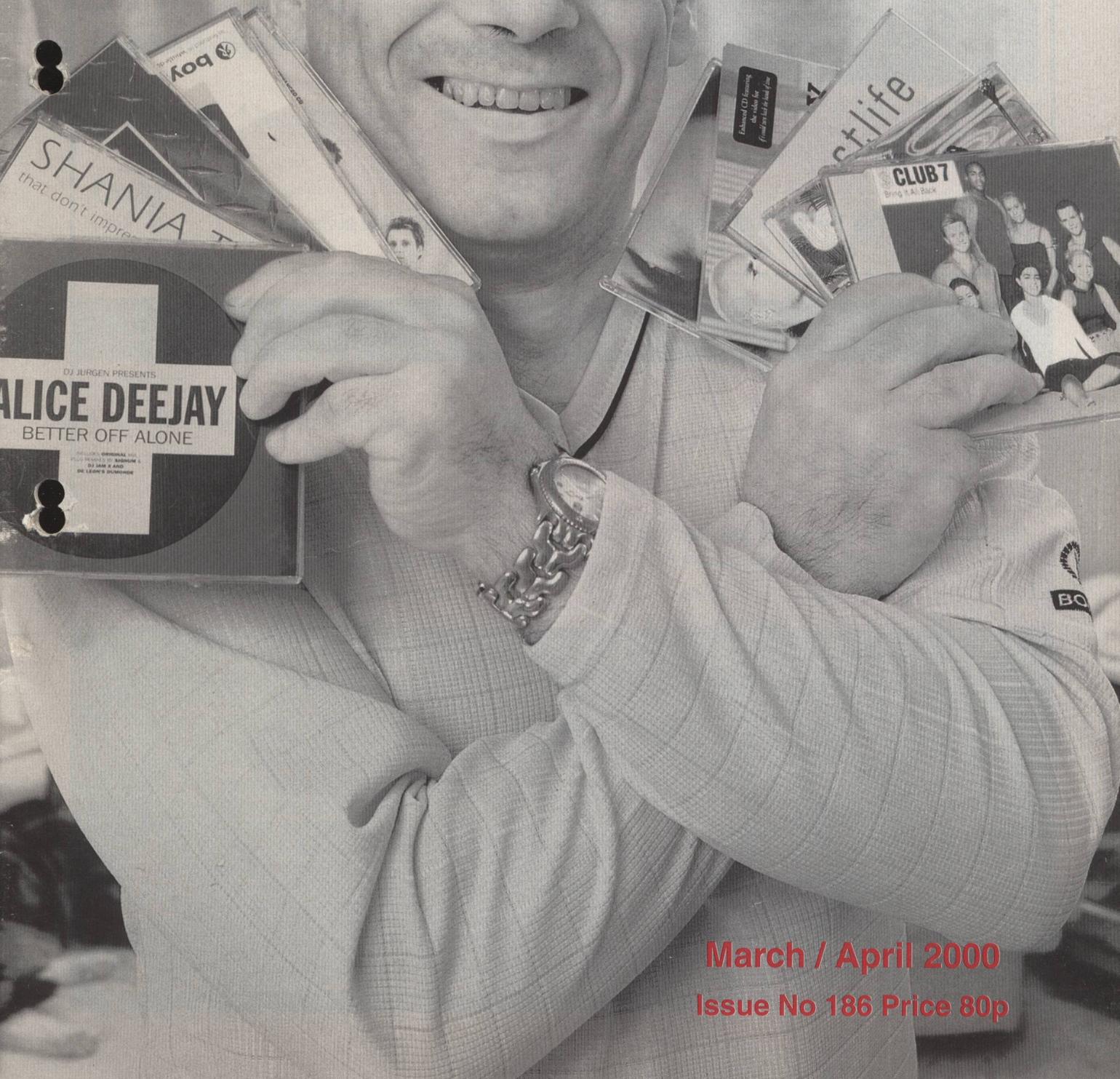


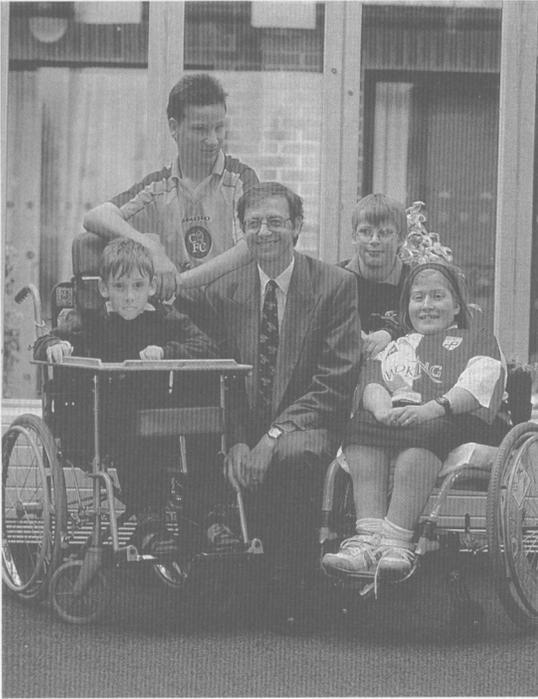
# Link

The magazine for people with  
Spina Bifida and/or Hydrocephalus



March / April 2000

Issue No 186 Price 80p



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# Contents

Good advice on flour	5-6
They make us tick	7
Musical VIP!	9
Benefits uprating	11-12
Pigeon Show	centres
Network News	17-24
Dave's Diary	25
Letters	26
Holiday lets / small ads	27
Local Associations	28

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Cover: Disc jockey Pete Smith – on page 7, he recalls the moment he notched up a Guinness world record for playing music non-stop in a taxicab company's window. Photo: John Gurd.

## Editorial

### *Dear Readers*

This issue represents something of a watershed for ASBAH. Following our readership survey last year and the exchange of opinions within a focus group, our Executive Committee has accepted a recommendation that we stop publishing our separate *Lift* magazine and our *Hydrocephalus Network News*.

The great news is that readers of both these publications will find a new home in *Link* which – from our next issue in May – will appear in full-colour, with completely re-ordered contents.

There should be something for everybody in the new *Link*, with special colour-coded sections for special interests – pages about people with hydrocephalus by itself, our disabled members forum YVIA, fundraising and local Associations.

That doesn't mean these will be the only places where you will find stuff that interests you. If the news value of any particular item warrants it, it will be put in upgraded news pages at the front of the magazine, or in longer features.

There will be stronger coverage of non-clinical stories and, from time to time, very readable medical update pages.

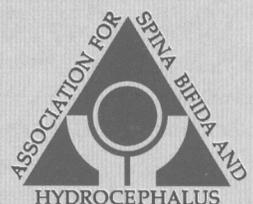
The aim is to re-unify ASBAH's membership behind one masthead, and we all look forward immensely to providing you with a modern, up-to-date magazine. One that you can continue to rely upon.



Tony Britton  
Publicity Manager

Patron: HRH The Duchess of Gloucester GCMG  
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ASBAH exists to provide advice, support and advocacy to people with spina bifida and/or hydrocephalus, their families, and their carers.



ASBAH aims to empower its service-users by providing up-to-date information, extending their choices, and maximising their opportunities for independence.

[postmaster@asbah.demon.co.uk](mailto:postmaster@asbah.demon.co.uk)  
[www.asbah.demon.co.uk](http://www.asbah.demon.co.uk)

# Daniel, that dunk and Tony Blair!

**THE BOY who hit the headlines by dunking his biscuit in the Prime Minister's cup of tea was only doing what came naturally.**

"He's never any different. When my son sets his mind on something, nothing will get in his way," said Cath Spencer, after nine-year-old Daniel got tongues wagging during a visit to 10 Downing Street as part of the *Woman's Own* Millennium Children of Courage awards.

Daniel – nominated to receive the award after being inspired by 'Lord of the Dance' Michael Flatley to take up tap-dancing – met Tony Blair, who had put his cup of tea on a table. Daniel, complaining his own biscuit was a bit dry, reached over and dunked it in the PM's cuppa.

"I was horrified. I thought: 'Daniel you can't do that! That's the Prime Minister's cup' but Mr Blair took it

ever so well. He grinned and went on drinking his tea," said Mrs Spencer from the family home in Gwespyr, north Wales.

"Did you hear what he did with his crutches later? As we were leaving, Daniel had stood in the hall to say goodbye with the other children. Most had been overawed and were keeping quiet. Daniel wanted to put his coat on but didn't know what to do with his crutches. As the Prime Minister came up level, he held out the crutches, saying: 'Tony, can you hold these for a minute?'"

"At this point, 10 aides rushed up saying they'd take the crutches. But Daniel said: 'No, Tony's helping me.' He forced the Prime Minister

to take the crutches. Later, after Daniel had got his coat on, Mr Blair said: 'Is he always like this?' I had to tell him: 'Always.'"

Daniel, who has spina bifida, and 10 other children were honoured with the Children of Courage awards. After touring 10 Downing Street, they had lunch at the House of Lords and then went to an awards ceremony at Westminster Abbey.

Daniel enjoys tap dancing from a chair and has danced in shows at his school and at Barbara O'Grady's dance school in nearby Rhyl.

"He saw one of Michael Flatley's shows and said: 'I want to be like him.' It broke my heart at the time to think that he couldn't ever quite be like Michael Flatley.

"But he dances in his chair and takes part in two or three numbers, and there's always a special focus on him. At the end of the show, he comes on stage with crutches for the first time and people see that he is disabled. That's when those little old ladies in the front row always get a bit weepy," said Mrs Spencer.

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● **POSTMAN Paul Bedford** put on his running shoes and raised more than £800 for Chester & District ASBAH. Colleagues at the Royal Mail in Chester sponsored him for his first marathon which he completed in less than four hours. Champagne fizzed when the cheque was handed over to Bob Ithell and his son Jamie (pictured).

# ASBAH welcomes flour advice

**GOVERNMENT advisers have recommended that folic acid be added to all flour to achieve a major reduction in the number of babies affected by spina bifida during pregnancy.**

A decision taken by Public Health Minister, Yvette Cooper, on 13 January to put the recommendation out to consultation was welcomed immediately by ASBAH, which has been campaigning on this issue for several years.

