

Link

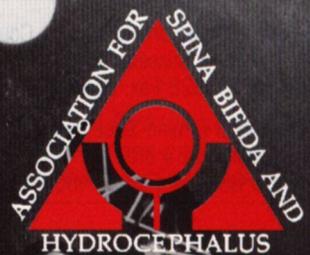
The magazine for people with
Spina Bifida and/or Hydrocephalus



April/May 1998

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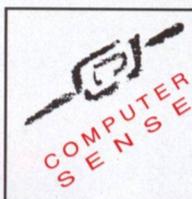
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Royal opening of new South East office

ASBAH South East Region staff were delighted to have the opportunity to talk to our patron, HRH The Duchess of Gloucester, when she officially opened the new regional centre in New Barnet, Hertfordshire.

The Duchess was welcomed at 209 Crescent Road by ASBAH chairman Godfrey Bowles, executive director Andrew Russell and ASBAH trustee Eric Prentice. She then toured the new offices, meeting small groups of advisers.

She chatted to specialist adviser Gill Yaz about women with spina bifida having children and then the importance of folic acid, with the Duchess ending the conversation by cracking a joke. 'Should I be taking it?' she said. 'Why not?' Gill replied. Staff were impressed with the Duchess's detailed knowledge of the conditions – enabling her to ask some very searching questions.

She also talked football with 15-year-old Arsenal supporter Jamie Brown, a wheelchair-user from Northolt, Middlesex, and received a basket of flowers from another ASBAH service-user Beverley Henson, from New Southgate.



HRH The Duchess of Gloucester leaves the new ASBAH South East Region Centre in New Barnet after the official opening

New ASBAH information sheets

ASBAH has published three new information sheets. They are: Information Sheet 11, *Spina Bifida Occulta*; Information Sheet 13, *Personal Care is not Sexual Abuse*; Information Sheet 14, *Benign Intracranial Tension*.

These sheets, and a list of other publications, are available from: *Information, ASBAH, 42 Park Road, Peterborough PE1 2UQ*. Single copies are free, but please enclose a large stamped addressed envelope.

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ASBAH is a registered charity

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

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Cover: Our patron HRH The Duchess of Gloucester met 15-year-old Jamie Brown when she opened the new ASBAH South East Regional Centre in New Barnet, Herts. Story this page.



A PART-TIME adviser has left ASBAH to work with Virgin Atlantic at Heathrow, ensuring the needs of travellers

with disabilities are met – from arrival at the airport to their seat on the plane.

Deryck Brown, a trained occupational therapist and physiotherapist, joined us two years ago as adviser for parts of North and West London. For eight months he also worked as a senior special assistant agent at Virgin and has now decided to go full-time with the airline.

Deryck's job at Virgin is to meet the needs specified by disabled passengers when they book their flight. This can be assisting wheelchair-users to board an aircraft; making oxygen available on the plane or even setting up dialysis machines.

Demand for travel on Virgin Atlantic by people with disabilities is increasing. For example, 10 to 40 wheelchair-users travel on Virgin's air services each day. "The idea is that everybody who travels with them is treated the same," Deryck said.

The philosophy of equal treatment for all passengers radiates from the top downwards. Deryck regularly sees Richard Branson sitting with passengers in economy class when he is travelling on business.

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TERESA Cole has been promoted to assistant director (services) as an acknowledgement of the importance of services to ASBAH.

Mrs Cole started at ASBAH 16 years ago as assistant head of fieldwork and within six months was made fieldwork manager. Her last post was senior services manager.

Mrs Cole's day-to-day work will not change very much with her change of title. Her prime role will continue to be raising ASBAH's profile outside ASBAH.

● *The post of assistant director (services) will continue after Mrs Cole retires in January 1999. See pages 14-17 of this issue of Link for more information about ASBAH's five-year strategy and the new management structure.*

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ROSE Hinchliffe has left ASBAH to take up an occupational therapy post in paediatrics at St James's Hospital in Leeds – popularly known as Jimmy's, and the subject of a BBC TV series.

After three years as OT for Northern Region and START, Rose will be providing a service to special needs schools in the Leeds area.

But she plans to continue working with ASBAH advisers in her new job – albeit in a different capacity.

Rose has enjoyed meeting people on the ASBAH courses, and one of the aspects about us she really values is the role ASBAH advisers have to play in providing advocacy to families outside of statutory services which, she feels, is a niche that needs to be filled.

"My time with ASBAH has given me an insight into the world of disability which I hope to carry on in my new job," she said.

● *The full-time specialist adviser/OT post in Northern Region, previously held by Rose, will be split into two part-time posts – one for the Northern Region and one for the South West of England.*

ASBAH has opened another business in Hemel Hempstead – as the affluent Hertfordshire town becomes home to the association's new computer powerhouse.

A new division of our well-established Apple Mac company, Computer Sense Limited, has started trading in IBM-compatible personal computers. The move gives the firm the ability to work across operating platforms.

Both companies will pass on all the profits they make to ASBAH. ASBAH finance director Derek Knightbridge, a board member of CSL, said: "Many customers are very impressed by the fact that by contributing to the success of CSL they will also be contributing to the success of ASBAH.

"The charity connection remains a very potent marketing tool."

The appointment of a new managing director to run the PC division paves the way for Computer Sense to be grown as a multi-million pound business. Peter Venes, who ran his own computer company in Hemel for 13 years, comes in to take the new hot seat.

"We're now ready to take on any cross-platform computer business, and deliver first-class solutions to networking, maintenance and Internet challenges anywhere in

Hemel Hempstead – home to our new computer powerhouse

the UK," said CSL board director Gwyn Martyn, one of the co-founders of Computer Sense.

"Peter's contacts and client list in the PC market are an ideal complement to what we already offer here at Hemel. Seventy five percent of the business we are after is PC-orientated, and the best way of getting to it is by bringing established people on board.

"It is a strategic shift in direction for CSL, and one which makes huge sense. We also keep our overheads down by plugging the new division into our existing administration and sales system."

The new division has been set up as a separate company, Computer Sense (PC) Ltd, so that its performance as a cost-centre can be measured, and it can be used as a springboard into the vast PC market. The Apple Mac operation remains a powerful success story, but it is very much niche marketing as Macintosh computers account for only five percent of the worldwide computer market.

Computer Sense, which started

trading in September 1993, now employs 19 people, including its own accountant and five sales people. A new PC sales engineer also joined in mid-February.

The company occupies two floors of a modern office unit at The Grovelands Business Centre, not far from the McDonnell Douglas aircraft company UK headquarters, which has been a customer of Computer Sense since its early days.

ASBAH to star in GMTV appeal

ASBAH will figure in this year's GMTV *Get Up & Give Appeal*, which will take place on 13-17 July.

Other charities taking part in July will be AFASIC (Association For All Speech Impaired Children), British Epilepsy Association, Contact the Elderly, and the Spinal Injuries Association.

Officers & Staff

Patron:
HRH The Duchess of Gloucester, GCVO

President: Dr Jeffrey Tate, CBE

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Finance Director:
Derek Knightbridge, FCCA

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Assistant Director (Services):
Teresa Cole, MICA

Services Manager: Milly Rollinson CQSW

START Manager/Northern Regional Co-ordinator:
Joan Pheasant, NNC

Senior Adviser – Health and Policy Issues:
Rosemary Batchelor SRN FETC

Appeals Manager:
Donna Treanor

Publicity Manager:
Tony Britton

Research and Information Officer:
Gill Winfield Cert Ed

Atkinson Morleys: six-month reprieve

A SIX-MONTH reprieve for the children's neurosurgical service at Atkinson Morleys Hospital, south west London, has been secured – after health service administrators were threatened with a High Court review of their decision to close the service at the end of this month (March).

The regional NHS Executive said purchasers would continue to be allowed to buy paediatric neurosurgery from Atkinson Morleys until the end of September. The decision to move the unit to King's College Hospital, Camberwell, has been put on hold to allow a period of reflection and further consultation.

The reprieve was achieved by the parent-led Hospital Action Group, whose barrister had been planning a High Court challenge of "serious flaws" in the decision-making process.

Action Group member Gill Farrington, whose 15-year-old daughter Kirsty has had 11 operations at Atkinson Morleys to revise her hydrocephalus shunt, said: "This is a result of parental pressure. We're quite elated. On the other hand, we don't want to be lulled into a false sense of security.

"We shan't rest easy until we can be quite sure of continued treatment for our children at Atkinson Morleys at the end of this time."

Staff at Atkinson Morleys, part of St George's Healthcare NHS Trust, had rejected an earlier plan to merge their children's neurosurgical service with the paediatric unit at St George's Hospital, Tooting.

NHS Executive spokeswoman Kate Wilcox said that a move to either St George's or King's would offer "a depth and breadth" of

expertise which is not available at Atkinson Morleys, with its single specialism. The move to a multi-disciplinary centre was favoured by expert clinical groups, such as the British Association of Paediatric Neurosurgeons.

She said that in no way was the decision to relocate the service a criticism of the Atkinson Morleys service, which was respected by both parents and paediatricians.

But, in view of the disquiet ex-

pressed by both groups over the proposal and the possible court action, the decision would be reviewed again in six months after a period of calm reflection and consultation.

Mrs Farrington commented: "For anybody with a blocked shunt, like my daughter has had 11 times, it would be an horrendous journey from our home in Ewell, near Epsom, through London traffic to King's."

Folic acid awareness campaign for Northern Ireland

AN ANNOUNCEMENT has been made that Northern Ireland is to get its own government-funded folic acid awareness campaign – in the same month that the three-year campaign in England is being wound down.

The decision, taken by the Province's Health and Social Service Department to focus public attention on the issue, is a tribute to the persistence of ASBAH's regional co-ordinator Margaret Young, who has been pressing the need for such a campaign on senior civil servants since 1995.

Northern Ireland has one of the highest rates of spina bifida births in the world. In 1995, the last year for which figures are available, 12 babies were born with spina bifida, 10 with hydrocephalus and three with anencephaly.

