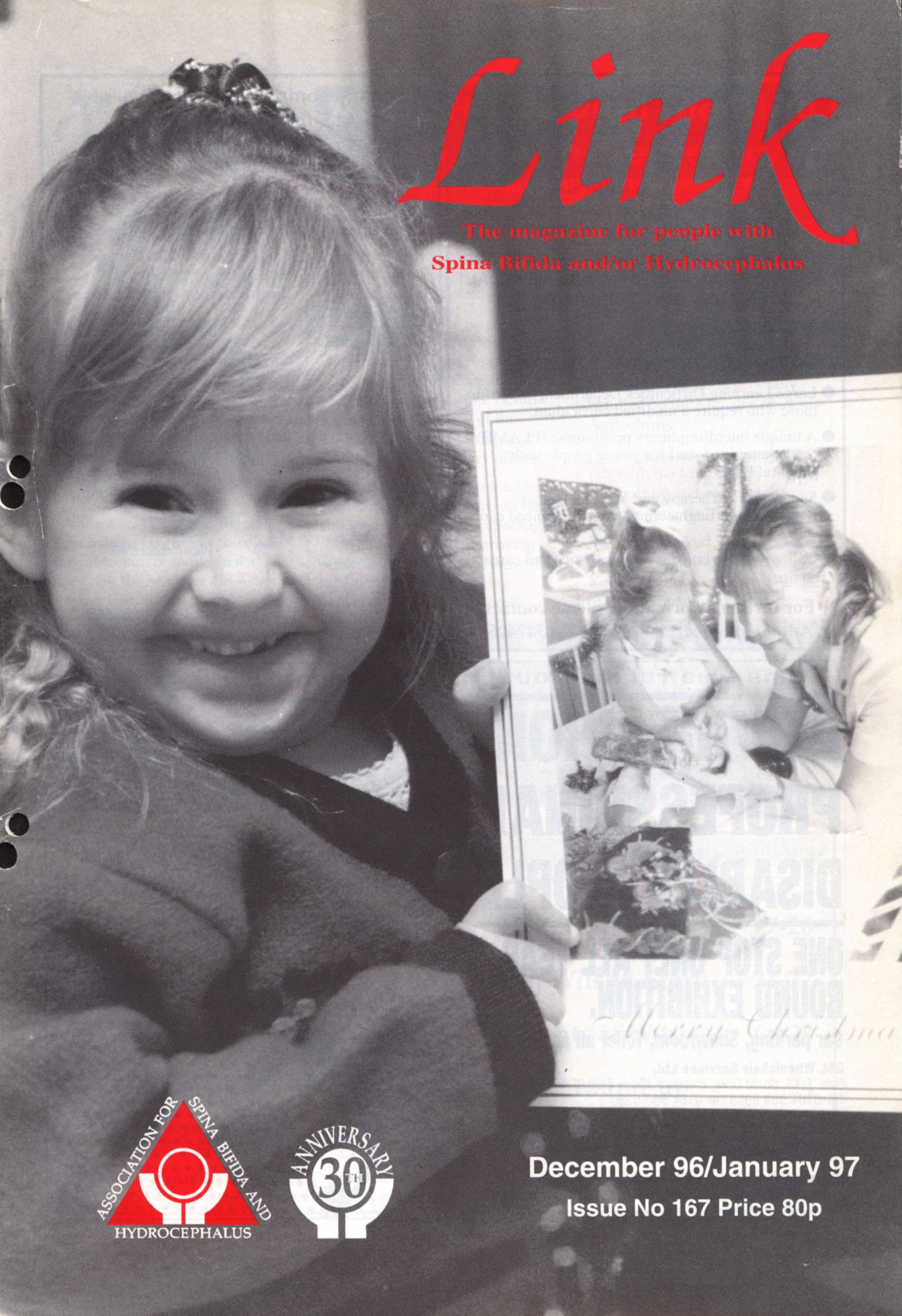
Link

The magazine for people with
Spina Bifida and/or Hydrocephalus



ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

ANNIVERSARY 30TH

December 96/January 97
Issue No 167 Price 80p

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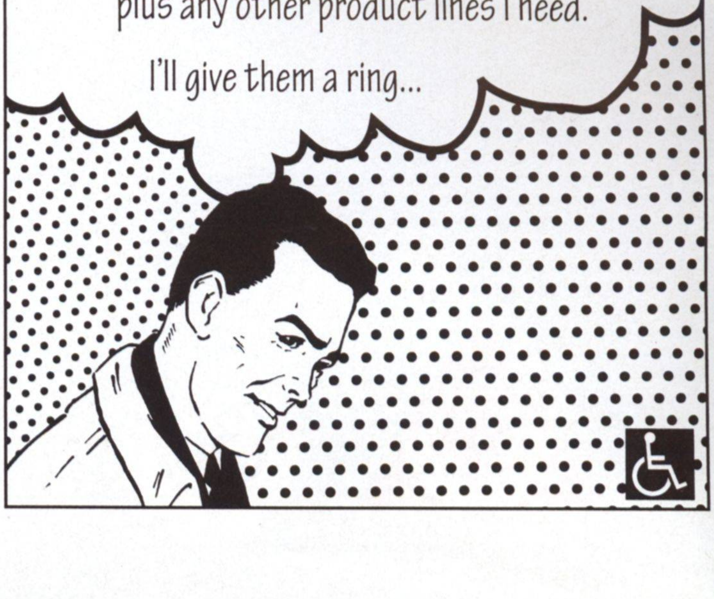


ASBAH has vital meeting with Health Secretary

ASBAH's pressure for widespread fortification of breads and breakfast cereals with folic acid led to an important meeting with the Secretary of State for Health.

The Health Secretary, Stephen Dorrell, agreed to discuss this issue and related matters with a delegation which included ASBAH executive director Andrew Russell.

"We felt we made progress, although Mr Dorrell did not pretend that he would be in favour of the wholesale fortification of flour because that goes against the grain of the government's political philosophy," said Mr Russell after the meeting at the Department of Health's Richmond House headquarters in Westminster.

"While it was clear that the government favoured choice and the protection of individual lifestyles, the Minister did listen to the fact that flour, salt and margarine are already fortified with other minerals – so there are precedents for going down the path we propose."