The recommendation came from COMA (the Committee on Medical Aspects of Food and Nutrition).

COMA called on the government to require millers to be required to put 240 micrograms of folic acid, a B-group vitamin, into every 100 grams of flour in order to reduce the number of spina bifida pregnancies by an estimated 41%.

ASBAH executive director Andrew Russell said: "COMA recommends a level of fortification, which its expert members consider is safe for the population as a whole.

"The government's present strategy encourages the voluntary use of folic acid as a diet supplement but it will always be limited in its effect because it will only ever reach women who plan their pregnancies. About 50% of pregnancies are not planned, and women who do not plan ahead don't take extra folic acid."

Mr Russell added: "We've waited an inordinately long time for COMA to report, but we now welcome the decision of the new Minister for Public Health to get to grips with it. A final decision must not become bogged down in arguments about allocation of responsibilities between the Department of Health, MAFF and the new Food Standards Agency, or we will be waiting another few years for action to be taken."

1998 figures, the latest available, show that almost 400 pregnancies were affected by spina bifida in England and Wales alone. This figure does not include the numbers of pregnancies affected in either Scotland or N Ireland.

Even if folic acid is added to all flour in future, women should still take a daily folic acid diet supplement to raise the folic acid level in their blood from well before conception until the end of the first 12 weeks of pregnancy – when their requirement for the vitamin is at its highest.

The Department of Health already advises all women planning a

pregnancy to take a daily folic acid supplement of 400mcg every day. Women specially at risk – those with previously affected pregnancies or with family histories of spina bifida – should ask their doctors to prescribe 5mg of folic acid daily.

Contrary to some reports, flour fortification would not be a first-time attempt at mass medication. Traces of two other B-group vitamins, niacin and thiamine, as well as calcium and iron, are already required additives in most types of flour.

## **Tell your MP what to do about folic acid**

PLEASE support ASBAH's campaign to have folic acid added to all flour by asking your MP to sign up to MP Helen Brinton's Early Day Motion on the subject. EDMs show the level of support among MPs.

Write to your MP at House of Commons, London SW1 0AA. Ask him or her to sign EDM 265, dated 13 January 2000, which urges as high a level of fortification as is consistent with public health, as soon as possible. *Text of EDM on page 6.*

Tell your MP that fortification of all flour with folic acid has been recommended to the government by the expert COMA committee to help protect all women from having spina bifida pregnancies.

## **ASBAH**

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Bangor, Gwynedd LL57 4BN  
Tel 01248-671 345  
Fax 01248-679141  
eleni@asbah.demon.co.uk

## **Contacts**

# FOLIC ACID AND SPINA BIFIDA PREGNANCIES

Below is the text of *Early Day Motion 265* tabled in the House of Commons by Mrs Helen Brinton, MP on 13 January 2000. Thirty one MPs had signed the EDM by 11 February 2000. They are:

*Brinton, Helen*

Adams, Irene  
Berry, Roger  
Cable, Vincent  
Davidson, Ian  
Godman, Norman A  
Hopkins, Kelvin  
King, Oona  
McDonnell, John  
Moffatt, Laura  
Turner, Desmond

Ballard, Jackie  
Bottomley, Peter  
Cook, Frank  
Dean, Janet  
Griffiths, Win  
Hoyle, Lindsay  
Llwyd, Elfyn  
Meale, Alan  
Ross, Ernie  
Vis, Rudi

Birmingham, Gerald  
Brand, Peter  
Cryer, Ann  
Etherington, Bill  
Hancock, Mike  
Jones, Lynne  
Mahon, Alice  
Michie, Bill  
Russell, Bob  
Wigley, Dafydd

**T**hat this House welcomes the long-awaited publication of the Report by the Committee on Medical Aspects of Food and Nutrition on Folic Acid and the Prevention of Disease; congratulates the Association for Spina Bifida and Hydrocephalus on its sustained campaign; recognises that COMA's recommendation of a fortification of 240 microgrammes of folic acid in every 100 grammes of flour would reduce the incidence of spina bifida pregnancies by 41 per cent; but draws attention to the lengthy delay already experienced; and calls on the Public Health Minister to ensure that the forthcoming consultation is as short, and the eventual fortification level as high, as is consistent with the health of the population in general, whilst being of maximum benefit to the 50 per cent of women whose pregnancies are unplanned.



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Surname \_\_\_\_\_

Job Title (if applicable) \_\_\_\_\_

Organisation (if applicable) \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

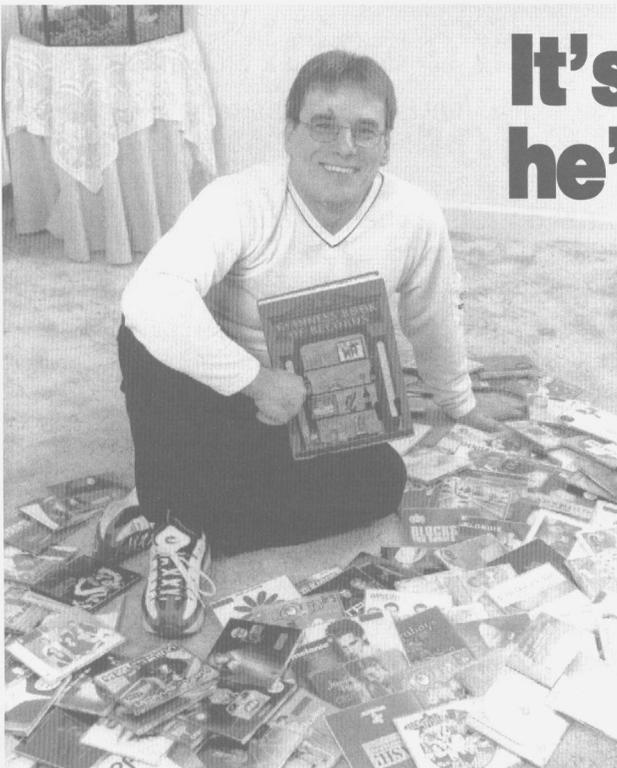
Postcode \_\_\_\_\_

Tel \_\_\_\_\_

Fax \_\_\_\_\_

Email \_\_\_\_\_

Return to: **Naidex 2000**, Touchstone Exhibitions & Conferences Ltd, Haleon House, 4 Red Lion St, Richmond-upon-Thames, Surrey TW9 1RW. UK. Fax 020 8332 0874



## It's his record – and he's hanging on to it!

**DJ PETE SMITH, known as 'Groovy Pete' around his stamping grounds, is a record-breaker – but not in the literal sense.**

His claim to fame is a mention in the famous Guinness Book of Records for playing music on a home-made mobile discotheque non-stop for 360 hours.

The 15-day session took place in the front window of an all-day taxi office in Basingstoke, when Pete worked as an assistant in the record department at Woolworths.

"I can't tell you whether I ever dozed off or not; I must have but you never remember afterwards," said Pete (47), who has spina bifida and wore callipers until he was two years old.

It wasn't long before he turned professional and went on to back some of the country's top DJs, including Emperor Roscoe and 'Diddy' David Hamilton. He also worked on local radio stations and gave his free time to charity events.

In November last year, he raised over £700 for the BBC Children in Need Appeal by doing a seven-hour DJ stint in the open air in the main square of his new home town of Crewkerne, Somerset, finishing only after heavy rain set in.

Father-of-seven Pete, who relaxes by taking his sons to see him motor racing in cars he builds himself, commented: "I've always liked charity work and am more than happy to do it."

His world record has been expunged from recent editions of the Guinness Book of Records to make way for others. But it still holds good; nobody has ever been daft enough to try to better it.

Pete's got it preserved in black and white, in a well-thumbed old edition. His marathon disco is recorded as having taken place between 15 and 30 November 1970.

## People they make us tick!

### Tanni CBE



● Congratulations to Tanni Grey-Thompson (*left*) who was promoted in the New Year's honours from MBE to OBE for services to disability sport. The famous wheelchair athlete is now preparing for the Sydney Paralympics later this year.

## Lester copes with the Welsh, and the Russians

**GRADUATE twice over and mother-of-two, Lester Bath has become the secretary for ASBAH in Wales – the first person you are likely to speak to when phoning our newest 'region'.**

Lester first came to Wales nearly 25 years ago to attend university and then moved to London for seven years where she did a variety of part-time jobs while her son was small.

A course in craft bookbinding led to a job as secretary of Designer Bookbinders which Lester started before returning to Wales.

Last summer, she graduated again from Bangor University in Welsh and Russian after the long realisation that she would never use her first degree in English and Drama.

As well as being interested in languages, Lester enjoys reading and listening to a variety of music – jazz, classical and the Rolling Stones.

She lives on the edge of the Snowdonia National Park, but has yet to walk up one of the surrounding mountains.



## A joyous image at Naidex

FREE tickets for disabled people are available for what is set to be one of the largest and most exciting product exhibitions of the year.

Naidex 2000 will be entertaining the crowds from 9 – 11 May at Birmingham's NEC with plenty to do, see, buy, learn and experience.

As well as an enormous range of new products on show, the event will also offer a 'mobility test track' and a 'new products showcase.'

A positive image of disabled people will be projected at Naidex through sports demonstrations, an art and photographic exhibition, martial arts, theatre, dance and music performances.

In addition, there will be separate programmes of seminars for disabled visitors and healthcare professionals with subjects ranging from sexuality to garden therapy.

A huge hydrotherapy tank from Arjo will also be a show feature. This glass-walled pool is large enough for a number of people to exercise at the same time, as well as offering a feeling of security, as the therapist can provide instruction and supervision at the same time.

To ensure that you are on the Naidex mailing list for FREE tickets call the Naidex Hotline on 0870-7511516.

A fax line is also available on 0870-7511509.

## New hydrocephalus leaflets for N Ireland

**A SERIES of 10 information sheets on hydrocephalus, written by our specialist adviser (education) Lorna Johnston, are now available.**

With some aimed at teachers, some at parents and one for job support workers/classroom assistants in Northern Ireland, the A4 sheets give an insight on a range of problems that carers and teachers may encounter.