The long-awaited public education campaign, to be conducted by the Northern Ireland Health Promotion Agency, will start in October. Details are still being

finalised but include TV advertising, a mini-magazine for distribution throughout the province and preparation of materials for healthcare professionals.

Mrs Young said: "This campaign should not be seen in isolation. There will be high profile TV and advertising, but the four health boards over here have already done a fair amount of work on folic acid education."

Details of ASBAH's support for individuals, their families and other carers will be included.

● ASBAH's contribution was praised at a lunch held in London in March to mark the end of the Health Education Authority's campaign in England. Organisers said it had resulted in raised awareness of folic acid among women planning their pregnancies, leading in many cases to 'behaviour modification', ie women actually taking extra folic acid before they become pregnant, not just knowing they should.

Fancy a root round an ASBAH shop? Phone Elissa on 01733-555988 to find out where they are.

ASBAH's 70th charity shop, which has just opened in Portsmouth, looks like turning into a winner!

A healthy £1,448 was taken in the first three days. Within a week, it had taken £2,050.

One secret of the shop's success is the prime shopping location; another is the happy faces of the staff, which seem to attract customers over the threshold.

"The place is absolutely humming," says ASBAH's national shops co-ordinator Margaret Gillmore. "We have two tills going on Saturdays because one till can't cope with the queue of customers. The whole shop has got a very happy atmosphere. All the volunteers like working there."

Shop manager Doreen Sumner added: "If people look into a shop and see smiling faces, they will come in.

"I train the volunteers to be friendly and helpful to customers and to work as a team."

Record takings for ASBAH shop



Mrs Sumner has an eye for attractive lay-out and the shop is large enough to have separate departments for furniture, books, children's, ladies and men's clothing.

But, with six more charity shops down the road, the market for secondhand goods in this busy part of Portsmouth is very competitive.

How do they get the business?

"We try to keep prices on an even keel so that ASBAH gets a good profit and the customers go away feeling they have got a bargain."

The Portsmouth North End shop is one of a dozen or so in ASBAH's chain on the South coast.

Help & Advice

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

London, Surrey, Kent, West and East Sussex

ASBAH South East, 209 Crescent Road, New Barnet, Herts EN4 8SB.
Tel: (0181) 449 0475. Fax: (0181) 440 6168. Regional Co-ordinator: Jo Francis.

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

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

Northern Ireland

ASBAH Northern Ireland, Graham House, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH. Tel: (01232) 798878.
Fax: (01232) 797071. Regional Co-ordinator: Margaret Young.

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

ASBAH North, ASBAH House North, 64 Bagley Lane, Farsley LS28 5LY.
Tel: (0113) 255 6767. Fax: (0113) 236 3747. Regional Co-ordinator: Joan Pheasant NNC.

Rest of England and Wales

ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ.
Tel: (01733) 555988. Fax: (01733) 555985.

ASBAH welcomes and appreciates the support of its commercial partners.

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

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

Coo! Almost £300,000 from the Pigeon Show

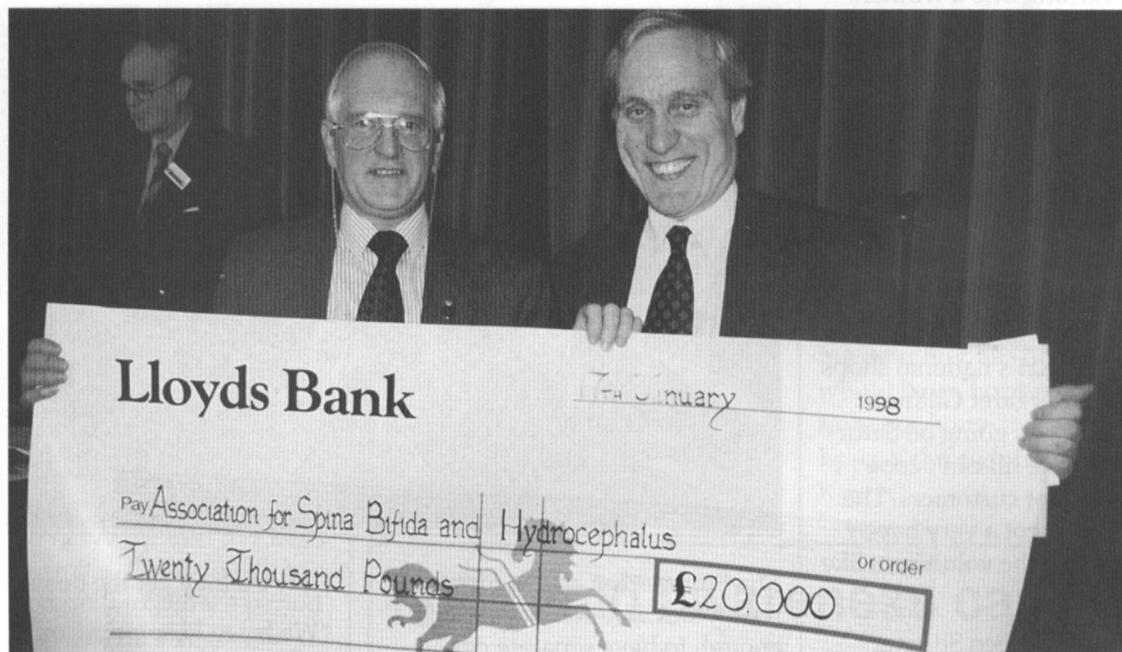


Photo courtesy of British Homing World

THE first donation to ASBAH came in 1973 in the form of a cheque for £3,000. . .

This year £20,000 was written on the cheque, bringing the total amount given to us by Britain's premier racing pigeon event over the years to a staggering £295,000.

Executive director Andrew Russell (pictured right) was at the Blackpool Winter Gardens for the British Homing World 'Show of the Year' in January, where he received the latest donation from show chairman Alan Heath. Since the start of the show, over £1 million of proceeds have been handed over to charity.

Over 50,000 people visit the event which is being extended from two to three days next year to include a large contingent of pigeon fanciers from abroad. It will be held from 22 to 24 January inclusive and, as usual, the ASBAH stand will occupy its prime position at the foot of the stairs leading to the ballroom.



A MUM was so grateful for the help she received from ASBAH that she nominated us for a charity event of the year, raising £1,800.

Glenda Wood is a secretary at Midland Bank's Business Banking Centre in Newcastle and is a member of the social committee.

Mum says thank-you

She put ASBAH's name forward for the charity event and, when accepted by the committee, organised a seven-mile riverside ramble – attracting some 40 bank staff, family and friends.

The event raised £900 for ASBAH, which was then matched pound for pound by Midland Bank.

One of Mrs Wood's two-year-old twins, Anna, has hydrocephalus, which was diagnosed when she was four months old. Anna was in hospital for six weeks after having a brain haemorrhage. A shunt was inserted but became infected and had to be taken out again within 24 hours.

Anna was sent home without a

shunt, but after three months another shunt was needed.

"It was just a coincidence that a few days before Anna went back into hospital we had a new health visitor who told us about ASBAH, otherwise we would never have known about you," said Mrs Wood, from Gateshead, Tyne and Wear.

"Your adviser, Anne Walton, came straight to the hospital the day Anna went in and she told us more about hydrocephalus than any of the nurses or doctors. We learnt so much from her, we felt like we wanted to give something back."

Pictured above left: Glenda Wood and her daughter Anna.

Deryck's job at Virgin Atlantic, from page 4

"It's quite a demanding job as I'll be working 12-hour shifts but Virgin has been very positive towards me and there is the promise of becoming part of its training team."

One of the perks of the job will be travel concessions and he will be going on familiarisation trips abroad, to make sure that the treatment of people with special needs is the same throughout the airline.

Although Deryck will miss working for ASBAH, he hopes to forge new links with us in his new job. "I have enjoyed working with the SE Region team and I would like to give some input on ASBAH weekends and study days," he said.

● **A re-organisation of ASBAH advisers in London will take place on Deryck's departure. His former patch will be enlarged to include West and SW London and Middlesex, but the new post-holder will lose parts of North London. Gillian Yaz's patch will be enlarged to include the whole of North and East London, incorporating three extra boroughs – Camden, Brent and Barnet.**

Kirsten's battle for a better trolley



KIRSTEN Battle is a young mum who bubbles with fun – except when she goes shopping at the local supermarket.

Juggling 23-month-old baby Abigail in one arm and shopping trolley with the other, she finds it difficult to get round the store.

"Supermarkets do not cater properly for parents in wheelchairs who go shopping with their babies," said Kirsten (pictured above with Abigail).

"We need low trolleys we can see over, fitted with baby or toddler seats, and which can clip to our wheelchairs. That would leave us

with both hands free to shop in comfort and safety.

"I'm not just speaking for myself, but for many hundreds of parents who are also wheelchair-users. The same thing applies to young able-bodied parents who take their babies shopping with a disabled member of the family."

Kirsten, of Cippenham, Slough, wants to hear from other disabled parents who feel the same way.

● **What do you think about Kirsten's plea for a better trolley? Please drop a note to: 'Shopping Trolleys', Link, ASBAH, 42 Park Road, Peterborough PE1 2UQ.**

The sky's the limit for grandmother

A GRANDMOTHER who likes to celebrate her birthday by doing something out of the ordinary spent the last one jumping out of a plane for ASBAH.

Trisha Stuart has driven a plane, ridden in a hot air balloon and this year plans to drive a helicopter.

But last year, she decided to do a tandem parachute jump at Headcorn Parachute Club in Kent and at the same time raise money for ASBAH.

Mrs Stuart's 18-month-old grandson, Bradley, has spina bifida and is doing very well.

But Mrs Stuart knew about

ASBAH before Bradley was born because 18 years ago she had a daughter with hydrocephalus.

"I made enquiries about ASBAH because, when my husband died, I wanted to make a donation," said Mrs Stuart, a civil servant working at Chattenden, Rochester.

"I thoroughly enjoyed doing the tandem parachute jump and would do it again."

Mrs Stuart (pictured right) raised £204 for ASBAH by persuading work colleagues, family and friends – including her son who is serving in Germany – to sponsor her.