Mr Russell was joined in the meeting by members of the Parliamentary All-Party Disability Group, led by co-chairmen Lord (Jack) Ashley of Stoke and Sir John Hannam MP, and Professor Nicholas Wald, of the Wolfson Institute for Environmental Health at St Bart's Hospital, who led a six-year investigation which in 1991 finally proved the link between folic acid deficiency and spina bifida pregnancies.

Other delegates were Peter Thurnham MP, Lord Rea (a doctor who chairs the Parliamentary Food and Health Forum), and Victoria Scott, who is secretary of the All-Party Disability Group and RADAR's parliamentary officer.

The delegation also told the Health Secretary that restrictions on health and medicinal claims on packaging were a hindrance to improving public knowledge of the benefits of folic acid, and to marketing enriched products effectively.

"We said a selective waiver of this rule for proven and agreed claims was needed, and that a similar policy now operated in the USA," said Mr Russell.

"Mr Dorrell was not familiar with the arguments for and against proper labelling. That wasn't surprising because packaging of food supplements is generally handled by the Ministry of Agriculture.

"But he said he would look into this with the Ministry of Agriculture and come back to us on both subjects," he said.

Mr Russell talked with Labour's Shadow Health spokesperson, Kevin Barron, on the same subject at a later meeting.

ASBAH's wind of change

YOUNG disabled service-users wanting to be part of the wind of change blowing through ASBAH attended a weekend training course in December organised by Your Voice In ASBAH (YVIA).

The course – Committee Skills and Disability Equality Training *– was held at Blackpool's Shellard Hotel. Alan Twyford, vice-chairman of YVIA, said: "The course gave people the experience, knowledge and skills they need if they want to offer their services – not only to YVIA but also to their own local committees."*

Contents

ASBAH is a registered charity

Cover: Six-year-old Amy Boler, a Sheffield ASBAH member, is featured on the 1996 CHRIS Fund Christmas card which raises money for research at the Sheffield Children's Hospital. Photo courtesy of The Sheffield Star.

Staff news

● GERALDINE POTUSZYNSKYJ has taken over the post of specialist adviser (medical) for Northern Region following the resignation of Mary White.

Geraldine will be splitting her working week between this post and her role as part-time adviser for North Yorkshire and York, Hartlepool, Redcar & Cleveland, Middlesbrough, Stockton-on-Tees.

She is based at the Northern Region office when working as a specialist adviser.

Office move

NORTHERN Region and START staff have moved out of Five Oaks, following the sale of the property, and are housed temporarily in the activity centre

For the most up-to-date contact details, contact Services Department at national centre on 01733-555988.

New regional co-ordinator

● JO FRANCIS brings a range of experience of different special needs to ASBAH as the new South-East Region co-ordinator.

The former branch adviser for the Motor Neurone Disease Association and local volunteer chairman of the Pre-School Playgroups Association, started on 18 November.

At the Motor Neurone Disease Association, Jo managed outreach workers at 100 branches in the North-East, Yorkshire, East Anglia and the Midlands. These volunteer workers were involved in visiting, giving talks, raising money and giving radio interviews. Jo said: "It was quite demanding. Because you were dealing with a terminal illness, people wanted you to act quickly and you had to cut through the red tape."

For the Pre-School Playgroups Association, Jo managed staff and a budget, and ensured staff had sufficient training and support.

Funded by the Milton Keynes Development Corporation, the playgroups association set up a project giving support to families made homeless and a special needs playgroup. Jo also became a lecturer in child development for the association on a further education course.

Of her new job, she said: "I am looking forward to the challenge of being involved in management again and supporting fieldwork staff. Their jobs are quite stressful and I will enjoy being there to listen."

She added: "A niece of mine has spina bifida so I have an interest in the condition. We also had a volunteer with spina bifida in the office of the Motor Neurone Disease Association."

Jo lives near Olney, Bucks.

New adviser for over-16s in East Sussex

● A FORMER paediatrics nurse with more recent experience in teaching and managing courses for nurses and health visitors is the new ASBAH area adviser for the over-16s in East Sussex.

Jo Gardner will be working 17 and a half hours a week, covering the area from Burgess Hill to Hastings, from 2 December. She lives in Cuckfield near Haywards Heath.

Jo started her nursing training in the late 1950s at Queen Mary's Hospital for Children in Carshalton, which treated many children with spina bifida and hydrocephalus. She believes she was there when surgeons did the first Spitz-Holter valve operation.

She completed her general training in Portsmouth where she went on to become theatre staff nurse and sister.

She was then sister on a paediatric ward in Sidcup in Kent and Portsmouth before returning to St Mary's as a ward sister.

By that time she had a son and decided to go into teaching. She completed a two-year training course to become a nurse teacher in paediatrics in Brighton.

After being a senior tutor for 10 years, Jo moved to Croydon in 1986 where she managed a variety of teaching posts. She retired from teaching last year.

"Since then I have been looking for the right sort of job. It needed to feel right and the job with ASBAH did. Although I've done a lot of academic work, I have never lost my interest in children and children with disabilities in particular."

More staff news on page 6

Mobility component

ATTEMPTS by disability groups to overturn new rules cutting mobility component of Disability Living Allowance have been taken up by the Labour Party.

The regulations state that if you are in hospital for more than 28 days (84 days for children under 16) you will cease to receive mobility component.

People staying in residential care homes or nursing homes arranged by the NHS are likely to be affected in the same way as if they were in hospital. *(For more details see Oct/Nov Link p 9-10).*

Labour has tabled a resolution to revoke the new rules and says it is pushing this to the top of its list of issues for debate and will be using party whips to do this.

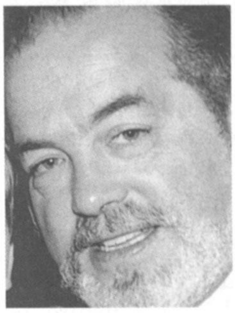
Disability groups which have campaigned for a debate on the cuts are now appealing for people to write to their MPs asking them to vote against the new regulations.

Anyone who has already lost out should contact **Margaret Lavery** at **RADAR** on **0171- 250 3222 ext 202** who is collecting evidence of hardship under the new rules.

UP-DATE ON LORD MAYOR OF BELFAST'S APPEAL

£70,000 in one year!

AN INCREDIBLE £70,000 – £20,000 more than the target – was raised for people with spina bifida and hydrocephalus in Northern Ireland by the immediate past Lord Mayor of Belfast, the Rev Eric Smyth *(pictured right).*



And the committee behind Councillor Rev Smyth has pledged to continue its fundraising efforts – this time directing all the money to ASBAH in Northern Ireland.