Practical solutions and useful approaches to learning are offered by Lorna based on her long experience and detailed observations of children and young people, and an exchange of information with parents/carers.

Margaret Young, manager of our Northern Ireland region, said: "We saw the need for them from Lorna Johnston's experience in her three-year specialist adviser (hydrocephalus) post.

"We are in the process of distributing them to key players in the education field in Northern Ireland but parents and teachers are welcome to request them on an individual basis."

The titles of the leaflets, which have been funded by the National



Lorna Johnston

Lottery Charities Board Northern Ireland, are:

**No 1** – Hydrocephalus and Physical Abilities: motor skills and co-ordination;

**No 2** – Hydrocephalus and Behaviour (for teachers);

**No 3** – Hydrocephalus and Literacy and Thinking Skills (for teachers);

**No 4** – Hydrocephalus and Mathematics (for teachers);

**No 5** – Hydrocephalus and Information and Communication Technology (ICT)

**No 6** – Hydrocephalus and Behaviour (for parents);

**No 7** – Hydrocephalus and Literacy and Thinking Skills (for parents);

**No 8** – Hydrocephalus and Numeracy (for parents);

**No 9** – Educational Statementing in Northern Ireland;

**No 10** – Hydrocephalus and Observations for Support Workers.

Single leaflets are available from: ASBAH Northern Ireland Region, Graham House, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH. Tel: 02890-798878; fax: 02890-797071; email: margarets@asbah.demon.co.uk

Adaptations of the leaflets, for use in England and Wales, are being prepared by ASBAH.

## ASBAH's medical conference of the year

**ASBAH's medical conference of the year will be held at Newport Pagnell, Buckinghamshire, just off the M1, in May.**

The conference, 'Spina Bifida and /or Hydrocephalus – current concepts and treatment', will give participants a chance to update their knowledge and share notes with some of Britain's foremost practitioners.

Consultant paediatric neurosurgeon Peter Richards and consultant paediatric surgeon Rowena Hitchcock, both

from Oxford, will speak – as will Professor Jim Stevenson, from the University of Southampton, who is leading a big ASBAH research project on psychology and hydrocephalus.

The venue will be the Marriott Hotel, Newport Pagnell, on Wednesday 17 May. Professionals £50 a head, but service-users, parents and carers will pay only £15.

Mary Malcolm, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, fax: 01733-555985.

# Disability Commission to start work

**THE DISABILITY Rights Commission – which starts work in April under the chairmanship of former RADAR director Bert Massie – will have 15 individual commissioners.**

The commissioners include Philippa Russell (director of the Council for Disabled Children and a member of ASBAH's education advisory committee). Ten members of the commission have disabilities.

The commission has been set up by the government to

put teeth into the fight for full, enforceable civil rights for disabled people.

The chairman will work four days a week for a reported £65,000 a year, while the individual commissioners will work at least 20 days a year for £134 a day, plus expenses.

RADAR'S new chief executive will be Peter Mansell, former director of the Spinal Injuries Association. He has worked as a policy manager at the Dept of Health.

## Dome from home

**THE FIRST residential conference for years aimed at ASBAH members in general will be held a short river ride away from the Millennium Dome.**

Local associations in our South East region are banding together to produce a big conference in Greenwich over the first weekend of September.

"The local associations here decided to organise the sort of occasion which their members really would enjoy. There will be quite a bit about helping people to live independently and YVIA input on things like assertiveness, but there will also be chances for people to meet socially and enjoy each other's company," said ASBAH regional manager Mrs Jo Francis.

The event – 'The Way Forward' – will be held at Avery Hill College, part of the University of Greenwich.

ASBAH-Surrey chair Alan Twyford, one of the organisers, said: "A river trip might go down down very well, or a trip to the Dome."

The programme is being finalised. The cost per weekend delegate will be £80, including accommodation and meals. Day spaces will also be available.

*If you would like to express an early interest in attending, please contact: Jo Francis, ASBAH, 209 Crescent Road, New Barnet, Herts EN4 8SB, tel: 0181-449 0475, fax: 0181-440 6168. jof@asbah.demon.co.uk*



**ASBAH president visits Peterborough**

ASBAH's president Jeffrey Tate, a world-renowned classical music and opera conductor, took time out from a busy schedule to visit our national centre in Peterborough at the beginning of February.

He met office staff (*above*) and senior officers of the Association (*below*) during the visit – part of a brief spell when he managed to return to Britain from commitments overseas and had some time to himself.

The French president has just awarded Dr Tate with the Légion d'Honneur to add to the CBE he received from the Queen some years ago. ASBAH's president is conducting in Europe and the United States over the coming year.

## Upbeat with the maestro!

● All together now!  
Jeffrey Tate with, from the left: treasurer Mike Allen, vice-president Patrick Daunt, chairman Peter Cottingham and executive director Andrew Russell





**EMMA Brown always knew she was strong because she used to beat the boys at school in arm-wrestling.**

But she never dreamt that one day she would be setting her sights on the Paralympics as a world champion power lifter.

The 20-year-old, from Tonteg, near Pontypridd, weighs less than 82 kilos yet is able to lift a hefty 132.5 kilos.

The former shot-putter unintentionally broke the national record in power lifting at 14 while competing at the Junior Games at Stoke Mandeville.

It was then that she realised her sporting talents might lay in another direction!

"At school, I knew I would be good at some sport but I didn't think it would be power lifting. I have finally found my niche," she says.

Emma is now lifting weights four times a week and doing aerobics three times a week in readiness for

this year's Paralympics in Sydney, Australia.

It's hard work but fun too as she's found an accessible and sociable gym where she enjoys a chat with others after training.

"I enjoy it, particularly meeting people and going round the world. Not many people my age have been to Australia, New Zealand, Dubai - near enough all round the world.

"Having a sport certainly gives you an incentive in life and positive thoughts. All the hard work is done beforehand; the competition is the easy part."

After the Paralympics' there is possibly the 2002 Commonwealth Games in Manchester - if a competition is created for disabled women power lifters as it has been for their male counterparts.

## *No need for strong-arm tactics to prove herself!*

**ASBAH will be launching our new Wales region in April with a reception in the National Assembly building in Cardiff.**

**We're proud to be building up our services in the Principality, which has such a strong identity of its own.**

**LIZ CAWTHORNE writes about two women who have already stamped their mark on Wales.**



**SINCE she was little, Susie Conway has helped others in need.**

Now she has become North Wales' Woman of the Year in recognition for her good work, even though she has not always been in the best of health herself.

Nominated by her mum Val, the 31-year-old was presented with a prestigious trophy by Welsh Assembly Member, Gareth Jones,

at St George's Hotel, Llandudno.

Susie helps out on flag days and offers her services to Llandudno Hospital, the Carer's Association and Aberconwy Stroke Club. She has also worked voluntarily for the Red Cross and Scope. She is a member of a Methodist Church and collects money for their Junior Missions Overseas.

For the past five years, she has written to a girl from Croatia through Operation Christmas Child and regularly sends parcels of donations.

She says these activities can take her

mind off her own problems. She is often in a great deal of pain from kidney stones.

Speaking from her home in Conwy, she said: "Having all my friends around me and my mum and dad is a big help. I couldn't do it without them."

Now she is raising money for a new microwave for Llandudno Hospital by going back to how she used to raise money when she was a youngster - making and selling paper flowers. In this way, the money that she raised bought a microwave, two TVs and a nebuliser.

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disability	
single	£22.25
couple	£31.75
severe disability	
single	£40.20
couple (one qualifies)	£40.20
couple (both qualify)	£80.40
disabled child	£22.25
carer	£14.15

\*for eligibility of under-18s and calculating amounts, see Child Poverty Action Group's National Welfare Benefits Handbook.

**Housing costs – deductions for non-dependants**

aged 18, or over, and in remunerative work – gross income	
£81–£119.99	£17.00
£120–£156.99	£23.35
£157–£206.99	£38.20
£207–£258.99	£43.50
£259 and above	£47.75
others, aged 18 or over and not in work or earning less than £80 or on income support and 25 or over	£7.40
aged 16/17, or 18/24 and on IS, in receipt of YT allowance	nil
<b>Allowances for personal expenses</b>	
residential & nursing homes	£15.45
dependent children	
under age 11	£6.15

**APRIL 2000 BENEFITS UPRATING**

**Means-tested benefits & tax credits**

aged 11/15	£9.00
aged 16/17	£10.40
aged 18	£15.00
hospital	
higher rate	£16.90
lower rate	£13.50

**Maximum amounts for accommodation and meals in:**

<i>residential care homes</i>	
old age	£221.00
very dependent elderly	£256.00
mental illness	£234.00
drug/alcohol dependence	£234.00
mental handicap	£266.00
physical disablement	
under pension age	£303.00
over pension age	£221.00
other	£221.00
Greater London	
maximum increase	£46.00
<i>nursing homes</i>	
mental illness	£331.00
drug/alcohol dependence	£331.00
mental handicap	£337.00
terminal illness	£330.00
physical disablement	
under pension age	£373.00
over pension age	£330.00
other	£330.00
Greater London	
maximum increase	£51.00

**Deductions**

for child maintenance	£5.30
for fines and council tax arrears	£2.65
for arrears of community charge	
single	£2.65
couple	£4.10
for direct payment of fuel debt	
5% rate	£2.65
for direct payment of housing costs and water rates arrears	£2.65
reduction in benefit for strikers	£28.00

**Disregards**

standard earnings	£5.00
earnings couple	£10.00
higher earnings	£15.00
war pensions	£10.00
voluntary & charitable payments	£20.00
student loan	£10.00
student's	
covenanted income	£5.00
income from boarders (plus 50% of the balance of the charge	£20.00

**Expenses for sub-tenants**

furnished or unfurnished	£4.00
where heating is included	£9.25

**Capital limits**

disregarded	£3,000
tariff income on capital between £3,000 and £8,000 – £1 for every £250 or part thereof	
upper limit	£8,000
child's limit	£3,000