Cash help for students

ARE you considering going into further or higher education? Do you need some extra cash to help you complete the course of your choice?

If the answer is yes, and you have spina bifida and/or hydrocephalus, then you can apply for money to a special grant-giving fund which is run by ASBAH.

The Bursary Fund was set up following a generous anonymous donation and is able help to about a dozen people a year.

Examples of people who have been successful in applying for money are given on this page and the next.

The Bursary Fund can give a grant – up to £2,000 – to help pay for accommodation, travel, course fees, books, equipment or field trips.

The money can be given as single lump sum for one academic year, or divided up and paid over two or more years.

ASBAH area advisers often play a key role in introducing the Bursary Fund to service-users wanting to continue their education and can help with applications.

You can make a grant application for recognised courses or qualifications at any time before or during the course, but grants must be claimed within the academic year/period for which they are agreed.

ASBAH cannot be the only source of support, so it is essential that the student also applies to other bodies for funding.

The Bursary Fund does not have unlimited amounts of money to be given away. Applications are considered on a first come, first served basis and not every application will be successful.

● For details and an application form, write to: Mr Andrew Russell, Executive Director, ASBAH, 42 Park Road, Peterborough PE1 2UQ.



AN AFTERNOON a week class grew into a full-time foundation course, then a BA and now a Masters Degree in Fine Art for 36-year-old mother-of-two Christine O'Reilly Wilson (*pictured above*).

Christine started drawing as a child to escape the emotional confines caused by the physical restraints of months of hospitalisation, being confined to bed, encased in plaster, then years of wearing a metal body brace.

She was awarded £1,000 from ASBAH's Bursary Fund to pay for the main tuition costs of her MA course at Chester University College.

At the end of the course, Christine was invited to mount her first painting exhibition at the newly-opened Blackthorn Gallery in her home town of Birkenhead.

Entitled *Holding the Light* , the exhibition reflected Christine's own positive attitude to life. The huge expanses of carefully constructed vibrant colour are a means of self-expression which, she says, are a form of communication far less limiting than the use of words, sign or symbol.

She has since had three more exhibitions – in Manchester and Liverpool – and has sold a steady stream of work

Describing herself as an 'abstract expressionist', Christine's art is all about colour and reflects a spiritual sense of inner being. "Art, for me, is a means of discovering aspects about myself in this image-conscious society.

continued at top of page 11

"You can have an immediate response with abstract colour. It has the power to evoke the senses physically and emotionally. Limiting myself to using abstract colour is a challenge and very satisfying."

The critical studies aspect of the MA explored 20th Century myths, ways of seeing, Marxist ideology and Feminist theory, and touched upon the broad expanse of Metaphysics. "It made me focus upon what I was trying to achieve through painting – to discover my own identity," Christine said.

"Art is good for anyone who is searching for a means to express their individuality. Art, at any level, is very therapeutic and rewarding. All the years I have been studying have been worth it, I have done a lot for myself and it is a great sense of achievement."

Christine's painting *Yellow Space* – the first to be sold in her first exhibition – is six foot square with the colour intensity built up in several layers of thin translucent acrylic paint. In places, the paint is removed to reveal colour underneath, while in other areas paint conceals previous marks – a process which evokes the experience of life and the facility of memory.

Contrasting colours, expressive gestural marks, smooth flat controlled areas, cool blues, passionate vibrant reds are all aspects involved in the way her paintings are constructed. The paintings evoke the intangible and refer to the paradox of human nature.

"I believe as we move towards the 21st Century we will reflect more upon the spiritual aspects of our existence, questioning our own mortality and seeking more than self-gratification and material satisfaction in an effort to reconcile our human need to belong," she said.

In September, Christine hopes to begin a one-year, full-time Post-Graduate Certificate in Education (PGCE) course and then become an art teacher in a secondary school.

MA leads to job in Austria

THE opportunity to do a fourth year in higher education led to a job in Austria for 23-year-old Vanja Karanovic (pictured right).

Through ASBAH's Bursary Fund, Vanja received £2,000 which, together with a further £490 from Leeds and Bradford ASBAH, paid the tuition fees of Vanja's MA.

The University of York awarded her the Master of Arts degree in linguistics with a distinction. She already has a BA in Language and Linguistics in which she studied Swedish, German and English.

Vanja and her family have lived in Britain since 1992 after receiving refugee status during the Bosnian war.

"Our town in Northern Bosnia was under siege by the Bosnian-Serbs. We were shelled and there was fighting, but the town never fell.

"We came to live in England in 1992, but I'd been coming to England every year since I was three because I have a doctor here who performed various operations and I had been coming here for check-ups every year. I also came here for a year when I was six."

The chosen subject for her MA was to find out the extent to which the Bosnian language was changing in Britain. She spoke to 13 families out of some 13,000 Bosnians who have received refugee status here.

"I spoke to 10 children, aged between 7-12, who came here in 1992 to find out how English was taking over and what was happening to their mother tongue. As I expected, the younger children were speaking English and losing their Bosnian language as there is not a Bosnian community over here, because of peer pressure and because of the med-



Vanja Karanovic

ia. Personally, I feel very sad that their mother tongue won't be passed on to the next generation."

With her MA completed last year, Vanja left Britain to become a language assistant for seven months in a school in Austria, where she is helping teachers and pupils speak English, and is practising her German.

"I want to express my gratitude to ASBAH because, without you, I wouldn't have done the course and, without completing the course, I would not have got the job. I am really grateful. You were the last organisation I tried for a grant."

Vanja applied for the job, which is EC-funded, through the British Council. "It was very competitive and I was the only non-English person to be chosen. While I am in Austria I will function like a British person and will be representing Britain in Austria – introducing the culture and language."

Vanja is due to return to Britain in May. She has already started applying for scholarships to do a PhD in second language acquisition and social linguistics at Essex and Reading Universities.



Spanish culture and disability by Paul Darke

I SPENT a few months in Spain recently, researching disability

culture in Spain, thanks to a Wingate Scholarship. It made a wonderful change to be spending November facing the sea's warm breeze in Barcelona, having a harbour-front supper of paella, sitting in a T-shirt at 10 o'clock at night. It was a pleasure indeed.

During the day, I was wandering around the city tracing disability arts and local government organisations. Taxis were exceptionally good in stopping for my wife, our son and me (unlike in London when using a wheelchair). Barcelona was more positive about disability than any other city in Spain that I did, and didn't, visit; and every disabled group and individual I met put this down solely to the Barcelona ParaOlympics.

Many more public buildings, public spaces and tourist sites were accessible than in most other European cities (including London) let alone those around Spain.

As for disability art, I attended one spectacular performance by Barce-

lona further education college students with disabilities drama group – who had performed in Nottingham and Leeds the year before – in an open-top renaissance courtyard. The performance consisted of four segments: two professionally performed and right on the button regarding disability culture – it was as progressive as anything in the UK.

The remaining two segments were professionally performed, but somewhat old fashioned in their political content – a perspective which is by far the dominant attitude towards disabled people in Spain. The disabled, to most Spaniards, are little pleading, tragic and lonely figures who just want to be loved, and could do with your charity to make their lives just that little bit better; or they are super-

crips. Rights, not charity, are a long way off in Spain for disabled people. Still, in a renaissance courtyard on a warm, late summer's evening, they could have been Victorian in attitude and I would have enjoyed it.

Barcelona has probably one of the most proactive, and largest, and fully funded specific disability anti-discrimination departments in

Europe in enforcing housing and public transport rights for disabled people. Its work is based on the comprehensive anti-discrimination legislation that exists. Sadly, it is only enforced in specific areas – housing and public transport – and has very little real effect on disabled people's lives as the 'welfare system' is so inadequate as to be almost pointless.

The main problem with the anti-discrimination legislation is that it is entirely at the discretion of each semi-autonomous region how they enforce it; Catalonia is the only one that does enforce it to any great degree and, even then, only in Barcelona.

Being disabled in Barcelona is hard financially and physically (it is very hilly if nothing else) but, equally, it offers a ray of hope for the future. In the rest of Spain it is virtually a nightmare.

In the main, people were warm and friendly in Barcelona and, at least, they were trying, but once we moved on to Madrid, Malaga, Burgos and Santander only the glorious weather was as warm as Barcelona. The people were often as friendly in the rest of Spain as in Barcelona, but there wasn't the same ray of hope for the future.



Claire Houseman

MORE than £10,000 has been raised in an appeal for a lift to give a 15-year-old access to her school's sixth form.

School lift appeal goes up

Claire Houseman has spent five happy years at Fulford Comprehensive School in York and wishes to continue her education there.

Staff are anxious that Claire and other children with mobility problems should be able to take advantage of their sixth form.

However, the local education authority has refused to fund a £40,000 lift, despite there being inadequate provision for sixth formers with mobility problems in York's mainstream schools.

So the school launched a 'Lift Off' appeal and a host of fundraising events are being organised by staff, pupils, Claire, her parents and Claire's younger sister, Helen. Donations have also been made by North Yorkshire ASBAH (£2,500) and Sir Jimmy Savile OBE (£500).

National ASBAH executive director, Andrew Russell, has written to the director of education in York in support of Claire and future children with mobility problems staying on at Fulford School's sixth form.

A mum's tribute

By Rosie McMaster

WHY? We asked ourselves time and time again. Why us? We weren't even sure what spina bifida was or how it would affect our child. It was 3 April 1980 and our first child and only son had just been born.

We are again asking ourselves those very same questions 17 years later. Why us? Why our child? Only this time the questions are over the death of our beloved only son Nathan.

Our initial questions, at his birth, have been answered time and time again. We are yet to find the answer as to why he was taken from us so suddenly?

Nathan proved to be a precious gift (his name means gift from God). He brought untold joy to us, his parents and his two younger sisters, Verity and Olivia, as well as to his grandparents, uncles, aunts and cousins. The list of gifts he brought are endless – love, courage, acceptance, fun, gentleness, compassion, calm and fortitude, to name but a few.