The money raised during Councillor Smyth's mayoral year was spent on 16 lightweight wheelchairs for children and a £30,000 urodynamics machine for the Royal Victoria Hospital for Sick Children in Belfast.

The number of wheelchairs could rise to 20 when all the appeal money has come in.

The biggest fundraising events of the year were two Charity Balls – one organised by the Lord Mayor; the other organised by the Lord Mayor's fundraising committee.

Councillor Smyth chose people with spina bifida as beneficiaries of his appeal because he has an adopted five-year-old son, Matthew, who has spina bifida and hydrocephalus.

Half of the eight members of the Lord Mayor's fundraising committee also have children with spina bifida.

Chairman, Vincent McCarthy, former chairman of Belfast ASBAH, whose seven-year-old son Jonathan has spina bifida, said: "As it was such a successful year, the committee wants to continue raising money for people with spina bifida.

"We have a link with Margaret Young (Northern Ireland region co-ordinator) and the advisers at ASBAH and would like to raise money for them."

Officers & Staff

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Appeals Manager
Donna Treanor

Publicity Manager:
Tony Britton

Research and Information Officer:
Gill Winfield Cert Ed

Morestaff news

● SUE Davies, adviser for almost four years in Bedfordshire and Hertfordshire, reluctantly left in October due to a job move by her husband.

Husband Tony has joined a partnership in Wiltshire. He is a photogrammetrist (a specialised computerised surveyor) – whose work has included surveys of Windsor Castle after the fire and the moat around the Tower of London.

Sue made many inroads in Bedfordshire – including starting support groups in Luton and Milton Keynes – but admitted Hertfordshire was more difficult to get to know.

She said: "The meetings in Luton and Milton Keynes pull out the positive because the mums and dads sit next to adults who give their experiences."

Over four years, Sue helped almost 150 clients. "I enjoyed the wide variety of the work. It's a privilege going into people's homes which enables us to work effectively and work with other agencies."

"It was great working with the other advisers and it's been an uplifting experience being part of East Region," she said.

One of the highlights of the job for Sue was four young members of Beds & District ASBAH taking driving lessons, with three out of four passing their tests.

"It was great seeing the younger ones develop their confidence," she said.

Another high point was being able to help young people sort out their benefits – taking some cases to tribunal.

"The young people can be turned down very easily. Once they get the income they're entitled to, their quality of life goes up."

When working with families, Sue saw herself as a catalyst, helping them to sort out their problems.

During 1995-6, Sue proved an invaluable link when Milton Keynes Mayor and Mayoress, Bruce and Helena Hardwick, raised more than £5,000 for ASBAH.

● TIM LEECH is the new national mobility adviser following the departure of Ann Wild.

He is based at ASBAH's national centre in Peterborough and works all day on Mondays and Tuesdays, and mornings only on Wednesdays.

Tim has a varied background. He worked previously as a manager for a small charitable trust, reviewing disabled people's needs – from transport to benefits.

Before that he advised English Heritage on how it should adjust to the Disability Discrimination Act. This included looking at the agency's employment record, equality training and advising on equipment.

He has also been a fundraiser for Disability Direct and before that an archaeologist, protecting all 300 miles of the Essex coastline.

He also assists his father in social surveys by designing questionnaires, analysing statistics and handling enquiries.

● NATIONAL specialist adviser (medical) Paula Thompson gave birth to daughter Molly on Sunday 13 October.

Paula will be back from maternity leave in January.

● LINDA Maxwell takes over a new post of specialist adviser (independence) in Northern Ireland on 6 January.

The 25 hour-a-week post was created after Northern Ireland ASBAH and Northern Ireland Region won £50,000 over two years to set up courses for ASBAH young people on mobility and social skills (see page 4 August/September *Link*).

● ADVISER Elizabeth Lawlor has remarried and moved, so changing her surname and the area she covers.

She is now called Elizabeth Miers and, because of the distance from her new home ('half-way up a mountain in Wales,' she says), no longer covers North Staffordshire.

Her patch now consists of Cheshire, Wirral and North Shropshire.

Her wedding was very much an ASBAH affair as her 'best woman' was adviser Elin Richards.

The ceremony took place on Anglesey – where Fred, a company director, and Elizabeth had their first date. They spent their honeymoon in Cyprus.

● BOB WILSON, part-time administrator for more than four years at national centre, retired.

A talented woodworker and artist, Bob presented a gavel and stand to ASBAH before he left and the splendid piece of woodwork was used to open the annual meeting.

An engineer before joining ASBAH, the desk job at Park Road was quite a change. "I relished the idea of a challenge," he said. "And with the help and assistance I received from everybody, I enjoyed doing the job."

Bob will keep busy in retirement with his hobbies – woodworking, drawing and do-it-yourself.

Join ASBAH's Clubability Challenge

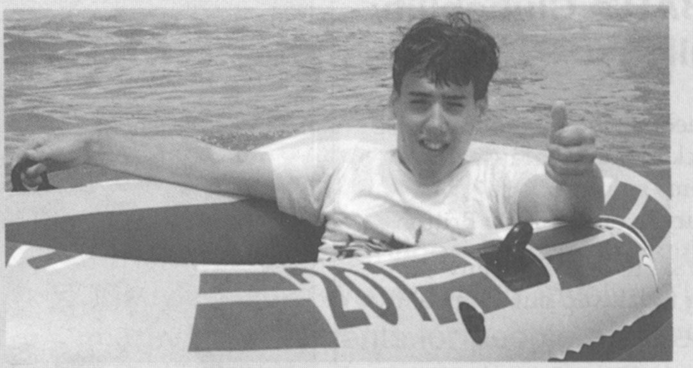
A YOUTH club is a great place for youngsters with disabilities to get out, make friends, try new activities and have fun!

Just like 13-year-old Robert (*opposite*) and 12-year-old Ben (*over the page*), many young disabled people would enjoy going to a club where they are made to feel welcome.

ASBAH, which has several thousand teenagers and young adults on its books, is searching for youth clubs willing to open their doors to disabled members.

"A youth club could be a life-line

more on page 8



"HELLO. My name is Robert. I'm 13 and live at Mount Hawke, near Truro, in Cornwall.

