneumatic tyres, rear wheels extend, chain drive, seat fully adjustable – swings 360°, with flip-up arms and buckle lap belt. Dismantles easily to fit into boot of car. Battery charger included. Cost £1,400, bargain £400 ono. *Tel: 01373-865329 (Wiltshire).*

**QUICKIE 2** wheelchair, cost £1,400 new, asking £750. Weight 13.5kg, frame width 305-508mm, seat sling depth 406mm, adjustable seat sling tension, width-folded 305mm, swing-away footrests, swing-away padded armrests, backrest with push handles. *Tel: 01869-324907 (Bicester, Oxon).*

**VAUXHALL ASTRA** Chairman 1.6L van, suitable for wheelchair user. Automatic, 33,000 miles. 1 rear seat. Lowering rear suspension, 9 months MoT. Excellent condition. Must be seen. £3,500, offers invited. *Jayne, tel: 01527-871201.*

## PRODUCT

**BIOFLOW** - Pain relief. Affordable magnotherapy for people and pets. Used by doctors and vets for the treatment of aches and pains. Free colour brochure and fact sheet – *Dilys Hunt, independent distributor, 2 Trevor Close, Merthyr CF48 2BG. Tel. 01685-350744.*

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## ACCOMMODATION

### ILKLEY, WEST YORKSHIRE

Sanctuary Housing Association wheelchair-accessible flat, sharing with two other persons (female). Emergency warden cover and support services available, if required. Semi-rural location with panoramic views across the Wharfe Valley. Half hour by train from Leeds and Bradford. *Contact Mark Best, tel/fax: 01943-603013.*

## HOLIDAY ACCOMMODATION

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

**ISLE OF WIGHT ASBAH** Fully-equipped, wheelchair-accessible, two-bedroom bungalow. Sleeps six. Clubhouse, indoor heated pool, shop etc. Lovely views, many interesting places to visit. Own transport advisable. *Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983-863658.*

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

**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).*

**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: 01621-772447.*

**ORLANDO, FLORIDA** House with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on golf course. Three double bedrooms, two bathrooms (Mangar bathlift installed), Cable TV, free local telephone calls, free Country Club membership. 24-hour 'on-call' management company. 15 mins Orlando Airport. 20 mins Disney. Paraplegic owner. *Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT, tel/fax: 0161-792 3029.*

### FOR SALE

**BEC ELECTRIC** scooter, VGC. Free, so long as collected. *Mrs Adams, 0181-690 6341 (Catford).*

**CARTERS INVACARE** child's folding 12" wheelchair, detachable back, anti-tip device, quick release

wheels, metallic purple. Very good condition. Accept £200. *Contact: Barry Norman (01480) 831212 (day-time). Cambridgeshire.*

**TOWN & COUNTRY 120** invalid bike, with basket, indicators, battery charger. Used just once. Cost £3,000 when new, asking £2,000 ono. *Mr Purcell tel: 0181-586 7630 (East Ham).*

**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, takeaway. 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 six – well-furnished and comfortable. Free club membership.

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

# LINK Rates

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Display Rates on application, from the Publicity Manager.

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