He was quite an exceptional young man. His ready smile could brighten the darkest of days. His acceptance of all that life threw at him never ceased to amaze us.

PROUD mum Rosie McMaster from Chester sent *Link* this tribute to her son, who died unexpectedly at the end of last year.

Mrs McMaster – who has helped ASBAH campaign for greater awareness on folic acid – says she wanted people to know the positive side of living with a child with spina bifida.

"He was not a cross to bear, but a wonderful person," she said. "He had a love of life and was a joy to be with, and was an example to us all. I was very proud of him."

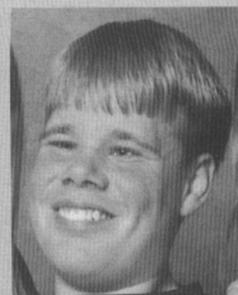
Nathan attended a special school in Flintshire, and plans had been underway for his 18th birthday party – a disco for all his friends.

He bore any illness with strength and always bounced back. "He always managed a smile. It was as if he knew people wouldn't

Nathan asked for so little and everything we gave him he gave back 10 times over.

We received over 200 messages of sympathy and over £1,000 in donations, which gives some small idea of how loved and admired he was by everyone who knew him.

We go through this life as best we



Nathan McMaster

want to be around someone who was moping and moaning," Mrs McMaster said.

Nathan loved being with his family – he and his two sisters used to go out every weekend with their parents.

He also loved music, particularly recordings by Lionel Ritchie. He liked WWF wrestling, the Gladiators, and cookery and quiz programmes on TV.

Nathan had no fears about death and had a great trust in God who, he believed, would come and take him to heaven.

can and just occasionally we may be fortunate enough to meet someone who is truly good, accepting of everything and everyone.

Well, we were lucky enough to meet that special someone, but much more than that, I am so proud and privileged to be able to say 'I gave birth to that someone', he was our beloved son Nathan.

Book of Remembrance

ASBAH has started a Book of Remembrance in response to demand from parents and carers.

The Book of Remembrance is available to anyone who has lost a baby – either through termination or miscarriage – or an older child.

Anyone who would like to have a loved one included in this book, should contact Rosemary Batchelor, ASBAH Services Department on 01733-555988.

Drive to independence

BSM has teamed up with the Centre for Integrated Living in Llangefni, Anglesey, to promote learning to drive as a means of achieving greater independence for people with disabilities.

One of the first people to benefit was one of the centre's administrators, Lisa Parry.

Lisa, who has spina bifida, received two hours of tuition a week from one of five BSM instructors working in north Wales.

Students take Mobility driving lessons in the BSM dual-controlled Vauxhall Corsa – equipped with a range of specialist adaptations to cater for most needs.

For further information about BSM Mobility driving tuition, contact Steve Blackburn at BSM on 01244-321170; call BSM's national Mobility helpline free on 0800 700 800; or visit BSM's Internet web site at: <http://www.bsm.co.uk>

2002 in pros

ASBAH executive director ANDREW RUSSELL introduces our new five-year strategic plan, and offers you the opportunity to find out more.

EVERY FEW years an in-depth review is carried out, examining ASBAH's overall position and operations, to see whether we are addressing aims that are relevant and realistic, in an effective manner. This strategic review, recently completed, was timely because of:

- (a) the changing context of disability and of charities;
- (b) the challenging financial climate;
- (c) the need to adjust our senior management structure on the retirements of the Finance Director and Assistant Director (Services).

The Executive Committee, working with senior staff during the last few months, has reviewed ASBAH's overall position, aims and finances.

The Committee has reaffirmed ASBAH's unique role as a national centre of expertise, services, research and lobbying for all those with spina bifida and/or hydrocephalus. At the same time, the part played by disabled people at all levels of the Association is explicitly recognised and emphasis will be placed on encouraging participation, to ensure that ASBAH is properly an organisation of and for disabled members and all people with sb/h.

FINANCE

Income from all sources has been reviewed carefully and forecasts made for the next five years. We have a reasonable expectation of increased income each year to 2001/02. (This ignores the possibility of specific Lottery or similar grants).

However, despite this, an expenditure projection based on present staffing levels leads us to

expect a deficit in each year to 2000/01, with surplus income thereafter.

ASBAH has sufficient general reserves to live through this five-year period, as long as the staff establishment is contained at the present level, other than in projects funded through specific grants.

Any surplus general income will be put to reserves in this period, to minimise the expected accumulated deficit.

INCOME

The main sources of income are: ASBAH (Trading) Ltd, Legacies, Appeals activities and Computer Sense Ltd (CSL). All these sources will be developed as actively as possible, and in due course ideas for a new subsidiary company will be examined.

CSL is the most likely immediate source of extra income, and the company is being developed as a priority. A new subsidiary company, Computer Sense (PC) Ltd, has been set up to expand the business from Apple computers into the personal computer market.

SERVICES TO USERS AND FAMILIES

ASBAH should offer services to individuals with sb/h and their families which enhance their ability to participate in society and to access the best possible health, educational and social support from relevant agencies. This focuses on "enabling" through helping to build the skill and confidence of service users.

At the same time, ASBAH must continue to acknowledge the specific challenges that spina bifida and hydrocephalus present to those with the conditions. This is not to "label" individuals, but to help them to recognise what their particular problems are and to offer informed support in overcoming them.

The types of services at present offered by ASBAH to individuals are effective and should be sustained, and where possible built on. The types of Adviser employed are considered to be correct, being the result of long experience in our field. Therefore a strategy of field Advisers, backed up by specialist Advisers, remains highly appropriate and will be continued.

Because of the continuing financial status quo, and our five-year forecasts on income and expenditure, no increase in staffing can be contemplated. There will continue to be evolution in the deployment of field services staff, as people retire or leave. This will mean some redistribution carried out by the Services

Department and committee as time p

It has long been it is unrealistic to cover of all areas ASBAH Adviser ability has been regarding area bo "fieldwork patch extend this flexi practicable, bear workload and ca

No blue nt is s ance of staffing continue to prov the fields of med pects, education independence sh raphical distribu be as equitable a ing in mind dem availability of fir

ASBAH Adviser as professional t bringing their ov Regionally mana non-regionalised accepted groupi their area. While already working the new strategy need for his. Th area bot aries rigid.

REGIONS

The strategy of r will continue, bu ical plan has bee uce the eventual ions from eight North West is to ed into the North there will be sor the boundaries of English Regions land and Wales ed. (See map on changes will tak April 1998.

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The implementation of further
Regions and the appointment of
Regional Co-ordinators cannot
be carried out until secure fin-
ance is available. However,
specific grants will be sought
which would allow projects and
additional staffing to be introd-
uced, including in areas which
are not yet formally Regions.

LOCAL ASSOCIATIONS

National ASBAH recognises the
distinct role of local Associat-
ions and their value as a focus
for information and family sup-
port. Many local Associations
have become weaker over the
years, and some have disband-
ed. However, many are playing
a very effective and useful role.
Local Associations should con-
tinue to be the democratic found-
ation of national ASBAH and
no change is proposed in the
constitutional structure or elect-
ion procedure to the national
Executive Committee.

ASBAH will consider how to
offer improved support to local
Associations by way of guid-
ance on communications and
networking, and on encourag-
ing full participation by people
with sb/h in their local area as
well as at National level.

USER FORUM – YOUR VOICE IN ASBAH

YVIA will be encouraged as the
most effective way of attracting
and involving adults with sb/h
in ASBAH's thinking, policies
and activities and the recent
appointment of a YVIA co-ord-
inator will assist in this process.

Efforts to establish local group-
ings of YVIA may result in some

continued on page 16

*You are welcome to attend our regional meetings to
discuss the strategy plan. The meetings are intended to
encourage discussion about the implementation of the
strategy in a manner that is sensitive to the needs of
Local Associations and members.*

*The dates and venues of the remaining meetings are
given below. Refreshments will be provided. Please tell
ASBAH Publicity, tel: 01733-555988, fax: 01733-555985, if
you would like to come.*

Tuesday 12th May

BOROUGHBRIDGE, North Yorkshire Boroughbridge Leisure Centre 7 for 7.30pm

Boroughbridge is off the A1 road about 12 miles north of
Wetherby. The nearest large town is Harrogate, to the
south west of Boroughbridge.

Thursday 14th May

ECCLES, Greater Manchester Eccles Library 7 for 7.30pm

Head for Eccles Centre, which is within easy reach of the
M602 (the extension of the M62), on the west side of
Manchester. Follow signs for the public library.

Tuesday 2nd June

BRISTOL

Frenchay Hospital, Children's Centre and Spina Bifida Unit 6.30 for 7pm

From M32, junction 1, follows signs to Frenchay Hospital.
Bear right at big roundabout at M32 exit. Don't use main
entrance to hospital but go to entrance a couple of
hundred yards further on, at a mini-roundabout.

Wednesday 3rd June

PETERBOROUGH ASBAH House, 42 Park Road 7 for 7.30pm

Head for city centre when leaving A1 at Castor, Orton or
Norman Cross turns. ASBAH House is just south of the
central library.

**Regional meetings which have discussed the
strategy plan have already been held in Northern
Ireland and in ASBAH's South East region.**

2002 in prospect

from page 15

new affiliations and will encourage some people to become individual members of ASBAH.

COUNCIL MEETING

The formal meeting of the Company ("Council") each Spring will be discontinued, because of the small number of local Association representatives who attend. The Annual Meeting of the Association and Company (Autumn) will continue. We will look at other ways of communicating and consulting with local Associations. A series of six meetings will be organised to communicate this strategic review to members around the country.

MANAGEMENT STRUCTURE

At the end of 1998 a new senior management structure will be introduced, to reflect the changes in the balance of work that have occurred recently, and to prepare for future years. The forthcoming retirements of Derek Knightbridge (December 1998) and Teresa Cole (January 1999), after many years of

highly effective and dedicated service, will mark the change point.