"I like watching my friends in the village play on skateboards in the local skateboard park. I'd like to watch them more often but it's difficult getting down there because the park is half a mile out of the village and I can't get my wheelchair along the rutted lane.

"The skateboard park has won some Lottery money and the skateboard area is being covered over. They hope to make it into a proper youth club, with snooker and pool. I'm looking forward to that. I hope the club will have disabled facilities.

"If the project gets off the ground, there will be plenty to do. But it could be difficult for me attending because I have transport problems as mum is often helping dad, who works from home.

"I've joined a youth club for disabled people at Redruth, six miles away. I go by taxi after school with my friends on Fridays from 4-6pm. We play computer games and do painting.

"I'm also learning to play drums in a silver band at St Agnes, two miles away. But I like hanging around with my friends who go skateboarding best. They are always helpful and great fun."

Help & Advice

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

London, Surrey, Kent, West and East Sussex

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

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

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

Northern Ireland

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

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

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

Rest of England and Wales

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

ASBAH welcomes and appreciates the support of its commercial partners.

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

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

ASBAH's Clubability Challenge *from page 7*

to someone who might otherwise be stuck at home because of problems getting about," said publicity manager Tony Britton.

"We want to hear from any club willing to take up our Clubability Challenge."

Young people with spina bifida and hydrocephalus are like any other youngsters. They want to get out, mix with their mates after school or in the holidays, and do something a bit different.

But the fact that they might use crutches or a wheelchair to get about means extra consideration does have to be given to them, particularly if the club premises and toilet are not easily accessible, or the club is having an outing.

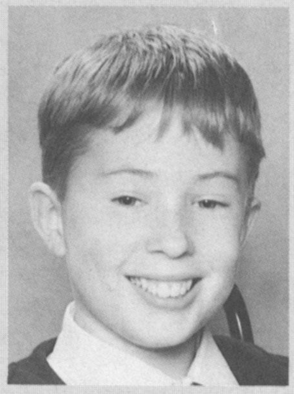
It would be no good, for instance, leaving them out if the able-bodied members want to go to the seaside for a day – just because somebody forgot to check if the disabled member can get on and off the coach.

With enthusiasm and imagination – and perhaps some extra funding for more staff, internal adaptions and wheelchair-friendly transport – ASBAH believes that full integration can be achieved.

Leaders wanting to take up ASBAH's Clubability Challenge have been invited, through an article in Youth Clubs UK magazine, to let Tony Britton have details about their club, particularly about how access for disabled people works out in practice or might be achieved.

The information will then be published in *Link* and *LIFT* so that ASBAH's own young members can decide for themselves if they want to find out more.

Meanwhile, if you know a youth club interested in joining our Clubability Challenge, complete and return the form below.



"HELLO. My name is Ben Shackleford, I'm 12 and I live in Earley, Reading. I'm a wheelchair user.

I attend a mainstream comprehensive school but live outside the catchment area so I go there by taxi.

I'm very busy after school with swimming, Scouts and Boys Brigade where I meet other teenagers from school or my neighbourhood.

I'm also a member of a PHAB Club and WAMDSAD – Windsor and Maidenhead District Sports Association for the Disabled. The trouble is that at PHAB the able-bodied people outnumber those with disabilities. At WAMDSAD, there are only four of us of my age and none of us live near each other. It would be better if more people my age went to this.

I'd like to join a youth club but the able-bodied members would have to be willing to include us in a game of pool, table tennis or basketball. Some able-bodied teenagers aren't very friendly.

I have quite a lot of friends at school – I'm the only disabled person in my class – but because I live outside the catchment area I wouldn't meet any of them at my local youth club."

Ben's mum Elaine added: "A few years ago I took my older daughter to the local youth club. It was unstructured and the kids seemed to mess about.

"A lot of 'yobby' kids seemed to go and I was unhappy about letting her attend. Unfortunately, the reputation of the club continues."

✂

YES! I know a youth club interested in joining ASBAH's *Clubability Challenge*.

NAME OF YOUTH CLUB ______________________

ADDRESS ______________________

____

CONTACT NAME ____________ **TEL** ____________

Any current good practice, aims or ideas for *Clubability Challenge?*

____

____

____

PLEASE RETURN COMPLETED FORMS TO: TONY BRITTON, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ

YOUR NAME ______________________

ADDRESS ______________________

____

____________ **POSTCODE** ____________

TEL ______________________

ARE YOU INVOLVED IN THE CLUB? IF SO, HOW? ____________

____

____

This Christmas, make a researcher very happy

ASBAH leads the way in the UK in the provision of services to people with spina bifida and hydrocephalus, and their families. We are also involved in funding research into prevention, and improving treatments for people affected – estimated by the International Federation for Hydrocephalus and Spina Bifida at 10,000,000 people worldwide.

ASBAH supports research projects in London, Oxford, Newcastle, Nottingham and Leeds. Dr Roger Bayston's work on improving hydrocephalus shunts is well known to many readers.

But we are also funding a study into the physical and intellectual outcomes of pregnancy where hydrocephalus is suspected. Another researcher is looking for an effective drug treatment into hydrocephalus. Another line of inquiry is how to boost the metabolic uptake of folates to achieve primary prevention of neural tube defects, including spina bifida and anencephaly. And we also contribute to a study on whether there is a link, via neural tube defects, between folate deficiency and cancer.

Much remains to be done. ASBAH – which relies almost entirely for its income on voluntary contributions – is restricted in the role it can play only by the limit of its donations.

Please help us make more research happen in this field by giving whatever you can afford to:

Christmas Research Appeal
ASBAH, 42 Park Road
Peterborough PE1 2UQ

Tel: 01733 555988 Fax: 01733 555985
Web site – http://www.asbah.demon.co.uk/
Registered Charity Number 249338

Yes, I would like to make a donation to ASBAH's Christmas Research Appeal.

I enclose a cheque/postal order (made to out to ASBAH) for £ ______

Name ____________________

Address ____________________

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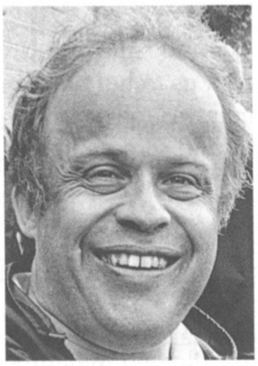
Every donation will receive our grateful acknowledgement

30th ANNIVERSARY

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Tribute to David Stacey



by George Earl
Somerset ASBAH Committee

DAVID STACEY, aged 37, lived his life to the full in spite of his restricted capabilities. He loved the theatre and went to many shows. Distance was never a problem. London, Plymouth, Bath and Bristol, by train or on Berry's coach were all within range.