*residential care*

disregarded	£10,000
upper limit	£16,000

**Cold weather payment** £8.50

**Sure start maternity payment** £200

**HOUSING BENEFIT**

**Applicable amounts, ie, personal allowances and premiums**

as for Income Support except	
single person aged 16/24	£41.35
lone parent under 18	£41.35
family premium – lone parent rate	£22.20

**Amenity deductions**

heating	£9.25
hot water	£1.15
lighting	£0.80
cooking	£1.15

**Meals deductions**

<i>full board</i>	
each person aged 16 or over	£18.65
each child under 16	£9.40
<i>half board</i>	
each person aged 16 or over	£12.40
each child under 16	£6.25
<i>breakfast only</i>	
each person (inc children)	£2.25

**Non-dependant deductions**

age 18, or over, and in full-time work – gross income:	
£259 or more	£47.75
£207–£258.99	£43.50
£157–£206.99	£38.20
£120–£156.99	£23.31
£81–£119.99	£17.00
all others (for whom a deduction is made)	£7.40

**Earnings disregards**

where disability premium awarded	£15.00
specified employments	£15.00
lone parent – not in receipt of IS	£25.00
where the claimant has a partner	£10.00

# Means-tested benefits & tax credits

from page 11

single claimant	£5.00
where carer premium awarded	£15.00
childcare costs – 1 child	£70.00
– 2 or more children	£105.00
<b>Other income disregards</b>	
maintenance	£15.00
charitable or voluntary payments	£20.00
war pensions	£10.00
student loan	£10.00
student's covenanted income	£5.00
income from boarders (plus 50% of the balance of the charge)	£20.00
30-hour adult allowance	
DPTC/WFTC	£11.25

## Expenses for sub-tenants

as for IS

## Capital limits

disregarded	£3,000
tariff income on capital between £3,000 and £16,000 – £1 for every £250 or part thereof	
upper limit	£16,000
child's limit	£3,000

## COUNCIL TAX BENEFIT

### Personal allowances & premiums

as for HB except that personal allowances are not payable for young people aged 16 and 17.

### Non-dependant deductions

aged 18 or over and in remunerative work – gross income:	
£259 or more	£6.95
£207–£258.99	£5.80
£120–£206.99	£4.60
up to £120	£2.30
all others (for whom a deduction is made)	£2.30

### Second adult rebate

second adult on IS	25%
second adult's gross income	
under £118	15%
£120 to £156.99	7.5%

### Capital disregards and tariff income

as for HB

### Earnings and other disregards

as for HB

## WORKING FAMILIES TAX CREDIT

Adult credit	£53.15
Adult credit for working 30 hours+ pw	£11.25
<b>Child credit</b>	
from birth to Sept following 16th birthday	£21.25
from Sept following 16th birthday	£26.35

## Capital and tariff income as for IS

### CHILD CARE CREDIT

70% of cost for 1 child up to £100.00  
70% of cost for 2 or more children up to £150.00

### DISABLED PERSON'S TAX CREDIT

#### Adult allowance

single people £55.15

## Non means-tested benefits

### Attendance allowance

higher rate £53.55  
lower rate £35.80

### Rate for Child addition\*

£11.35  
*If you have a dependent child, you could receive the Child addition if you receive any of the following benefits: retirement pension, widowed mother's allowance, short-term incapacity benefit, higher rate and long-term incapacity benefit, invalid care allowance, severe disablement allowance and short-term incapacity benefit if beneficiary is over pension age.*

### Child benefit

only, elder or eldest child £15.00  
for other child(ren) £10.00  
for only, elder or eldest child (lone parent rate) £17.55

### Contribution-based jobseekers allowance

under 18 £31.45  
aged 18/24 £41.35  
25 and over £52.20

### Disability living allowance

*care component*  
higher £53.55  
middle £35.80  
lower £14.20  
*mobility component*  
higher £37.40  
lower £14.20

### Earnings rules

Invalid care allowance £50.00  
Therapeutic earnings limit £58.50

### Guardian's allowance/ child's special allowance\*

£11.35

### Industrial injuries benefits

Disablement benefit  
100% assessment £109.30  
20% assessment £21.86  
Reduced earnings allowance (maximum) £43.72

couples/lone parents £84.90  
30 hours allowance £11.05

### Child allowances

from birth to Sept following 16th birthday £21.25  
from Sept following 16th birthday £26.35

### Applicable amount (ie taper threshold)

single people £71.10  
couples/lone parents £91.45  
disabled child's allowance £22.25

### Capital and tariff income

as for FC, except upper limit £16,000

### Invalid care allowance

£40.40  
increase for adult dependant £24.15

### Incapacity benefit

short-term (under pension age)  
lower rate £50.90  
higher rate £60.20  
short-term (over pension age)  
lower rate £64.75  
higher rate £67.50  
long-term £67.50  
increase of long-term for age  
lower rate £7.10  
higher rate £14.20

### Invalidity allowance (transitional)

higher rate £14.20  
middle rate £9.00  
lower rate £4.50

### Maternity allowance

lower rate £52.25  
higher rate £60.20  
new standard rate £60.20  
MA threshold £30.00

### Retirement (Categories A & B) and widow's pension and widowed mother's allowance

single person £67.50  
wife or adult dependant (retirement) £40.80

### Severe disablement allowance

adult dependant £40.80  
age-related addition  
higher rate £14.20  
middle rate £9.00  
lower rate £4.50

### Statutory maternity pay

lower rate £60.20  
earnings threshold £67.00

### Statutory sick pay

standard rate £60.20  
earnings threshold £67.00

\* This is reduced by £1.50 for any child for whom you receive the higher rate of child benefit.



## All for the chop!

A THICK matting of human hair covered the floor of a famous pub as regulars queued up to meet the demon barbers of Battle – during a bare-faced stunt for ASBAH.

Long hair, luxuriant thick tresses, the grey wispy bits circling some bald pates, even one long ginger beard, hit the deck as a couple of dozen usually sane locals had their locks lopped off at the 1066 pub in the East Sussex village.

Two barmaids, Tracey Chittenden and Hannah Thomas, went beyond the call of duty and allowed their crowning glories to be removed by the haircutting crew from Chaps barber shop.

Almost 1,000 years on, victory was

claimed this time by Craig Lovett, full-time carer for his three-year-old son Samuel, who has hydrocephalus. He's never organised or seen anything quite like it before.

Craig said: "It was an absolutely brilliant night. So many people took part, even two barmaids joined in the fun. And we are on the way to collecting £2,800, with more money due to come in."

Landlord Colin Burton agreed, though he's been left with a legacy he'd sooner do without.

"Now they're calling me Dandelion. Since I had my hair shaved, I've not been able to do a thing with it. Even though I have had another haircut, it still stands up in spikes!"

## Our work on equality recognised by Abbey National



OUR work in improving equal opportunities for people with disabilities was recognised by the Abbey National Charitable Trust.

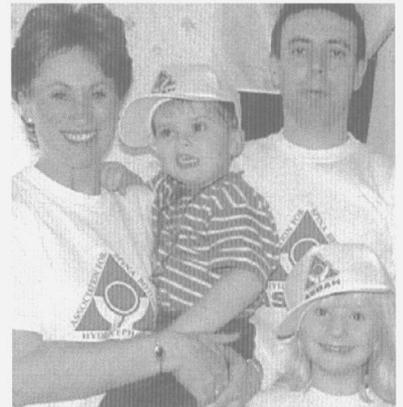
Wayne Rand, Peterborough branch manager for Abbey National, visited national centre to present a £1,000 cheque to our new chairman, Peter Cottingham. ASBAH's trusts and legacies officer Jane Ayres is

pictured above with Mr Cottingham (centre) and Mr Rand (left).

Mr Rand said: "ASBAH invests significantly in providing education and training opportunities for young people with spina bifida and hydrocephalus. We applaud this work which accords very closely with our own policies and practice."

**APPEALS**  
With **PAGE**  
a little help from   
our friends!

## Neighbours rally round



THE GOODWILL went round and round and it came out here ... when neighbours Christine Arnold and Kevin Dyer put on their t-shirts to run for ASBAH in the Great North Run in October.

Christine has already run five of these half-marathons before for other charities, and Kevin wanted to show on his birthday that life just begins at 40. They were recruited by the mother of three-year-old Alexander Nicklen (pictured), who has spina bifida, and Jacey, aged nine.

"Christine's a friend living three doors way, who has already done the Great North Run a couple of times, for cancer and autism – while Kevin is my cousin's husband and he lives next door," said Mrs April Nicklen, of Ellington, Morpeth, Northumberland.

"Alexander's spina bifida is very mild, thank goodness, but Ian, my husband, and I will need continued support. Asking them to run for ASBAH is one way of saying thank you."

The good neighbours collected £313 between them which has now been handed over.

# Will tax breaks spark 'a civic patriotism'?

**GOVERNMENT plans to squeeze an extra £1bn out of the economy for charity donations and volunteering schemes have been outlined at a conference in London.**

The Chancellor, Gordon Brown, said the scheme should spark an outbreak of 'civic patriotism' among Brits, by encouraging people to give more time and more money to charity.

Under sweeping reforms of the tax relief system, the Treasury will top up contributions given by individuals up to 50p in the £ to help boost donations, he told the National Council for Voluntary Organisations.

The Chancellor also said that he is aiming to simplify guidelines for charitable donations from business, as well as making it easier for individuals to work within the voluntary sector.

In a statement, Mr Brown said: "I believe people want to mark the new millennium by making Britain stronger as a community.

"I do believe this thirst for a new civic patriotism, which we're responding to today, is something that is very British indeed."

For every pound that an individual gives after April, the Treasury will make up another 28p. And, for every pound

people give to payroll giving, the Treasury will give up to 50p.

"And we've got new rules that will make it far easier for companies, who give only a fifth of what is given in the United States to charity and community activity, to do so as well. So we are changing the whole financial foundation to make it far easier to give money and time."

The government will also use the internet and a community TV channel to put volunteers in touch with suitable projects, he added.