The Senior Management Team, reporting to the Executive Director, will be as follows:-

- A Finance Director will be appointed on a part-time basis, a person with commercial expertise who is a qualified, senior level accountant.
- A new post of Assistant Director (Policy and Marketing) will be created to bring additional focus to ASBAH's policy formulation and representation, particularly on external issues. This post will draw together the functions of the Information, Publicity and Publications, and Appeals Departments and will assume line management responsibility for them. The marketing function is concerned with projecting to the world what ASBAH stands for in terms of aims, key policies and activities. This post will start in October 1998.

● Assistant Director (Services) – Teresa Cole is being appointed to this post immediately, to give due recognition to the importance of services to users, in ASBAH's overall mission and aims. In January 1999 the Services Manager will be promoted to the post, and the post of Services Manager will be abolished.

● From January 1st, 1999 the post of Assistant Director (Personnel) will become Deputy Executive Director and Director of Personnel and Information Technology, carrying responsibility for the Association's internal and staff policies and procedures.

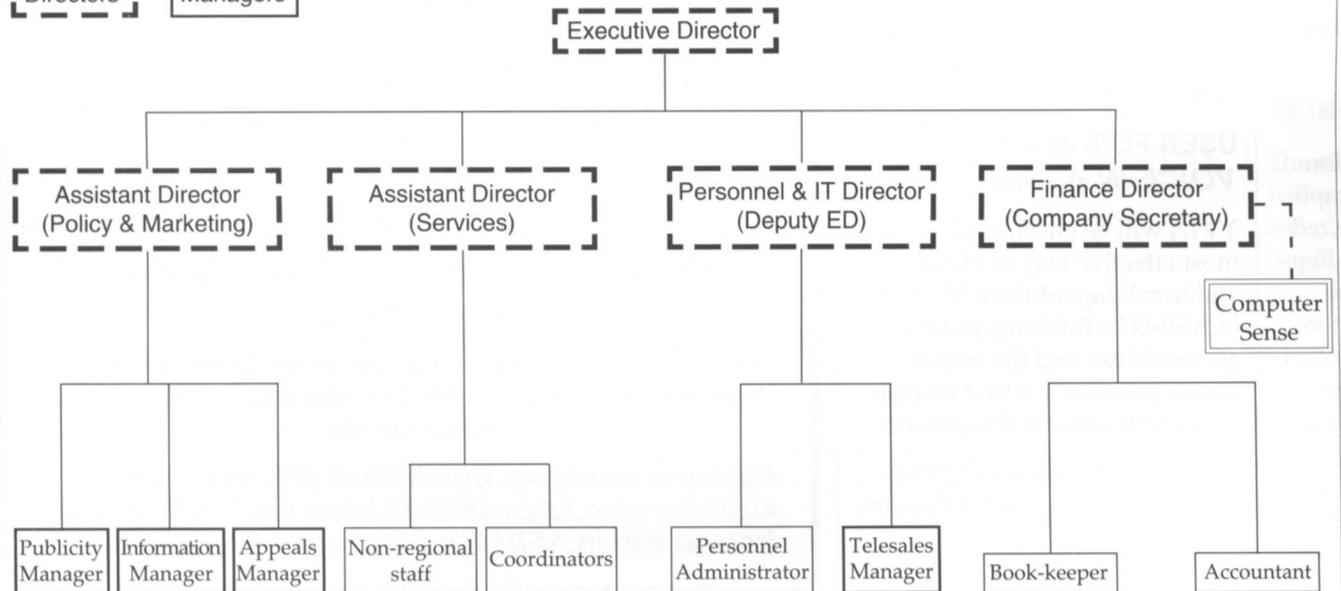
No additional cost to ASBAH will be involved when this new structure is in place.

The management diagram of the new structure is given below.

This new structure should enable ASBAH to function successfully as a service provider, and to improve our policy representation and lobbying, into the next millennium. We aim to act in collaboration and partnership with other associations, but to remain a specialist organisation reflecting the wishes and needs of those with sb/h and their families.

NEW MANAGEMENT STRUCTURE

Key:



LIST OF COUNTIES BY REGION

1. Northern Region

Cleveland, Cumbria, Durham, Greater Manchester, Humberside, Lancashire, Merseyside, Northumberland, Tyne & Wear, North Yorkshire, South Yorkshire, West Yorkshire.

2. Central Region

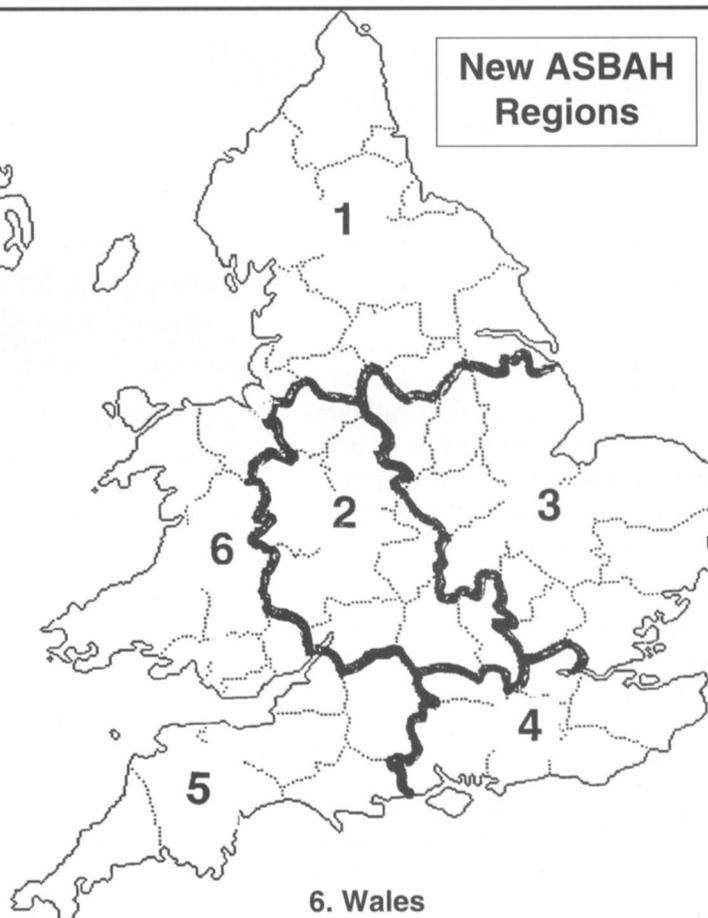
Buckinghamshire, Cheshire, Gloucestershire, Hereford and Worcestershire, Oxfordshire, Shropshire, Staffordshire, Warwickshire, West Midlands.

3. Eastern Region

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

4. South East Region

Berkshire, Greater London, Hampshire, Kent, Surrey, East Sussex, West Sussex.



New ASBAH Regions

5. South West Region

Avon, Cornwall, Devon, Dorset, Somerset, Wiltshire.

6. Wales

Whole of Wales.

7. Northern Ireland

Whole Province.

Lift on audio cassette tape

ASBAH's *Lift* magazine, which goes out free four times a year to people with sb/h, will be available as a cassette tape from the current issue (Spring '98).

In this issue, there is a six-page feature on becoming a parent in which three mums and a dad with spina bifida talk about their experiences.

Other items include another in the popular series, *From Our Foreign Correspondent* – this time focusing on what life is like for someone with spina bifida and/or hydrocephalus in Norway.

ASBAH specialist adviser (mobility), Tim Leech, gives some new information about the Wheelchair Voucher Scheme, and the *Lift* Con-

sumer Column looks at car insurance and announces the withdrawal of a lightweight, affordable wheelchair – rated the best manual chair by ASBAH mobility adviser Tim at the last Naidex Exhibition.

The front page story launches a young mum's campaign for a new type of supermarket shopping trolley, which can be clipped onto a wheelchair and with a seat for a baby or toddler. Kirsten Battle's campaign is also included on page 9 of this issue of *Link*.

● If you would like to go on the *Lift* mailing list, write to: *Lift*, ASBAH, 42 Park Road, Peterborough PE1 2UQ, stating whether you would like to receive the magazine in printed or tape format.

Holidays

WINGS On Wheels organises group holidays for those with and without special needs to exciting and sometimes unusual places.

This year, holidays are planned to Cyprus, Thailand and Holland, as well as shorter breaks in the UK.

Groups number about 30 and include a nurse who is available to give some help with personal care. Discounts of £100 are made to those who are accompanied by a friend, parent or carer.

To find out more, phone Peter Gooch on 01403-823696 or write to him at: Associated Incentive Travel, c/o 10 Bridge Road, Rudgwick, Horsham RH12 3HD.

PARENTHO

NOT so long ago, JACKIE DOUGHTON hit the headlines as the first person with spina bifida to gain an HGV driving licence. Now aged 38, Jackie became a proud mum last December and is finding it relatively easy settling into her new role as someone who is more responsible – happy to put herself second and Luke first.

“I was very much in the dark about how people with spina bifida handle pregnancy. I spoke to Liz Henshall, my ASBAH area adviser, a number of times and she was a great help, talking through things.

“My pregnancy had been planned from the word go. I had been taking folic acid before becoming pregnant, and continued taking it for a further 16 weeks into the pregnancy.

“The doctors didn’t think I could manage the latter part of labour – the pushing part – so they thought I’d need a Caesarean and I couldn’t have an epidural because of my spina bifida.

“My pregnancy was quite straightforward in the early stages – I had

SPRING is here – an appropriate time of year for ASBAH soon to be launching a leaflet on Spina Bifida and Pregnancy – see page 20. *Link* editor LIZ CAWTHORNE takes up the theme by talking to new mum Jackie Doughton to find out how she coped with pregnancy, childbirth and having a new addition to her household. Over the page, Graham Barlow explains how becoming a husband and a father dramatically changed his life.

no morning sickness and few cravings.

“After the first three months, I had the first of many scans. Once I could see the baby inside me, I couldn’t wait to be a mother. I went out buying things for the baby and bought all the pregnancy magazines.

“One problem I found was finding maternity clothes. A lot of dresses tied at the back, so were unsuitable for me because I’ve still got half of my spinal lump on my back. I found two dresses in Mothercare which were gathered under the bust and had plenty of material back and front, which I lived in.”