The Brewhouse Theatre in Taunton was a regular haunt. My wife and I saw him there many times, and sometimes with his mother. We offered him a lift home, but he would always politely reply 'No thank you.' Only on one occasion when there was a downpour was he forced to abandon his independence and say 'Yes please.'

This brings me to his nickname which David knew I called him: 'Mr Independence.' Anyone who knew David would not dispute this for his lifestyle was, and I quote the chairman of Somerset ASBAH, "An inspiration to those who sit back and say 'Woe is me'."

David was the vice-chairman of Somerset ASBAH and had been a member of the committee for 10 years. He offered many gems of wisdom without speaking for the sake of hearing his own voice.

David was also a member of the national Council of ASBAH and Your Voice in ASBAH.

David spent many Saturdays over the years with a tin on his knee collecting money throughout Somerset for a number of charities.

In 1984 his efforts included competing in the Taunton Half Marathon. I offered to accompany him but because of his speed, the only way I could keep up with him was to use my Honda 90 motor cycle. It was at this time that I learned how well known and liked David was in Taunton for his sponsorship forms must have had the names of staff from over half the shops in the town, which included all the girls from the TSB.

The National Trust was another of David's interests. He was a life member of the local support group, The Quantock Centre, which ran outings all over the country, very much enjoying the various gardens.

David led a very full, active and independent life and this was in spite of his medical problems which often resulted in difficult and traumatic periods in hospital. I feel David can best be summed up in these words by Tennyson:

"That which we are, we are,
Made weak by time and fate, but strong in will,
To strive, to seek, to find and not to yield."

Falling for ASBAH

EIGHTEEN-year-old Katherine Marsh and confidence-building course instructor Kathrine Connery celebrated their birthdays by falling out of a plane for ASBAH.

Both received the tandem parachute jumps as birthday presents.

Katherine Marsh, from Cambridge *(pictured right)*, decided to help ASBAH after visiting her aunt – who has spina bifida – in Canada. Her aunt is a professional pianist and plays for the Canadian National Ballet School.

She raised £323.00, including £200 from Midland Bank.

Kathrine Connery, a trained therapist and mother-of-two from Salisbury, Wiltshire, has spina bifida which restricts her mobility.

Her brother Peter, a former member of the Parachute Regiment, talked Kathrine into making the jump and presented it to her as a 37th birthday treat.

"I've always believed in mind-over-body experiences but this is ridiculous," said Kathrine, whose biggest test so far was a 150ft abseil down a cliff face in Wales last year. "I'm hoping to get lots of sponsorship because there is no way I would want to let my supporters down."

Children's book from down-under

A CHILDREN'S book about what it is like living with disability has been written by a 13-year-old boy with spina bifida in New Zealand.

Marty and his Red Wheel Chair, by Marty Van der Kley, has colour pictures on each of its 24 pages.

ASBAH members can obtain a copy of the book by sending a cheque for £6 (including postage) to: ***Jim Fenton, 4 Northway, Shavington, Crewe, Cheshire, CW2 5AR.*** Allow five weeks for delivery in case more books have to be ordered from New Zealand.

Disabled drivers can now teach

BUDDING driving instructors with physical disabilities are now being considered by BSM.

The applications have been received following the Department of Transport's (DoT) revision of the Driving Licence Regulations. Under the new ruling, disabled drivers who are licensed to drive an automatic vehicle will be able to apply to become Approved Driving Instructors (ADIs).

Before qualifying as an ADI, a disabled person will, however, be required to pass an assessment, showing that he or she can take control of a vehicle in an emergency situation.

BSM's mobility consultant Keith Cameron welcomed the DoT's decision to alter the definition of 'qualified driver' within the Motor Vehicles Regulations as it has opened up a new area of employment for people with disabilities.

The country's largest driving tuition services organisation, BSM has specialists who teach people of all ages with a wide range of mobility problems in its 153 branches throughout the UK.

"As a result of the DoT's decision, I think we will see an increase in the number of people with disabilities who seek advice about learning to drive, because disabled instructors will not only lead by example, but disabled learners will be able to choose instructors who can empathise even further with the kind of problems they experience," said Mr Cameron.

"We are therefore very keen to include disabled instructors within our network of BSM mobility specialists."

Appreciation of Alison Martin 1959-96

By Brenda Sharp, secretary of South Wales ASBAH

South Wales ASBAH recently lost a long-standing member – Alison Martin, who has also been a trustee since 1989.

Alison attended Ysgol Erw'r Delyn School in Penarth and was a strong supporter of the Old Scholars Association. She was also a founder member of the Barry Breakaways Club.

Despite severe problems in her later years, Alison was determined to live an independent life in her bungalow and continued to battle with authorities to obtain the facilities and equipment she needed.

At the last SWASBAH meeting Alison attended she proudly introduced us to her new friend and helper, Joseph, a 'dog for the disabled' and said he had 'changed her life.'

John Lewis, chairman of SWASBAH, said: "Alison was a spirited fighter who never accepted that her disability should be allowed to hamper her progress through life nor her enjoyment of it."

We will all miss Alison and send our deepest sympathies to her family, friends, Darren and all those who were uplifted by contact with her courage and determination.

Keeping fit and feeling great

FIFTEEN service users aged between 12 and 16 went home feeling fitter, healthier – but perhaps a shade tired – after taking part in ASBAH SE Region's 'Keeping Fit and Feeling Great.'

The teenagers signed up for the two and a half day course at the Guttmann Sports Centre, Stoke Mandeville in Aylesbury to try out new activities and think about healthy eating.

Basketball, swimming, keep fit, netball, other ball games and track events were just some of the sports on offer. Aerobics teacher, The Rooster, led a fun session of rough and tumble with huge, soft, orange balls.

The Body Shop from Aylesbury did a toiletries and make-up demonstration and there was a healthy eating game and a slot on personal hygiene.

A disco and other activities such as table tennis were available in the evenings.