**Hundreds of cynics pitched in with trenchant views about a possible rise in civic patriotism on the BBC Online internet service, after it opened a forum on the subject.**

*Early comments included:*

- You live in a dream world. No one wants to give money to charity when we can hardly afford to live as it is. You've got so much money in the government and you waste it on rubbish like the Dome.
- With what we pay in income tax, and the supposed constant improvement and growth of our economy, why should we have to depend on charities at all?
- Well, you know what they say? 'Actions speak louder than words!' Can anybody lend me a fiver?

## New legal rights for carers

A NEW bill which will enable carers – teenagers as well as adults – to receive services in their own right is being pushed through Parliament by the government. For the first time, carers will be able to seek support, even if the person cared for has refused an assessment.

The Carers and Disabled Children Bill was introduced at the end of January by Labour MP Tom Pendry. Direct payments could go to people as young as 16 and 17 years of age. One in six British households contain a carer, many of them full-time.

# Pigeon show p in by the th

**ONE WEEKEND** in January every year, Blackpool is a mecca for tens of thousands of pigeon fanciers. The weekend walks away better off by many thousands.

**The repeated generosity shown by the UK racing pigeons has made it national ASBAH**

Over 17 years, the figures on cheques written by the British Homing World 'Show of the Year' have totalled £325,000.

In recognition of generosity, ASBAH has a strong presence at the massive show in Blackpool Winter Gardens. Our fundraising volunteers turn

Just before the winter is under way in January, ASBAH's show is set up in the Empress Ballroom complex. 1,200 donated prizes won in a tombola

Thousands of raffle prizes are brought to the show too – either in the Gardens on the show too – either in countless competitions to be sold in a large auction.

When the doors opened, 30,000 pigeon fanciers from Europe



● Photos show, from the left: (1) ASBAH volunteer (2) our Reg, husband of ASBAH adviser Anne V (3) our Reg, husband of ASBAH adviser Anne V (4) a £10,000 cheque (5) a good day out for ASBAH t

# pulls 'em ousands

Blackpool becomes a  
fanciers. And ASBAH  
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UK's largest show for  
ASBAH's biggest donor ever.

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Ireland, Scotland, Belgium and elsewhere flocked through to check out the results of the judging, to buy and sell birds at the huge pigeon auction, purchase equipment from hundreds of trade stands and, of course, to meet other enthusiasts.

Large trophies and cheques are presented on the Saturday afternoon. This is the big moment for the best racing pigeons, their proud owners and the benefiting charities. For many years, an ASBAH cup has stood among the glittering silverware on the top table,

waiting to be awarded as one of the prizes.

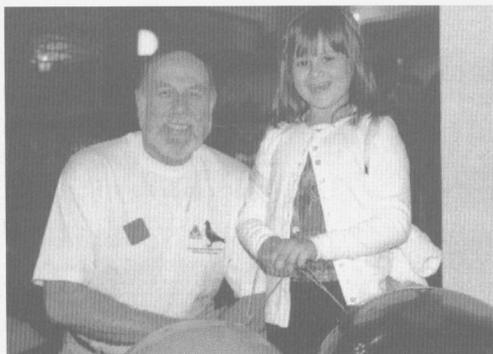
This year a cheque for £10,000, being part of the proceeds of last year's event, was presented to Andrew Russell, our executive director.

Donna Treanor, ASBAH's fundraising manager, said: "We thank the Royal Pigeon Racing Association for their support. Thanks also to Peter Bryant, show manager and general manager of the Royal Pigeon Racing Association, and all the ladies in the show's administration office."

*ASBAH  
enjoys a  
bumper  
weekend  
with  
the fancy*



THE GAZETTE, BLACKPOOL



volunteer Reg Walton encourages a youngster to dig deep in a tombola bucket (2) one of the pigeon fanciers  
ne Walton, busy again (4) show chairman Alan Heath presents executive director Andrew Russell with our latest  
AH trusts and legacies officer Jane Ayres and husband Shaun, working at the show for the first time.

**Saturday 25 March**

Hydrocephalus – tackling the difficulties. Conference & series of workshops exploring learning, emotional and behavioural strategies, organised by ASBAH, Botleigh Grange Hotel, Hedge End, Southampton, 9.30 – 4.30pm. £10 parents, £20 professionals (inc two-course lunch and all refreshments). *Liz Clayton, Corner Cottage, Chazey Heath, Mapledurham, Reading RG4 7UG. Tel/fax: 0118-972 4013.*

**Sunday 26 March**

Hydrocephalus – tackling the difficulties. More informal day for people who have hydrocephalus, their partners, brothers or sisters. For people aged 14 and over. Botleigh Grange Hotel, Hedge End, Southampton, 9.30am – 4pm. £8, inc lunch and all refreshments. *Liz Clayton, Corner Cottage, Chazey Heath, Mapledurham, Reading RG4 7UG. Tel/fax: 0118-972 4013.*

**7 – 8 April**

Spina Bifida, Sex & Relationships, a course for adults with spina bifida run by people with spina bifida, West Shore Hotel, Llandudno (fully wheelchair accessible). Cost £30, including dinner, bed and breakfast, plus sandwich lunches, coffee and tea. Llandudno is accessible by rail and participants can be met at the station. *Details from ASBAH Advisers Angela Lansley (tel: 0151-733 8392) or Elizabeth Miers (01490-450360).*

**28-30 April**

'Mobility Issues' residential weekend, organised by Your Voice in ASBAH (YVIA), Wigan Moathouse Hotel, near Wigan. Workshops include Orange Badge entitlement, rail and ferry concessions, Motability, insurance issues, wheelchair skills. Cost £30, including all activities, meals and accommodation. *John Burke, YVIA co-ordinator, ASBAH House North, 64 Bagley Lane, Farsley, Leeds LS28 5LY, tel: 0113-255 6767.*

**9 – 11 May**

ASBAH at Naidex 2000, the independent lifestyle show, Hall 1, NEC Birmingham.

**Wednesday 17 May**

Spina Bifida and/or Hydrocephalus – current concepts and treatment; whole-day conference organised by ASBAH Eastern Region. Courtyard Conference Centre, Marriott Hotel, London Road, Newport Pagnell, Bucks. Speakers to include Peter Richards, cons paediatric neurosurgeon, Radcliffe Infirmary, Oxford, and Rowena Hitchcock, cons paediatric surgeon, The Radcliffe Hospital, Oxford, with additional expert input on education and challenging behaviour. Professionals £50 each, service-users, parents and carers £15 each, price includes refreshments and two-course buffet lunch. Assistance with cost may be available from

your local association or ASBAH adviser. *Mary Malcolm, Regional Manager, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, fax: 01733-555985, marym@asbah.demon.co.uk*

**21 – 24 June**

The 44th annual meeting of the Society for Research into Hydrocephalus and Spina Bifida, Atlanta, USA. *Details: Miss Carol Sobkowiak, hon secretary SRHSB, Child Development Centre, Memorial Hospital, Holyhurst Road, Darlington DL3 6HX.*

**23 – 25 June**

Mobility Roadshow, Donington Park, Derbyshire.

**31 Aug – 3 September**

12th Congress of the International Federation for Hydrocephalus and Spina Bifida, 'The Right to be Different' Centre des Congrès Pierre Baudis, Toulouse, France. *ifHSB Office, Cellbroersstraat 16, BE 1000 Brussels, Belgium. Tel +32 2 502 11 29 Fax +32 2 502 04 13.*

**1 – 3 September 2000**

The Way Forward, ASBAH South-East Region Local Associations' Conference, Avery Hill College, Greenwich. £80 per delegate (day and residential places available). *Details: Jo Francis, ASBAH SE Region Office, tel: 020-8449 0475. email: jof@asbah.demon.co.uk*

*Please note the new contact details for the International Federation for Hydrocephalus and Spina Bifida (ifHSB).*

**Holidays – one call does it all!**

HOLIDAY Care, the UK's central source of holiday and travel information for disabled people, is now offering a telephone reservations service for all disabled people and their carers throughout the UK.

The new service will ensure that callers can book their accommodation directly through Holiday Care, gaining instant access to some of the leading hotel groups.

By using the service – tel: 01293-773716 – you have the assurance that accommodation has been inspected for access by Holiday Care or the tourist boards to ensure that it is fully accessible and able to meet particular needs.

A USEFUL website if you are travelling to a place in the UK for the first time is [www.multimap.com](http://www.multimap.com)

Type in the postcode of the family you are visiting, or a street name (London only), and the house will be marked on a street map for you. The service is free and no extra software is required, just access to the Internet.

**LINKS**

- [www.freespace.virgin.net/hol.care](http://www.freespace.virgin.net/hol.care)  
**Holiday Care website**
- [www.multimap.com](http://www.multimap.com)  
**Free street map marking service**

# Hydrocephalus Network News

# Ann

Spring 2000

## The last issue of Network News

**AFTER** a lot of careful thought, ASBAH has decided to stop producing the Hydrocephalus Network Newsletter.

**This will be the last one you receive.**

After a careful review of all our publications following our readership survey last year, a recommendation was approved by ASBAH's executive committee in January that our main membership magazine *Link* should carry all the HN news, true stories and letters in the future.

Many members of the Hydrocephalus Network already receive *HN News* with *Link*. So, for you, the change won't be so very different.

However, for readers who subscribe to the *HN News* as a separate publication, we propose to send you *Link* magazine until your existing subscription runs out. At that

point, we shall invite you to take out a new subscription to *Link* magazine at a cost of £4.80 a year for readers in the UK\*.

If your subscription has already run out, we would like to send you free copies of *Link* magazine for a couple of issues – for you to try out.

We think you will like what you see.

From May, when *Link* returns to its former position as ASBAH's only magazine, it will appear in full colour. It will also contain many new features, including a section about people who have hydrocephalus alone.

It appears six times a year,

*Continued on HNN page 2*

*Help break through the barrier to a better test*



*Researcher Helen Wood*

SCIENTISTS are a step away from developing a blood test for ventriculo-peritoneal (VP) shunt infections – but they need help from people with these types of shunt who are unlucky enough to get an infection.