Towards the end of her pregnancy,

Jackie got very big, so moving around became a major problem. “Pushing my chair was very difficult because having a lump in front of you alters your centre of balance. I found it difficult even to dress because I couldn’t reach my toes.”

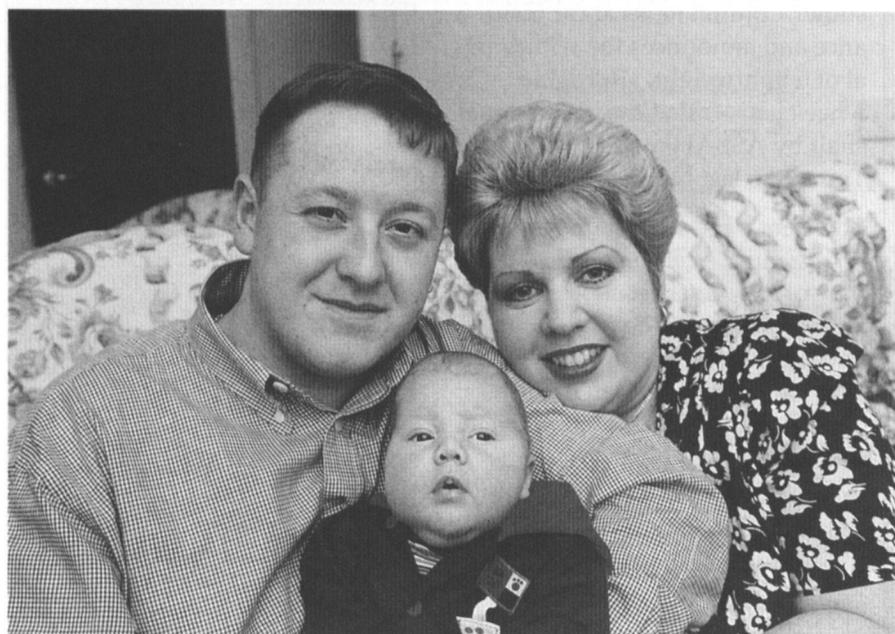
Another unfortunate effect of being larger was that Jackie’s legs swelled up to three times their normal size. There was a suspected clot in one leg, but this was never confirmed.

“But the thing that worried me most was my susceptibility to pressure sores. I was hoping that the Caesarean wasn’t going to lay me up for too long, then I’d get a pressure sore and would be stuck in bed or on a rubber ring with my precious baby out of reach.”

To avoid this problem, Jackie persuaded the hospital to hire a ‘ripple’ mattress, which is plugged in to give a ripple effect, keeping the skin moving.

“They hired the mattress at a cost of £700 but it did the trick. I used it throughout my 12-day stay and didn’t get any pressure sores. At first, I was mobile so I only used it at night but I was in bed for a few days after the operation and then the mattress was essential.

“I also asked the staff to turn me every two hours, and pay some attention to my bottom – checking for red areas and keeping it well moisturised with baby lotion.”



Jackie, her partner Phil, and baby Luke

OD



Jackie Doughton and her new baby Luke

Jackie had a Caesarean Section at 35 weeks and was cut down the middle to avoid interfering with the way her continence is managed.

"Everything went more smoothly than they thought and I'm amazed myself at how quickly I got back to normal."

Due to having a general anaesthetic, Jackie didn't see Luke until more than an hour after he was born. Her partner Phil saw Luke first.

"I first saw Luke in Phil's arms and was amazed at how large he was – weighing 7lb 15oz. Everyone was expecting a small, premature baby."

The day before Christmas Eve, Jackie returned to her bungalow with Luke. She was pleased to be home as it is purpose-built for her, whereas the hospital beds, toilets, baths and showers were inaccessible.

Jackie had been looked after well, but maternity staff admitted they had little or no experience of an expectant mum with special needs.

"They kept asking me to tell them

what to do and let me dictate the pace. They were very attentive."

Jackie coped very well at the hospital and is doing well at home with the new baby.

"I do everything – I feed him, wind him, change him and dress him. I can even carry him in one arm and push my chair with the other. You find ways of doing these things because you have to.

But Jackie admits that looking after a baby is very demanding and that you are no longer able to do what you want, when you want.

"You lose your independence and freedom. I think that's why I left having a baby so late because I'd fought so hard for my independence.

"Before I had Luke, I had only myself to look after. I've always been a great one for my make-up and my hair. Now I have to do these things in fits and starts.

"Mornings are frantic and I don't really sit down until late afternoon.

Finding time for myself is difficult but I try to get myself organised."

Although Jackie is able to get herself and her wheelchair into the car, she can't cope with Luke, his car seat and the pram. Also, she can't push the pram when she's out, so going places together is limited to the times when someone else can accompany her.

When Phil is not around, she has, to some extent, solved this problem by having a family helper – arranged through Social Services for two hours, three days a week – in addition to her usual home help.

"My family helper is not meant to be a baby-sitter, so I can't go out by myself when she's here, but I can wash my hair, or take Luke to visit my parents. She also helps me bath Luke, and we go to the baby clinic together.

"I'm so happy that we've come through it so well. Luke's such a treasure to Phil and myself – he is our miracle baby and it's great having him here."

GETTING married and having a child has made 32-year-old Graham Barlow from Whitefield, Greater Manchester, a much happier person.

He met his wife, Andrea, who also has spina bifida, when he joined Sports For All, aged 16. It wasn't until the second week that they noticed they were in the same team, 'cracked the ice' and started to get to know each other. They have been married now 10 years and have an energetic three-year-old.

"I'm happier now than I ever have been. I used to be a real misery. When I was at home, my sister used to call me 'grouch'," Graham recalls.

"If I hadn't got married, I'd be going to a day centre and driving myself bonkers.

"I've got two people to think about now, besides myself. I'm happiest when James's enjoying himself, and I am upset when he does something erratic. He does good things one day and crazy things the next, like a typical three-year-old."

Andrea takes James by car to nursery every morning.

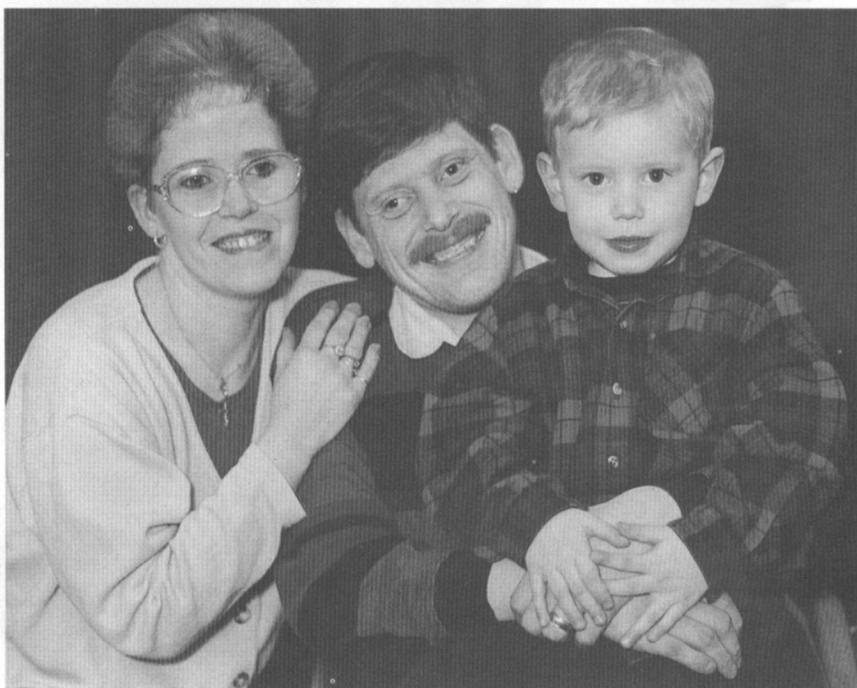
Graham said: "When he's home James likes watching cartoons on the TV. He's kept occupied most of

● **NOTE:** If you have spina bifida, or spina bifida is in your family, and you are planning a pregnancy, or are at risk of getting pregnant, don't forget to take the higher dose of folic acid – a 5 milligram tablet each day.

The higher dose of folic acid has to be obtained on prescription from your doctor. If you have to take medication for epilepsy, you must discuss this with your doctor before taking folic acid.

A supplement should be taken from the time you start planning for a baby – that is, when contraception is stopped – and for the first 12 weeks of pregnancy.

PARENTHOOD



Graham and Andrea Barlow and their son James

the time but, if we're tired, we let him run riot in his bedroom. He can't play outside because we live in a flat with no garden."

Since becoming a dad, Graham doesn't think his friends view him any differently: "I still have my night out with the lads on a Friday. Andrea stays with a friend on Saturdays."

His advice to others who would like to settle down and raise a family is: "If it is something you really want, it will happen.

"Go for it, go looking and don't stop until you find what you need. As it happened, I wasn't looking for anyone when I met Andrea and then it hit me. So expect the unexpected."

Spina bifida and pregnancy – our new leaflet

A NEW free leaflet – **Spina Bifida and Pregnancy** – will be available from ASBAH later this spring, giving information and advice to women with spina bifida on all aspects of pregnancy – including preparing for pregnancy, ante-natal screening, continence management, the birth and after, breastfeeding and going home from hospital.

ASBAH has produced this

leaflet in association with Parentability – a national network of parents with disabilities and parents-to-be.

Parentability offers a contact register, newsletter, practical helpline and resource list. Their helpline number is: 0181-992 8637, or you can write to Parentability, c/o National Childbirth Trust, Alexandra House, Oldham Terrace, Acton, London W3 6NH.



THIS historic picture of all the staff – bar the regional secretary – of Northern Ireland Region was taken a few days after the move from Coleraine to Belfast. From left to right, back row is: Janet Davidson, Heather McKee, Lorna Johnston, Linda Maxwell, Marie McGonnell, Colette McCann. Front row, left to right: Rosemary Whalley, Marian Doherty, Margaret Young, Fidelma Murray, Helen Clarke, Veronica Buckland.