Denise Taylor, secretary for SE Region, said: "Everyone said how much they enjoyed themselves and would like to do it again"

Pedalling 80 miles a day for ASBAH

DEVON builder Jonathan Treadaway pedalled from Land's End to John O'Groats and raised £520 for ASBAH.

Jonathan, aged 30 from Newton Abbot, cycled 80 miles a day over 13 days, with no back-up and stayed at youth hostels en route.

He chose ASBAH because of his friendship with The Anchor Café owner Barry Messenger, who has a 13-year-old daughter Claire with hydrocephalus.

Barry, who runs the café in Plainmoor, Torquay, said: "I've done a lot of fundraising and Jonathan asked me which charity I'd like to nominate and I said ASBAH."

REPORTS FROM ASBAH'S 30TH ANNUAL GENERAL MEETING

New wheelchair schemes

THE NEW wheelchair voucher and powered wheelchairs schemes were the subject of a talk by guest speaker Mrs Patsy Aldersea at ASBAH's 30th Annual Meeting.

Mrs Aldersea is wheelchair project officer at the College of Occupational Therapists, and author of the Department of Health 'Aldersea Report' on wheelchair services.

On 23 February 1996, Ministers announced £50 million for wheelchair services over a four-year period to provide in England:

1. Indoor/outdoor powered wheelchairs, and
2. A voucher scheme.

Initially, the voucher scheme is intended to apply to manual wheelchairs only. Over the first year – £6 million will be allocated to powered wheelchairs; £2 million to the voucher scheme. After four years both schemes become part of the NHS budget.

Some 701,000 people currently use NHS wheelchairs but there are others who get their chairs from sources such as education, employment, private purchase, charities and insurance.

Under the new rules – the National Health Service (Wheelchair Charges) Regulations 1996 – NHS wheelchair users will have the following options:-

1. Accept the prescribed chair.
2. Be given a voucher for a 'partnership scheme' in which you are given an identified range of chairs and have to pay the additional cost. The NHS will still own and maintain the chair.
3. Be given a voucher for a wider choice of chairs, with approval of their suitability from a qualified therapist. You pay any additional cost above the voucher value. You own the chair and are responsible for maintenance.

One cause for concern, Mrs Aldersea said, was the time it is going to take to run the new service. Another problem was the inequality likely to arise in the range of powered chairs available among the 155 wheelchair centres in England, Wales and Northern Ireland. Guidelines have been drawn up for purchasers by the Department of Health but these do not have to be followed.

The criteria for a person getting a powered wheelchair are:

- Unable to propel a manual wheelchair outdoors.
- Able to benefit from the chair through increased mobility and improved quality of life.
- Able to handle the chair.

Applicants will be assessed by a qualified therapist who will say what type of wheelchair is suitable.

Chair users will be given insurance for breakage but will be expected to take out their own third party insurance (ie in case they injure another person).

ASBAH information officer, Gill Winfield, attended an informal discussion about the guidelines for the new NHS Wheelchair voucher scheme at the Department of Health (DoH), so was able to provide up-to-date information.

Mrs Winfield said: "The Department of Health is very keen to get it right for disabled people. It wants to hear from users."

The DoH has produced a leaflet about the schemes, available from ASBAH's Information Department.

Mrs Winfield added: "If anything goes drastically wrong with the wheelchair you have purchased under the 'independent option' and you are unable to get it repaired or replaced, then the DoH assures us that there will be a safety net. The NHS would, under its duty of care, ensure that no one is left with their basic needs unmet and you would be able to get a wheelchair from them."

£70,000 end-of-year surplus

HONORARY Treasurer Charles Ortner reported that ASBAH had a surplus of just over £80,000 for 1995-6 which was satisfactory.

This was largely due, he said, to managers keeping within their budgets and fundraisers' unstinting efforts.

He said he was sure that at next year's annual meeting he could give some good news of new income.

Nearly half-way through the current year, he could report that legacies had again contributed more than expected, and that telephone sales were doing well.

Mr Ortner said: "It looks like there will be a surplus at the end of next year and if this continues there could be some expansion."

Computer Sense Ltd (CSL) was now regularly turning in profits – at the end of last month it had wiped out half the losses made in the company's early years.

Mr Ortner looked forward to the time when CSL was making significant contributions to ASBAH.

REPORTS FROM ASBAH'S 30TH ANNUAL GENERAL MEETING

A BEAUTIFUL piece of framed embroidery by Your Voice member Christine Helliwell **(pictured left)***, and an impressive gavel and stand, carved by former ASBAH administrator Bob Wilson, were presented at the Annual Meeting.*

Although unable to be present herself, Christine sent a message of thanks to the meeting, read out by Chairman Mr Godfrey Bowles.

Christine said the sampler had been made as a small thank-you to the staff and volunteer workers for the work they had done. She said: "It's hard to put into words how much what you do means to us."

The gavel and stand, made of old English Oak as a farewell gift due to Mr Wilson's forthcoming retirement, were used by Mr Bowles to open the meeting.

A year of achievement

EXECUTIVE director Andrew Russell reported a 'very positive' year for ASBAH.

He remarked that over 30 years the role of charities had changed – that they were now respected for their expertise.

ASBAH continued to speak out not just *for* disabled people but *by* disabled people. It was vital, he said, that charities remain "stroppy" and keep independent of government.

In services, the aim was to obtain proper provisions for people and work with authorities, trusts and schools, and see services deployed and to resist any trend to retreat from state-funded services for disabled people.

Mr Russell said: "The 1990s have not been an easy time for charities and ASBAH has had to work hard to increase our income."

This meant we had been prudent in expansion, although we were half-way towards creating eight regions.

ASBAH continued to look to local authorities and local associations for funding. The amount from local authorities rose to £67,000 last year.

There was now a Bristol-based adviser and an education adviser based in Northern England. Thanks to money from Health and Social Services, there was now an adviser in Lincolnshire.

Mr Russell said: "As well as our ongoing fundraising with trusts and companies, we are constantly looking for particular grant-giving schemes to which we target specific bids, to build up our services."

This had occurred in Northern Ireland (DHSS); Wales (Comic Relief); Welfare Grants and training events for children (Children In Need) and the 'Towards Womanhood' course (EU Helios programme).

START had carried out detailed individual assessments for a variety of customers and had put on courses on independence training and parenting skills.