Dr Roger Bayston and his team in Nottingham have already produced a diagnosis for ventriculo-atrial (VA) shunt infections which has proved very successful worldwide.

It has cut the rate of complications developing from infections and made early successful treatment possible.

However, most shunts nowadays drain into the abdomen (VP) and, unfortunately, the test does not work for VP shunts.

Now, after three years of work, Dr Bayston's colleague, research worker Helen Wood, has made a breakthrough in finding a similar diagnostic test for VP shunts.

*Continued on HNN page 3*



Published by the **Association for Spina Bifida and Hydrocephalus**  
**42 Park Road, Peterborough PE1 2UQ.**  
 Tel: 01733-555988 Fax: 01733-555985.  
 e-mail: rosemaryb@asbah.demon.co.uk  
**Registered Charity Number 249338.**

## Hnn contacts

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0113-255 6767.

### Hydrocephalus (Northern

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028-4277 2191.

### User-forum

(England & Wales):

Jon Burke 0113-255 6767.

### User-forum

(Northern Ireland): Helen  
Clarke 028-4488 1898.

## Northern Ireland leaflets

PRACTICAL solutions and useful approaches to learning are offered in a series of 10 leaflets on hydrocephalus published by ASBAH for Northern Ireland. They have been written by Lorna Johnston, our Specialist Adviser (Education).

Some are aimed at teachers, some at parents and one is for job support workers/classroom assistants. They have been funded by the National Lottery Charities Board Northern Ireland. Single leaflets from: ASBAH Northern Ireland Region, Graham House, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH.

## The last issue of Network News

*Continued from HNN page 1*

compared with the four issues you have been receiving of *HN News*.

The news reporting and editorial comment at the front of *Link* will be improved. There will be stronger coverage of non-clinical stories and, from time to time, medical update pages.

### Important information:

The closure of *HN News* does not mean the end of the Hydrocephalus Network – far from it.

### The Network will continue.

Rosemary Batchelor will stay as its co-ordinator, answering and following up all your inquiries. Rosemary and her colleague, Lynn Thomas, will continue to maintain the Network's unique and

confidential database of information.

Lynn will deal with any problems you may have about subscribing to *Link* and pass them on to the editorial department. Please let her know if you have any worries on this score.

● If you want to order *Link* now, send a cheque or postal order for £4.80, made payable to ASBAH. This is the cost of ordering six issues a year.\*

The coupon below is included for your convenience.

Send to:

**Link, ASBAH, 42 Park Road  
Peterborough PE1 2UQ.**

\* If you live abroad, the annual subscription rates are: Europe and surface mail £7.50; airmail £15 a year.

Yes, I want to receive the *Link* magazine in future.  
I enclose my cheque/postal order for £4.80, made out to ASBAH.  
My name and address are:

# Help break through the barrier to a better test

Continued from HNN page 1

She desperately needs serum samples from known cases of shunt infection to develop a final test which can be put into general use.

Using very complex technology, Helen has produced possible proteins for use in the test.

Dr Bayston, a member of ASBAH's Medical Advisory Committee, said: "If you or any of your friends with hydrocephalus are unlucky enough to have a shunt infection, we would be very grateful if you would alert your doctor to this work, which we feel is in everyone's best interest, so that samples may be sent to me.

"Ask your doctor to telephone one of the numbers below to discuss what is needed. We hope that you do not get a shunt infection, but if you do, your blood could help others.

"Your assistance would be greatly appreciated."

Prompt diagnosis of shunt infections is vital yet, at present, they are often confused with other conditions because the symptoms are often unspecific.

A delay in diagnosis usually means that the chances of successful rapid treatment are less.

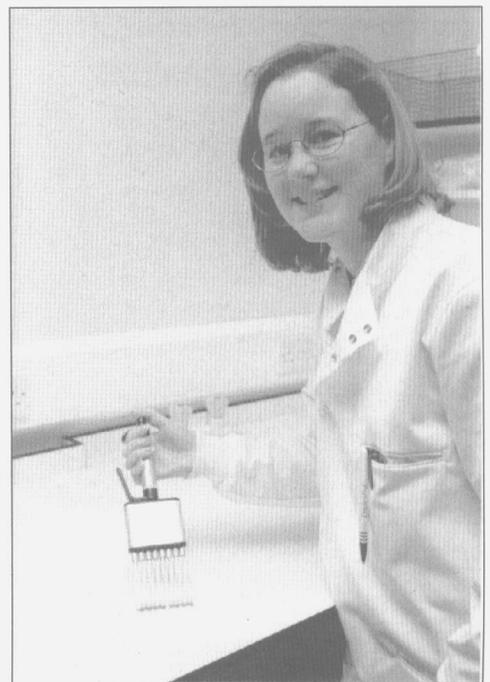
The risks of brain damage and complications such as repeated shunt blockages are also higher.

For more information or to send samples, please contact either

**Helen Wood, tel: 0115 8404895, email – mryhw@MRN1.MBIOL.nottingham.ac.uk**

or **Dr Roger Bayston, tel: 0115 8404747, email – roger.bayston@nottingham.ac.uk**

Or write them at: Biomaterials-Related Infection Group, University of Nottingham Division of Microbiology, Clinical Sciences Building, City Hospital, Nottingham NG5 1PB England.



**M**Y son is about to leave for Australia. Seeing a bit of the world is more enlightening than going straight into higher education, he argues. I like his outlook and admire his guts. As I see him off at the airport, I reflect on the difficult path that he and I have travelled to take him to this gateway.

In September, 19 years ago, he announced his arrival two weeks early. My husband and I had settled down to watch the Morecambe and Wise show in the maternity ward. I was having regular contractions but a pethidine

injection was considered justified to calm things down for an expected delivery early the next morning. Two hours later all hell broke loose.

Drugged and exhausted by 24 hours of contractions, I floated in and out of consciousness while a team of nurses and a doctor struggled with forceps to get the baby out. The biblical words 'Thou shall bear thy offspring with pain and agony' sprang to mind.

My first-born was whisked off to the intensive care unit (ICU), by-passing my husband in the corridor and leaving me, too tired to care,

Continued on page 4

## Beating the odds

How does a mum cope when she learns that her new-born son has special needs? Physiotherapist **GUNNEL BERRY** tells her story. Reprinted by courtesy of **Therapy Weekly.**

from page 3

## Beating the odds

to be stitched up. A sitting ring was essential for me, while a wheelchair proved to be my only mode of getting around for the next few days.

The other mums in the ward cuddled their babies, fondled them and showed them off with pride to visitors. I went to the bathroom and cried my eyes out, while my baby lay prone – with a boxer's scar and bruising – on an alarm mattress in the special care unit.

He stopped breathing 36 hours after delivery and, after finding blood in the cerebral spinal fluid, the paediatrician diagnosed a CVA, although this was not conclusive as blood can appear as a result of needle insertion.

### There was no physical contact between us

At 1.30am my husband was in the ICU, looking dazed and bewildered, having been told that our baby's prospect of survival was 50/50. A deaconess christened the child inside the incubator with saline solution and a bit of cotton wool. His body was pierced and his heel was red from blood sampling.

Sitting next to the incubator I felt no attachment; there was no physical contact between us and no bonding took place. Did he suffer? I did – to the

very core of my soul. A mature ward sister urged me to talk to my son. Talk about what? How could he hear me?

I thought about disabled children – brain damage, physical disability. How on earth would I cope? Being a foreigner to these shores, my own family was not at hand to help me.

On the ninth day post-delivery it was suggested I could take my son home. I had still not held him. Promises of help within 24 hours never materialised. I was shattered by anxiety and the baby cried all the time. I had no idea what to do, but you cope, somehow.

### No wonder he cried!

A community nurse called a couple of times, as did the local doctor, but neither made any suggestion about the cause of my baby's constant crying.

Three weeks later the paediatrician diagnosed hydrocephalus. No wonder he cried! We arranged an emergency appointment with a neurosurgeon at Great Ormond Street Hospital for Sick Children.

It is frightening to watch your baby being anaesthetised, put into a scanner, and being held down with weights to stop it wriggling. Yet once the consultants know you are 'in the trade', you are expected to behave like a professional. My husband knew nothing of the dangers ahead and lived in blissful ignorance of the situation while I worried continuously.

The outcome of the head trauma was the insertion, at seven months, of a Spitz Holter shunt system into the right ventricle and three feet of tubing into the peritoneum. I spent 10 days at the hospital sharing a room with a complete stranger whose child was undergoing his 20th abdominal operation. Another mother was there with her six-year-old son, whose shunt had failed repeatedly. Was this going to be my routine for weeks and months to come?

### Physical contact became my way of communication

We had to have access to the neurosurgeon within 24 hours in case the shunt blocked up. Work became a non-starter – my husband's career took a steep dive, and so did our income.

I ignored the baby gurus, who suggested putting the baby in a separate room to cry himself to sleep. Physical contact became my way of communication. He used to wake up every night and scream in what seemed like terror for two hours. He clung to me like an ape, and sometimes he bit me (out of frustration or fear?). He was also aggressive to his sister – born three years later – so to teach him gentleness we got him a kitten, which would either run away or claw back.

We ended up with a physical diagnosis of 'mild unilateral motor dysfunction in left upper and lower limbs.' The baby's head used to tilt into a functional

torticollis, so we moved the television to the other side of the room to encourage an opposing tilt. Building Lego cars was excellent for learning upper limb motor skills, and he quickly learned to cycle and swim.

### **My son climbed Mount Snowdon at the age of nine**

Nocturia was a problem every day for nine years. It was resolved with five sessions of reflex therapy, massaging the kidney areas once a week for 20 minutes. He has been dry ever since.

Asthma was diagnosed at the age of 12. I ignored advice and, following my instincts that it was more likely to be a peculiar infection, stopped using the Becotide. He recovered shortly afterwards.

My son climbed Mount Snowdon at the age of nine and I thought we were well on our way, but this is when he began to show signs of unco-ordination. Tremors were commonplace and a meal was never completed without the spilling of half the contents of a jug. My heart sank when, at 14, he sustained a supracondylar fracture with displacement of the humerus. But with the insertion of a plate and 12 screws he regained full function.