24 – 26 April

'An Employment Weekend', presented by *Your Voice In ASBAH*, Ashwellthorpe Hall, near Norwich. Cost: £25. Workshops include: getting into employment, recognising skills, presenting previous experience, personal development, rights to support and equal treatment, alternatives to traditional full-time work. *Jon Burke, ASBAH North, 64 Bagley Lane, Farsley, Leeds LS28 5LY. Tel: 0113-255 6767 Fax: 0113-236 3747.*

25 – 26 April

'Girl Talk', residential weekend for 18-25 years olds with SBAH, Balmoral Hotel, Belfast. *Linda Maxwell, tel: 01232-761814.*

Wednesday 29 April

Spina Bifida, Sexuality and Relationships, an information day for

DIARY DATES

people with spina bifida, their families/partners and interested professionals. West Everton People's Project, 33 Everton Brow, Liverpool L3 8PU. Contains separate group discussions, run by disabled people, for young people, adults and carers. Cost: person with spina bifida £5; two members of a family £7.50; professional £10. *Elizabeth Miers, 01490-450360; Angela Lansley, 0151-733 8392.*

Monday 11 May

ASBAH South Beds Support Group, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Valerie Bottoms, 01582-605749.*

Saturday 16 May

'The Forgotten Parent', a study

day for fathers/stepfathers of children/young people with SBAH. Post Graduate Education Centre, City Hospital, Nottingham. 10am-3.30pm. £10 per person, including buffet lunch. *Lynn Thomas, ASBAH House, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, fax 01733-555986, email: lynnt@asbah.demon.co.uk*

5 – 7 June

Having fun, feeling great! National ASBAH activities and workshop weekend for people aged 18 and over, Plas Menai, Portdinorwic, North Wales. Activities include sailing, kayaking, speedboat, climbing, abseiling. Cost £50 per participant. *Mrs Jill Bartlett, ASBAH, 4 Ta'ir Felin, Felinheli, Gwynedd, North Wales LL56 4JF.*

DoE bronze award expedition a 'great experience'



Canoists Liane, Paul, Rod and Mairead find some choppy water

SIX young people in Northern Ireland took to the waters of Lower Lough Erne, County Fermanagh, last summer to complete their Duke of Edinburgh's Award bronze expedition.

We had already learnt how to handle the Canadian canoes on three training days at Castlewellan Forest Park and the River Quoile, and now our skills were to be put to the test. Conditions on Lower Lough Erne were different, with such wider expanses of water.

On the first day, the wind was quite strong so we took the advice of our canoeing expert Rod and drove south to a jetty – paddling north from there, with the wind behind us. We had to navigate around some of the hundreds of

**By Rosemary Whalley
ASBAH adviser**

islands to find our way back to the Share Centre where we were camping. We kept near to the banks to give us shelter from the wind. We also had to keep a look out for the cruisers which use the Lough.

After an uncomfortable night in the tents when some promised mattresses failed to materialise, leaving us with Karrimats, we were in canoes again the next day and this time canoed in the bays around the Share Centre.

The expedition was exhausting but the mission was accomplished and for five members of the group it was the last activity needed to

complete the bronze award. Afterwards members of the group were asked for some comments. 'I enjoyed it and learned to canoe. The camping was great fun.' 'I enjoyed being part of a team.' 'The expedition was very worthwhile and very good fun. I learnt a lot about canoeing.' 'The expedition was a great experience and I'm looking forward to the next one.'

The Duke of Edinburgh's award offers young people aged 14 to 25 a challenging programme of activities which include a physical activity, a service to others, making progress in a skill, and the expedition.

It is not competitive, and it is a marathon rather than a sprint, taking persistence and commitment to gain an award. It gives young people a chance to try new activities and to discover more about themselves.

Apart from the expedition, these young people have bred tropical fish, visited elderly people, helped at Girls Brigade, helped at a PHAB nursery, learnt computing and keyboard skills, played the piano, taken part in a fitness programme, attended an athletics club, ridden horses, gone indoor bowling and played basketball.

● **Rosemary Whalley is ASBAH adviser for South & East Belfast, parts of North & West Belfast and North Down.**



Left to right: Kathryn Gordon, Liane Smith (standing), Alison Crawford, Mairead McNeice, Dawn Gilliland and Paul McKillop, with Gary, Chris and Rod from the Belfast Activity Centre

INCOME SUPPORT / INCOME-BASED JOB SEEKER'S ALLOWANCE**Personal allowances**

single	
under age 18*	£30.30/£39.85
aged 18-24	£39.85
aged 25 and over	£50.35
lone parent	
under age 18*	£30.30/£39.85
aged 18 or over	£50.35
couple	
both under age 18*	£60.10
at least one aged 18 or over*	£79.00
dependent children	
birth to Sept following	
11th birthday	£17.30
from Sept following	
11th birthday to Sept	
following 16th birthday	£25.35
from Sept following	
16th birthday to day	
before 19th birthday	£30.30
Premiums	
family	£11.05
family – lone parent rate	£15.75
pensioner	
single	£20.10
couple	£30.35
enhanced pensioner	
single	£22.35
couple	£33.55
higher pensioner	
single	£27.20
couple	£38.90
disability	
single	£21.45
couple	£30.60
severe disability	
single	£38.50
couple (one qualifies)	£38.50
couple (both qualify)	£77.00
disabled child	£21.45
carer	£13.65

* 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: £78-115.99	£16.00
gross income: £116-151.99	£22.00
gross income: £152-199.99	£36.00
gross income: £200-249.99	£41.00
gross income: £250.00 and above	£45.00

APRIL '98 BENEFITS UPDATING**Means-tested benefits**

others, aged 18 or over and not in work, or earning less than £78, or on income support and 25 or over £7.00
aged 16-17, or 18-24 and on IS, in receipt of YT allowance nil

Allowances for personal expenses
residential & nursing homes £14.45
dependent children
 under age 11 £5.95
 aged 11-15 £8.65
 aged 16-17 £10.05
 aged 18 £14.45
hospital
 higher rate £16.20
 lower rate £12.95

Maximum amounts for accommodation and meals in:
residential care homes
old age £213.00
very dependent elderly £247.00
mental illness £225.00
drug/alcohol dependence £225.00
mental handicap £257.00
physical disablement
 under pension age £292.00
 over pension age £213.00
other £213.00
Greater London
 maximum increase £44.00
nursing homes
mental illness £319.00
drug/alcohol dependence £319.00
mental handicap £325.00
terminal illness £318.00
physical disablement
 under pension age £359.00
 over pension age £318.00
other £318.00
Greater London
 maximum increase £49.00

Deductions

for child maintenance £5.10
for fines and council tax arrears £2.55
for arrears of community charge
 single £2.55
 couple £3.95
for direct payment of fuel debt
 5% rate £2.55
for direct payment of housing costs and water rates arrears £2.55

reduction in benefit for strikers £27.00

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 £20.00
(plus 50% of the balance of the charge)

Expenses for sub-tenants

furnished or unfurnished £4.00
where heating is included £9.25

Capital limit

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

Maternity expenses payment £100

Cold weather payment £8.50

HOUSING BENEFIT

Applicable amounts, ie, personal allowances and premiums
as for income support except
 single person aged 16-24 £39.85
 lone parent under 18 £39.85
family premium –
 lone parent rate £22.05

Amenity deductions

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

Meals deductions

full board
 each person aged 16 or over £17.95
 each child under 16 £9.05
half board
 each person aged 16 or over £11.95
 each child under 16 £6.00

continued on page 24

Means-tested benefits from page 23

breakfast only

each person (including children) £2.15

Non-dependant deductions

aged 18, or over, and in full-time work – gross income:

£250 or more £45.00
£200 – £249.99 £41.00
£152 – £199.99 £36.00
£116 – £151.99 £22.00
£78 – £115.99 £16.00

all others (for whom a deduction is made) £7.00

Earnings disregard

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

single claimant £5.00

where carer premium awarded £15.00

childcare costs £60.00

Other income disregards

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 £20.00

(plus 50% of the balance of the charge)

30-hour adult allowance

DWA/FC £10.80

Expenses for sub-tenants

as for IS.

Capital limit

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 and 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:

£250 or more £6.00

£200 – £249.99 £5.00

£116 – £199.99 £4.00

up to £115.99 £2.00

all others (for whom a deduction is made) £2.00

Second adult rebate

second adult on IS 25%

second adult's gross income under £116 15%

£116 to £151.99 7.5%

Capital disregards and tariff income

as for HB.

Earnings and other disregards

as for HB.

FAMILY CREDIT

Adult credit £48.80

Adult credit for working

30 hours+ pw £10.80

Child credit **

from birth £12.35

from Sept following 11th birthday £20.45

from Sept following 16th birthday £25.40

protected rates

age 11 before 7 October '97 £20.45

age 16 before 7 October '97 £25.40

age 18 before 7 October '97 £35.55

Capital and tariff income

as for IS.

Disregards

childcare costs £60.00

no earnings disregards – other

income disregards as for HB.

Expenses for sub-tenants

as for IS.

Applicable amount (ie, taper threshold level) £79.00

DISABILITY WORKING ALLOWANCE

Adult allowance

single people £50.75

couples/lone parents £79.40

30 hours allowance £10.80

Child allowances**

from birth £12.35

from Sept following 11th birthday £20.45

from Sept following 16th birthday £25.40

protected rates

age 11 before 7 October '97 £20.45

age 16 before 7 October '97 £25.40

age 18 before 7 October '97 £35.55

Applicable amount (ie, taper threshold)

single people £59.25

couples/lone parents £79.00

disabled child's allowance £21.45

Capital and tariff income

as for FC, except upper limit

£16,000

Disregards

as for FC.