ASBAH had been consulted on a number of issues at national level including: giving evidence to the Commons Select Committee on Child Health; efforts to get more folic acid into the diet through fortification of bread and health information on food packaging; how much access charities should have to the criminal records of recruits; the Schools Access Initiative; the effectiveness of the Education Code of Practice on Special Educational Needs, and the Tribunal system; and the importance of further education to disabled young people.

On the publicity front, Mr Russell highlighted the folic acid campaign and our 30th Anniversary, with special mention of our high-profile 30th Anniversary Conference.

The publication of a series of advisory leaflets for teenagers on a range of sensitive subjects were another important feature of our 30th Anniversary Year.

Executive elections

THERE were seven re-elected retiring and new members of ASBAH's Executive Committee.

Austin Crowther, Katrina Grounsell, Brenda Sharp and Bob Ithell were re-elected following retirement.

Jane Franklin, Kevin Towner and John Hawkshaw were elected to the Executive as new members.

Dr Martin Bax has resigned from the Executive Committee for 'technical reasons.'

REPORTS FROM ASBAH'S 30TH ANNUAL GENERAL MEETING

A charity with 'whizz'

SEVEN years ago Michael Dickson had never given a thought to the fact that some children find it difficult or impossible to get around. Now he's the chief of a highly successful charity which has raised millions of pounds for mobility aids for more than 1,000 children.

Mr Dickson told the remarkable story of how Whizz-Kidz grew from a 'bit of a jolly' to a major charity at ASBAH's Annual Meeting.

He raised a lot of laughs as he described how his fundraising future started when he was challenged to run the London Marathon at a drinks party. The laughter turned to poignancy as he described his meeting with a little girl in Lincoln, who desperately needed a mobility aid.

Although running was not his strong point (he took more than six hours to complete the marathon), fundraising obviously was – he raised £9,000, more than enough to buy Sammy the mobility aid which changed her life dramatically. He started Whizz-Kidz in 1990.

Mr Dickson said: "Last year we raised £1.1 million, this year £2.2 million and it's all done by 10 people: six people raise the money; three people look after the children, and me. We have open plan offices in central London. It's a very enthusiastic place to work because there is a happy ending."

Kate Organ, mobility manager for Whizz-Kidz, described how children under 18 with any type of disability could apply for a mobility aid from Whizz-Kidz. Most applicants have cerebral palsy. Ten per cent (129) have had spina bifida. The average amount spent on each aid is £2,000; the most expensive has been £12,500.

Types of aids supplied range from trikes to buggies as these may not available from wheelchair services. Light manual chairs and sports chairs are also supplied.

The question of how an applicant's need is assessed was raised by Alison Walter of Northants ASBAH. She asked: "How much investigation does Whizz-Kidz do to find out if a chair is suitable? A lot of children don't need the most expensive chair."

Ms Organ replied that the number of cheap aids issued by Whizz-Kidz was increasing but there were cases where expensive equipment was best for the child.

"A child doesn't *need* to play basketball or reach a tin of baked beans from the top shelf by using an elevated wheelchair, but their quality of life will be improved. "

Paperchain appeal

Whizz-Kidz has re-launched its Paperchain Appeal which raises money by people taking their glossy paper junkmail and greetings cards to white recycling bins. The bins are positioned at selected Gateway, Safeway, Sainsbury and Somerfields stores. Stewards and Crazy Prices in Northern Ireland.

Darke at the Cinema *by Paul Darke*

AMPUTEES are in vogue at the moment in big Hollywood comedies. Apart from the obvious example of the lower limb amputee 'Nam Vet' in *Forrest Gump* (Gump's best mate in the film) we have had two more comedies that feature upper limb amputees: *Kingpin* and *Happy Gilmour*. The first is a film about ten pin bowling and the latter is a golfing comedy (not that I ever found golf funny; boring, yes).

In *Kingpin*, Woody Harrelson (of *Cheers* fame) is the new king of the bowling alley until he loses his arm and turns to drink. His life as a failure is marked by one bad joke after another, with possibly the most gross joke, about sex and a bowel evacuation (at the same time), ever made as the epitome of life as an arm amputee failed ex-bowling champ. His surname, in a touch of comic genius, is used by the others as a by-word for all that implies pathetic failure in the world of the 'American Dream'. I loved it!

Happy Gilmour, on the other hand, has the amputee as secondary to the main character. Happy, the name of the central character, is an ice hockey player who cannot skate but has an incredibly powerful shot and needs money to get his granny out of debt, so he takes up golf. He takes advice from a one-armed, ex-golfing pro called Chubby. Chubby has had one arm bitten off by an alligator whilst looking for his ball in the water on the golf course. Chubby's prosthesis is mangled, glued together and re-mangled and no end of comic references made about it throughout the film.

The difference between the two movies is that *Kingpin* is excellent and *Happy Gilmour* is a little weak. *Kingpin* is laughing at life, (if it happens to us it's tragedy, if it happens to someone else it's comedy), because life is funny.

Happy Gilmour is not about the comedy of life but the comedy of seeing the disabled as comic fodder – it is personal rather than about everyone at the same time. That Chubby gets killed (by a dead alligator!) whereas Woody Harrelson's character gets the girl, gets rich and makes a comeback also helped *Kingpin* seem up-beat and better film.

Latex allergy and spina

LATEX allergy and spina bifida – is it a problem to be aware of or just the latest scare story? We try to piece together the evidence and ask why, if latex allergy is a problem, more isn't being done to prevent it by the government and health authorities.

SENSITIVITY to latex (natural rubber) can be a problem for people with spina bifida because of the frequency with which they come into contact with it.

Many healthcare products contain latex so people with spina bifida (and medical professionals) are exposed to it on a regular basis – either during surgery (through the use of latex gloves and anaesthetic equipment) or during bladder and bowel management (through the use of latex tubing, gloves and catheters).

Latex allergy occurs when the body's natural defences against an allergen come into force. It involves the production of antibodies when there is contact with a specific antigen (in this case latex).

Antibodies are produced by the initial reaction to latex which sensitise the cells in all tissues. The severity of subsequent reactions depends on the means of entry of the antigen.

Exposure to latex occurs when products containing rubber come in contact with a person's skin or mucous membranes such as the mouth, eyes, genitals, bladder or rectum. Serious reactions can also occur when latex enters the bloodstream. In addition, the powder from balloons or gloves can absorb particles and become airborne causing reactions when breathed by a latex sensitive person.