He struggled with reading, writing and mathematical questions, while school reports revealed only 'average performance.' We asked ourselves if this was because of laziness ('boys are always later than girls'),



lack of interest, or higher centre dysfunction; dysarthria became a source of anger and frustration for both of us.

### **Maybe the problem was mine rather than his**

Testing for dyslexia or other special needs proved negative. Ten years too late, I learnt that some children read better from right to left. We tried turning the book upside down and it worked. Using a yellow background was easier for him, too.

We swung on a margin from normal to abnormal, trying not to find a problem where there wasn't one, yet always looking for a missing link. Maybe the problem was mine rather than his – the Ben Nevis attempt at seven months' pregnant, or moving the washing machine upstairs just before birth. I understand how mothers, acting on biological function, reject their baby if it is not normal – sleeplessness and money worries can, at times, turn you into a 'desperado.'

My son is now six feet four

inches tall, weighs 80kg, and has nine GCSEs, an advanced GNVQ in business studies and an offer to go to university. He never makes a fuss about himself and has demonstrated an amazing will to survive and lead a full life.

I am very proud of him.

● *Gunnel Berry is a chartered physiotherapist from Basingstoke*

## **GLOSSARY**

### ***functional torticollis***

means literally 'twisted neck', where the head inclines to one side due to contraction of muscles in the neck

### ***nocturia***

night-time wetting

### ***Becotide***

a bronchodilator used by asthmatics as a preventative

### ***supracondylar fracture***

a broken hip or elbow (the condyl is the space at the end of the long arm bone, or the long leg bone)

### ***dysarthria***

difficulty in speaking



## What's in the March *Link* magazine?

Good advice on flour	p5-6
They make us tick	p7
Musical VIP!	p9
Benefits uprating	p11-12
Pigeon Show	centres
HNN	p17-24
Small ads	p27

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Payment should be in GB£, with cheques made payable to ASBAH. Please send to:

*Link*, ASBAH  
42 Park Road  
Peterborough PE1 2UQ  
UK

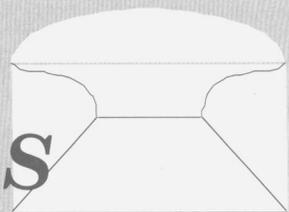
### TTT absorbed

THE Toxoplasmosis Trust, featured in the last *HNN* as it celebrated its 10th anniversary, has been absorbed by a larger charity dedicated to finding the answers to problem pregnancies.

The decision that TTT's work should be continued by Tommy's Campaign was taken to ensure a secure financial future for a specialist area of work.

Fact sheets on toxoplasmosis are still published on the website [www.toxo.org.uk](http://www.toxo.org.uk)

Hydrocephalus  
Network News  
*Hnn* LETTERS



## A LETTER FROM MALTA

 OUR SON, George, is a four-year-old boy, who was born with hydrocephalus. He had a VP shunt inserted when he was 10 days old and started having fits after three months. These were controlled with phenobarbitone and clonazepam and he was taken off medication after one year.

Last year, he had another operation wherein the tube from the shunt to the stomach was changed because it had become short and a cyst at the back of his head was removed. Since the operation, he started having fits again which the doctors are now trying to control with Epilim.

George is neuro-developmentally delayed, functioning at the age of approximately 18 months. He has started to babble, can walk supported by us and understands four words and phrases. This October, he has started attending mainstream kindergarten school with a facilitator.

Could any parents with the same problems as ours, please contact us?

**Charles Mifsud**  
Plot 294, Triq l-Argentina,  
Is-Saghjtar, Naxxar, Malta

## Anyone there in the south?

 I WOULD like to make contact families with children with hydrocephalus in London and/or the South East.

At the moment, I have only one contact in Scotland which is too far away and meeting up with the family is very unlikely.

I have a child who is four years old and would very much like to hear from other families living in London.

**Mrs T Hussain**  
168 Palmerston Road  
Walthamstow  
London E17 6PY

## Liz was spot on

 I DID enjoy the article by Liz Galfskiy on low pressure in the Winter 1999/2000 issue of *HNN*. She put into words a lot of the problems I am having and haven't been able to describe.

**Gwen Bayley**  
Acomb, York

Please continue to send your letters, *True Stories* and feedback to:  
Rosemary Batchelor  
HN Co-ordinator ASBAH  
42 Park Road  
Peterborough PE1 2UQ.  
They will be considered for *Link* magazine.

# True story

## Hamza proves the doctors wrong

MY SON developed hydrocephalus after a brain haemorrhage at one week old.

At birth he was short of breath and had to be given oxygen. He was taken to the special care baby unit straight after birth and the doctors didn't know what was wrong with him.

At about one week old my son was very ill and the hospital wasn't too sure what was wrong with him. They even suspected meningitis. Later on they thought that it may be a heart condition and sent for someone from a specialist hospital to have a look at him. The specialist straight away diagnosed Hamza with a complicated heart condition.

He was rushed to the specialist hospital and kept stable there for a few days. They decided not to operate because he was too poorly. Instead they sent him to a local hospital in the city.

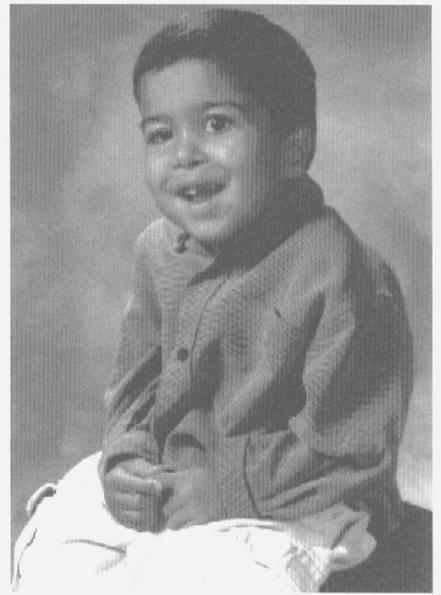
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**By Tanveer Hussain**  
**Walthamstow**  
**London E17**

---

When Hamza was a bit better, he had the heart operation and later on that year he had a shunt inserted.

Hamza is now four years old and, amazingly, he has proved the doctors wrong who, at first, told us that he would not be able to walk



*Hamza Hussain*

and would be very delayed physically and mentally. He is only delayed by one and a half years, which is incredible, and is such a content four-year-old.

He attends a mainstream nursery, he has the most beautiful smile, and has given me the most happiness in the world. He is totally amazing: he is learning new things every day and talking in many full sentences.

I am very pleased with his progress and couldn't ask for a better first child.

---

## Artistic website?

A BUDDING cartoonist wants to set up a website featuring some of his cartoons and other artistic work done by disabled people.

Richard Cleal, whose work was featured in our last *Lift* magazine, wants to hear from anyone wishing to contribute.

He would also like to receive any feedback/suggestions on the creation of such a website and would be interested to know if anyone else has done anything similar.

*Please write to Richard at: 5 Andrew Evans House, Innage Lane, Bridgnorth, Shropshire WV16 4HJ . email: richard.cleal@classicfm.net*

*Ann - Thank you for reading Hydrocephalus Network News. We're signing off now but in future you can catch up with all our news, True Stories and other information in ASBAH's Link magazine.*

**ASBAH, 42 Park Road,  
Peterborough PE1 2UQ,  
tel 01733-555988**

*rosemaryb@asbah.demon.co.uk*

**W**ITH all the big hassles in life, like operations and dealing with a major disability, it can be easy to forget the routine minor things we need to do to keep our body in one piece. Things like remembering to go to the dentist regularly, for example.

Despite my Mum regularly dragging me off (kicking and screaming) to a dentist when I was young, recently I'd forgotten to see one as often as I should have – a lapse which has cost me dearly.

I realised I had a problem while eating lunch a few days ago. Between one bite of fish and chips and the next, a great chunk of tooth fell out. If fish and chips make my teeth fall out there's not much hope for me is there?

The dentist I go to has its surgery up steep stairs, but if you can't get up them they can put you with the dentist downstairs (where the screams come from), or arrange a home visit. Well, them bringing

their stuff to you sounds a great idea if you can't use a dentist's chair or room, and more of them should offer this service to us disabled types. But would you really want 'the Mad Driller' turning up on your own door step? I went up the stairs.

The dentist fixed the great hole, then cheerfully told me I needed nine fillings! Ouch! Even on the NHS, filling all those teeth will make a huge hole in my wallet. Thankfully, only my wallet has felt any pain from these fillings.

The dentist started off by sticking a needle full of pain killer in my gums. Despite being a total coward, I've never had an injection for a filling. It just seems rather feeble after years of operations. So having a numb face was a new and weird experience. For six hours I was 'Mr Mumble, the drooling fool'!

As I face the prospect of several more sessions with a numb face, an old poem by Pam Ayres springs to mind: 'I wish I'd looked after me teeth'!



**GET MY  
TEETH  
FIXED!**

**Dave's  
diary**

[david.fulford-brown@virgin.net](mailto:david.fulford-brown@virgin.net)



## BOOKSHELF

ONE OF our external advisers, Dr Nicola Grove, achieved nationwide recognition for her writing skills at the end of 1999. She was joint winner of the NASEN Academic Book Awards for her book, *Literature for All*.

Dr Grove, who is a member of ASBAH's Education Advisory Committee, was praised by the chairman of the judging panel, who said the emphasis in schools on literacy too easily obscured the role of literature in developing qualities such as empathy, engagement and understanding. "Nicola Grove shows how great literature from Shakespeare to Thomas Hardy, poetry from John Keats to Roger McGough can

come alive to enrich the learning of secondary school children with the most severe disabilities", said Professor David Galloway. The author lectures at the City University, London. *Literature for All*, David Fulton Publishers, £14. ISBN 1 85346 495 3

A GUIDE to educational opportunities for students wanting to get into higher education has been published by Skill, the national bureau for students with disabilities.