** *New rules apply in respect of credits for children on claims for FC and DWA made on or after 7 Oct 97. See Child Poverty Action Group's Welfare Benefits Handbook 1997/98 edition.*

Non-means-tested benefits

Attendance allowance

higher rate £51.30

lower rate £34.30

Child addition * £11.30

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 £11.45

for other child(ren) £9.30

for only, elder or eldest child

(lone parent rate) £17.10

Contribution-based jobseeker's allowance

under 18 £30.30

age 18-24 £39.85

25 and over £50.35

Disability living allowance

care component

higher £51.30

middle £34.30

lower £13.60

continued on page 25

I RECENTLY complained that the City of Westminster wasn't in the Orange Badge Scheme. I'm told they *do* have a 'White Badge' scheme for residents and people who work full-time in Westminster, or go there for dialysis. That's great for regular travellers to the CoW, but for visitors like me it's about as much good as a poke in the eye. It's unhelpful, aggravating and depressing.

I'm a bit depressed at the moment. After three decades of discomfort, hassle and people whose sole purpose in life seems to be to make me fill out endless forms, tell me it's 'not invented here', or generally get in my way, I'm getting a bit grouchy. My perky has peaked. I'm less Forrest Gump, more David Grump!

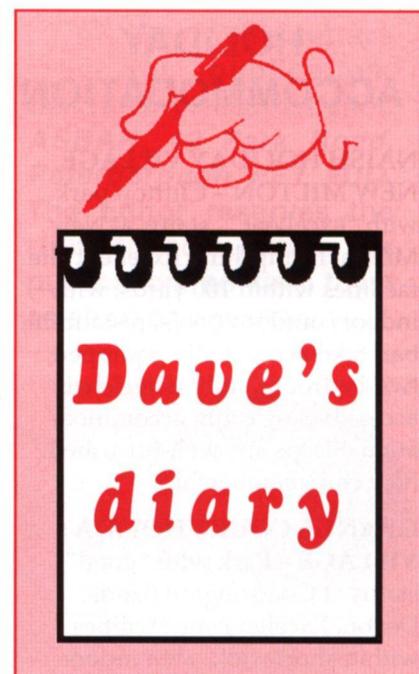
A major cause of my depression is the wretched media. It's been two years since I first pointed out that the papers print garbage about spina bifida bods being happy, smiley and popping their clogs early – and they're still at it! I despair. If they are going to make SB 'Disability Of The Day', could they at least check their facts?

These days it feels like SB is mentioned everywhere in the media. I'm sure that ASBAH's folic acid

campaign has a great deal to do with it and I'm glad it's been so successful in 'spreading the word.' Lord knows I wouldn't have people be ignorant of SB, but sometimes I feel like now everyone knows 'my secret.' I rather enjoyed being exotic and mysterious, making people guess what was wrong with me, knowing they couldn't pigeon-hole me and that I knew things that other people didn't.

All too often my information on new things comes from friends or family living abroad. It was my Auntie Christine in Canada who, on her last visit, noticed I was a bit down and suggested I try the herbal medicine 'St John's Wort/Hypericum' to shift my depression.

In Germany, St John's Wort is pretty much an accepted treatment. No such luck here. I asked my doctor but she didn't know much about it. Which isn't to say she was unhelpful. Doctors tend to be either against something they don't believe could work, or take a neutral view of: *I'm not recommending it but if it works for you, great.* She did suggest I tried a prescription anti-depressant, but I just wanted a mild pick-me-up rather than something heavy duty. So I said I'd try out the Wort first,



thanks. I did and it works for me. If you're depressed and plan on trying it, contact your doctor first, ok? Another word of warning: if you want some St John's Wort/Hypericum, for pity's sake buy it from a chemist or health food shop. If you go down to the woods today and you pick the wrong thing, not only are you in for a big surprise, but you can end up solving all your problems *permanently!*

David Fulford-Brown

Non-means-tested benefits, from page 24

<i>mobility component</i>	
higher	£35.85
lower	£13.60
Earnings rules	
Invalid care allowance	£50.00
Therapeutic earnings limit	£48.00
Guardian's allowance/child's special allowance*	£11.30
Industrial injuries benefits	
Disablement benefit	
100% assessment	£104.70
20% assessment	£20.94
Reduced earnings allowance (maximum)	£41.88
Invalid care allowance	£38.70
increase for adult dependant	£23.15

Incapacity benefit	
short-term (under pension age)	
lower rate	£48.80
higher rate	£57.70
short-term (over pension age)	
lower and higher rate	£62.05
long-term	£64.70
increase of long-term for age	
higher rate	£13.60
lower rate	£6.80
Invalidity allowance (transitional)	
higher rate	£13.60
middle rate	£8.60
lower rate	£4.30
Maternity allowance	
lower rate	£50.10
higher rate	£57.70
Retirement (Category A & B) and widow's pension and widowed mother's allowance	
single person	£64.70

wife or adult dependant (retirement)	£38.70
Severe disablement allowance	
	£39.10
adult dependant	£23.20
age-related addition	
higher rate	£13.60
middle rate	£8.60
lower rate	£4.30
Statutory maternity pay	
lower rate	£57.70
earnings threshold	£64.00
Statutory sick pay	
standard rate	£57.70
earnings threshold	£64.00

* This is reduced by £1.40 for any child for whom you receive the higher rate of child benefit.

● Information supplied by Child Poverty Action Group.

HOLIDAY ACCOMMODATION

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.

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, pay-phone, colour TV, midi stereo etc.

Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. *Details from Mrs B Nunn, tel: 01903-763473.*

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.*

MAR Y SOL – TENERIFE – Wheelchair accessible apartments. Heated pool with hoist. Restaur-

ant, poolside bar, equipment hire. Sunshine guaranteed all year round. Ring today for cheapest prices. *Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX, tel: 01753-685718.*

ALGARVE – PORTUGAL – Wheelchair-friendly luxury villas with swimming pools, or small friendly hotels with adapted rooms. *Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX, tel: 01753-685718.*

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 Horizon adult electric wheelchair, with attendant control. £700 ono. Shoeburyness, Essex. *Mr R Morgan, tel: 01702-291 3464.*

CONCERN for Comfort, single Wallhugger bed, 6ft 3 inches long, with massager. Cost new £3,100 when purchased in September 97. Will consider sensible offers. Stevenage, Herts. *Tel: 01438-367873.*

HAND/foot/brake/ accelerator controls for automatic car. (Metro or sim. size). Cost £230, bargain £45, as new. *Sue Fisher, tel/fax: 0161-792 3029.*

NISSAN Versa 2.3 litre diesel. Adapted for a Ricon wheelchair lift. 5 seats, 1995, N-reg, 17,500 miles. Seven months remaining on warranty. Powered steering. Immaculate condition. £10,500. *Tel: 01244-660637.*

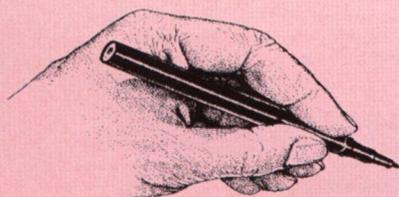
ADJUSTABLE, 3’ 3” with built-in therapy, remote control, fitted sheets. Cost £2,650, 15 months old, in beautiful condition. *Phone: 0181-953 9643.*

CARMOBILITY 180° travel seat giving easy access from wheelchair to car. Hardly used. Cost £890. Will accept £400. *Tel: 01525-222268. Fax: 01525-222152.*

ACCOMMODATION

SHELTERED accommodation in self-contained flats for single people with physical disabilities. If interested, contact: Miss Linda Patton, Head of Home, Cheshire House, Kinsale Park, Waterside, Co Derry, N Ireland. *Tel: 01504-341861.*

MY NAME is Paul Cooper. I’m 33 years old and have hydrocephalus. I live at Lucerne House in Bexhill, which is a small group home for people with learning difficulties. It is a friendly, happy home, which currently has a vacancy so, if anyone with hydrocephalus is seeking a home, why not call for more information on 01424-224181.



Letters



I AM a 34-year-old mother. Our baby Weronika (pictured right) was born 15 May 1997 with spina bifida and hydrocephalus.

Shortly after delivery, she was treated surgically – firstly for meningocele (open spina bifida), secondly for hydrocephalus. She was in hospital from 15 May until 1 July last year. She was in hospital again from 25 July to 16 September due to a hospital infection and then surgically treated again for hydrocephalus.

We think we should be in touch with experienced doctors and with parents who are caring for children with such problems.

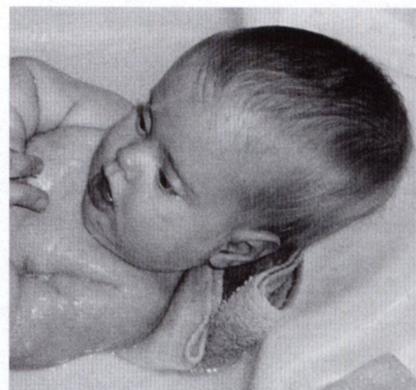
We know that, in future, we are likely to face a lot of questions and difficulties concerning our daughter.

We would be very grateful if any parent could write to us.

Rosita Turowicz-Wlazniak
ul Kolberga 3 m 19
PL 02-650 WARSAW
Poland



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



WOULD any *Link* readers be willing to help me in my research programme, which I shall be involved in this summer?

I am reading for my MPhil/PhD at De Montford University, School of Physical Education, Sport and Leisure. My particular interest is in the factors that influence disabled individuals' decisions to participate, or not, in sport and exercise. The title of my study is 'Intentions to exercise amongst disabled individuals.'

In the longer term, I hope to show that decisions people make with regard to sport and exercise participation could be helpful in determining more adequate levels of resources and provision.

If you feel this is an area that you are interested in, may I invite you to discuss with me, informally, the development of suitable questions that I could incorporate in my questionnaire. This is to be administered later in the summer.

I anticipate that the questions will range over a number of areas including environmental, physical, psychological and social factors.

You can contact me at the address below, if you wish, or telephone between 6pm and 9pm on week-day evenings.

Janet Rice
22 Hills Close
Roxton
Bedfordshire MK44 3EE
Tel: 01234-870574

LINK Rates

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Small adverts for the next issue of *LINK* (June) should be submitted by Friday, 8 May. Please send them to the Editor.

Display Rates on application, from the Publicity Manager.

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