It's called *Higher Education 2000* and in 92 pages explores the market, giving profiles of disabled people in higher education, showing how they overcame discrimination. £2 to disabled students, trainees and job seekers: £6.50 to others. Tel: 020 7450 0650.

COMPUTERS are great for those who know how to handle them. In terms of presenting and organising work, they give quantum gains. But

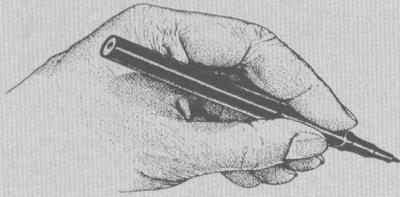
for many families with no keyboard or word-processing skills, they can be like hitting your head against a brick wall.

Paediatric OT Dorothy E Penso unravels the mysteries, turning problems into opportunities, in *Keyboarding Skills for Children with Disabilities*, from Whurr Publishers.

At £18.50, it's pricey but the book does contain 100 work sheets which can be photocopied, providing methods of learning the keyboard using both hands, one hand only or just a couple of fingers, as well as simplified worksheets for those with poor memory skills.

The book does not tackle the needs of children with severe learning difficulties who need to use complex electronic devices and switching systems.

DON'T forget, ASBAH's 1999 book *Hydrocephalus and You* is available for sale, price £10.99 (inc p & p). It's a treasure trove of information. *Information*, ASBAH, 42 Park Road, Peterborough PE1 2UQ.



# Letters

## Christine didn't sort all the church access!

 I WAS disappointed when reading *Orders for Access*, the article about making our church accessible to all (*Link*, January), to find that you had given me all the praise and had not mentioned our clergy or the congregation who have also worked extremely hard.

I have played a large part but so have a lot of other people – not least our curate, the Rev Marie Teare. She has played a large part in organising the community services, making sure that the needs of disabled people are considered and ensuring that disabled people who wish to attend the church each week have transport. I cannot speak

highly enough of her.

Thanks too are due to our former vicar, the Rev Giles Harris-Evans, who played a big part in the plans to re-order the church, and to Marie's husband, the church social committee and the many community-minded organisations and individuals who are only too happy to offer their services to this exciting project. The energy that everyone is putting into the project is amazing, and that is something you should record.

*Christine Helliwell*  
10 Croft Place, Brighthouse  
West Yorkshire HD6 4AP

## ACCOMMODATION

ILKLEY, WEST YORKSHIRE – vacancy in Flat 3, Denton View, Five Oaks Housing Scheme. Suit ambulant person (there are stairs to the first floor). The self-contained accommodation comprises: spacious bedsitting room, kitchen, bathroom and hallway. Superb view from the b/s room towards North Yorkshire Moors across the Wharfe Valley. A care and support package can be arranged with Bradford Social Services. *Contact: Mark Best, tel/fax: 01943-603013.*

## FOR SALE

POWER TREK 40 electric wheelchair. 3 years old, very low mileage, requires new batteries. £800 ono. *Mr Vavangas, tel: 0118-969 3970 (Reading). dshphoto@aol.com*

DMA electric wheelchair, one-year-old, with all accessories. £1,000. *Mrs B Brough, tel: 020-8679 6083 (Mitcham, Surrey).*

SLEEPEEZEE electric adjustable bed. Single. Owner prefers double bed. Cost £1,600; asking £800. *Mrs Diana Cranston-Miller, tel: 01252-315734 (Aldershot).*

SUNRISE Medical Sterling 3 electric wheelchair, with battery-charger. Navy blue, basket included, lights and indicators. Only used three times. Cost £3,250, asking £1,500. *Tel: 01992-577090 (Epping, Essex).*

RENAULT Caravanette Renoir, can carry a wheelchair and four passengers. Fridge can operate on electricity, gas or batteries, folding ramps, high top, twin/double bed. £6,000. *Tel: 020- 8204 0934/3293.*

## WANTED

ACCESS wanted to private swimming pool in North London. Girl aged eight with dyspraxia from hydrocephalus would greatly benefit from access to warm pool to learn to swim in a calm atmosphere. Attends a primary school. Suggest contributions to ASBAH in return. *John, tel: 020-7485 1299.*

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

## Barking up the wrong Motabilatree?

 I WAS disappointed in the calls for an overhaul of Motability (*Link*, January). The councillor will have good mileage payments. The lass has taxis available for work and other vital journeys should her hand-controlled vehicle be in for repair.

No scheme will suit everyone and their call for 'complete overhaul' seemed somewhat dramatic in connection with what was one of the visionary schemes of the 20th Century.

*Elsie Wilson*  
298 Kirk Road, Wishaw, Scotland

## Can you help this Swedish family?

 I AM WRITING on my daughter's behalf – she is eight years old and she was born with spina bifida (T12 lesion).

I'm trying to help her get in contact with other children in her situation, preferably in England, since my husband is English and we go there frequently. Then she might have a chance to meet them when we are visiting.

I hope you can help us to get in contact with someone, so that Linnea and I can learn about and take part in other families' experiences. We're Swedish but English is not a problem for us.

*Mona-Lisa Warthel*  
Sadelvogen 24,  
Helsingborg S-252 86, Sweden  
*mona.lisa@hem.utfors.se*

**NAISH HOLIDAY VILLAGE, NEW MILTON** – Clifftop 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 six – well-furnished and comfortable. Free club membership.

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

**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).

**ORLANDO, FLORIDA** – House with 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

## HOLIDAY ACCOMMODATION

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

Orlando Airport. 20 mins Disney. Paraplegic owner. Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT, tel/fax: 0161-792 3029.

**ISLE OF WIGHT ASBAH** – Recently refurbished, fully equipped, two-bedroom bungalow. Sleeps six. Wheelchair accessible. On site clubhouse, shop, local indoor heated pool suitable. Interesting places to visit, lovely views. Own transport advisable. Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983 863658.

**BERWICK COTTAGE, EAST HARLING, NORFOLK** – Purpose-built modern cottage. Ground-floor accommodation for up to 2 people with disabilities. Scan 700 beds. Clos-o-Mat. Overhead track hoist bedroom-to-bathroom. First floor accommodation for up to 4 carers/family/friends. Awarded Grade 1 Holiday Care Service. Open all year. Low rates Winter/Spring. Info/bookings: Mr W G H Tickner, The Lin Berwick Trust, 0181-595 7056.

### 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.

### WESTGATE ON SEA, KENT

Semi-detached bungalow, sleeps eight, plus cot. Fully equipped for wheelchair use. Enclosed garden summer house, swings. Ideal sandy beaches with free parking and disabled toilets. Full details from Doug Endersby, 020-8293 4598 (Greenwich ASBAH).

### FOR SALE

RENAULT Traffic, N-reg 1996, 28,900 miles. Power steering, ramp, carries two wheelchairs, four passengers. VGC. £6,500 ono. Tel: 01704-544940 (Southport, Merseyside).

## Link ad rates

### ● Classified Rates:

£3.75 for 30 words max.

£5.25 for 30-45 words.

£6.25 for 45-60 words.

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

### ● Classified adverts for the next issue of LINK (May) should be submitted by Friday, 7 April.

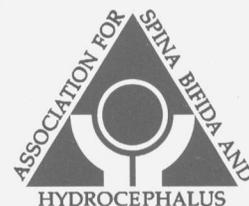
Please send them to the Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ. Tel: 01733-555988.

[lizc@asbah.demon.co.uk](mailto:lizc@asbah.demon.co.uk)

### ● Display Rates on application from the Publicity Manager, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

Tel: 01733-555988.

[tonyb@asbah.demon.co.uk](mailto:tonyb@asbah.demon.co.uk)



**AFFILIATED ASSOCIATIONS**

**BARNLEY**

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

**BEDFORD**

Mr R C Simmonds  
16 Parkstone Close  
Bedford MK41 8BD  
Tel: 01234 400068

**BOURNEMOUTH, CHRISTCHURCH & DISTRICT**

Mrs G Lanning  
2 Riverway, Christchurch  
Dorset BH28 2QW  
Tel: 01202 567649

**BRISTOL & DISTRICT**

Mr G Egan  
64 Rookery Road  
Knowle, Bristol BS4 2DT  
Tel: 0117 9777942

**BUCKS & EAST BERKS**

Mrs Margaret Humphreys  
15 Brackley Road  
Hazlemere, High Wycombe  
Bucks HP15 7EW  
Tel: 01494 714270

**BURY & BOLTON**

Mr David Clyne  
51 Cuckoo Lane, Whitefield  
Manchester M45 6WD  
Tel: 0161 798 7804 (after 4pm)

**CAMBRIDGE & DISTRICT**

Mr Tony Proud  
10 Newlands Road  
Whittlesey  
Peterborough  
PE7 1YX

**CHESTER & DISTRICT**

Mrs P Ithell  
34 King Edward Street  
Shotton, Deeside  
Clwyd CH5 1DW  
Tel: 01244 811074

**COVENTRY**

Mrs N Newman  
11 The Earls Court  
Cheylesmere  
Coventry CV3 5ES

**DERBYSHIRE**

Mrs A Hewitt  
St Merryn, 20 Burley Hill  
Allestree, Derby DE3 2ET  
Tel: 01332 841893

**DUDLEY & WOLVERHAMPTON**

Mrs Lorna J Wootton  
14 Leveson Road  
Wednesfield, Wolverhampton  
West Midlands WV11 2HF  
Tel: 01902 738724

**GRANTHAM**

Mrs J Asken  
88 Goodliffe Road  
Grantham, Lincs NG31 7QB  
Tel: 01476 401643

**GREENWICH & DISTRICT**

Mrs M Mears  
29 Wellmeadow Road  
London SE13 65Y  
Tel: 020 8244 3526

**HAMPSHIRE NORTH, W SURREY & S BERKS**

Miss Vicky Beken  
41 Lynchford Road  
Farnborough  
Hants GU14 6AN  
Tel: 01252-845765

**HERTS AND SOUTH BEDS**

Mrs Jennifer Hammond  
28 Gladeside  
St Albans  
Herts  
AL4 9JA

**HUDDERSFIELD**

Mr Stephen Bolton  
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