The most potent and life-threatening reaction is entry into the vascular system, which can lead to changes in blood pressure and circulation (anaphylactic shock).

Skin contact produces a less severe reaction – this is usually raised, pinkish, itchy weals, which develop suddenly and last a few days, but leave no visible trace.

Research has shown in the United States that between 18 and 73% of children and adolescents with spina bifida are sensitive to latex as measured by history or blood test.

Although widely accepted in the United States, latex allergy is still not considered a problem by authorities over here. This is partly due to lack of research into the extent of latex allergy among patients and medical staff, and partly due to a belief that it is impurities in the latex which cause the allergic reaction, not the latex itself. More is known about latex allergy in hospital staff and dentists than in patients.

But things are changing. The Royal College of Nursing's Society of Occupational Health Nursing (SOHN) did a survey of health departments in 1996 to find out the number of staff with a latex allergy in UK hospitals. These figures will be used to lobby the government and to encourage hospitals to introduce allergy screening for new staff and patients, and to work out how to deal with patients and staff who have latex allergy.

The Department of Health's Medical Devices Agency has suggested that health professionals ask patients about previous allergic reactions to latex. However, some believe nurses should go further and ask patients about any food allergies as the two are cross-related *(see panel on page 16).*

The mother of our case study *(panel, top right)*, says: "George seems an isolated case at the moment. We're fighting for his problem to be recognised. People don't believe it. If he ever had to be adr
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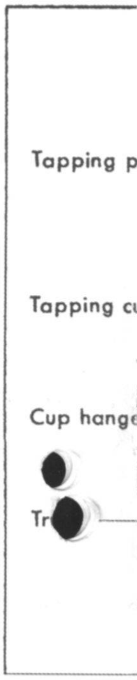

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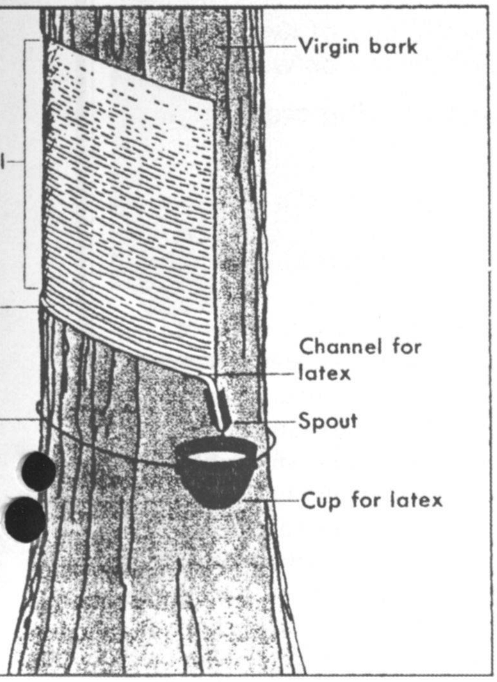
PRODUCTS CONTAINING LATEX

Latex is the sap from the *Hevea brasiliensis* tree. Common household and hospital products containing latex:

Household gloves
Condoms
Wheelchair tyres
Some urinary catheters
Protective sheets
Balloons and rubber balls
Dental dams
Elastic on clothes
Hospital gloves
Condom incontinence aids
Adhesive tapes (sticky plasters)
Some enema tubing
Colostomy/urostomy products
Art supplies
Baby bottle nipples and pacifiers
Beach toys

There are alternative, non-latex products for all of these items. Usually, these alternatives are made of plastic, vinyl or silicone.

bifida – myth or reality?



per tree is tapped for its latex

**MBBS, FRCS, Consultant Paediatric
geon and member of ASBAH's
dvisory Committee, writes:**

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rubber and should avoid contact with rubber products, particularly during medical or surgical procedures.

In addition, it says people who have experienced allergic reactions during surgical or medical procedures should consider wearing a medic-alert bracelet or necklace. The Spina Bifida Association of California issues medical alert cards stating that spina bifida patients often have a severe allergic reaction to latex.

GEORGE – A CASE STUDY

"OUR 15-year-old son George *(not his real name)* has spina bifida, but no hydrocephalus, and is walking. Over the years he has had problems with his bladder and bowels. So far, he has had five operations.

"He first had problems, possibly with latex, when he was about six years old. When he came home from school one day, his face started to swell, his nose disappeared and his eyes were like tiny slits. I rushed him to our GP who wanted him to take medication daily (I think some sort of anti histamine). The doctor said it was the worst case he had ever seen. I gave him the medicine but as the weeks went by no other attack followed. As he was already on permanent antibiotics I felt uneasy about so much medication and eventually stopped giving it to him. From then on, about 2-3 times a year he would have swollen watery eyes, feel unwell and sometimes his face would swell, but never as badly as the first time. We started to think of hay fever, but our GP thought it was not worth having him tested. We started to suspect latex when we bought him a latex mask at the seaside. He wore it for a short time before we realised his face was red and swollen.

"When George was about 14, after a dental examination, he came out in red blotches, swelling and blisters around and in his mouth. The next visit, very soon after, was worse. He then had the same symptoms but also could not breathe properly and had pains in his chest.

"At this stage I insisted that he was tested. He was diagnosed as latex alllergy Type 1 at Hope Hospital, Manchester. The skin prick test also showed a very small reaction to pollen.

"Since then he has had two reactions, once when he had to leave a hospital where he was visiting a patient because his eyes were very sore and watery, and recently he came home with sore, watery eyes and also breathing problems and chest pains."

ASBAH SURVEY ON LATEX ALLERGY

Child's name ______________ **Date of birth** ______________
Address ______________ **Disability** ______________
____
Telephone ______________ **Parent's name** ______________
When and how was latex allergy diagnosed? ______________
____
How does it affect the child / symptoms? ______________
____
Does the child have any other allergies? ______________
Does anyone else in the family have a latex allergy? ______________

Please cut out or photocopy completed forms and send to Rosemary Batchelor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.

P L May on latex allergy, continued from centre pages

the form of skin rashes or more serious manifestations of sensitivity. In 1991 this incidence was reported to the FDA to be somewhere between 18-40%. It was noted by the American workers that children appeared to be particularly at risk of hypersensitivity with this allergen.

The Medical Devices Agency in the United Kingdom has been monitoring the subject of latex allergy for several years because of concerns raised by American reports of increased incidents of latex allergy among healthcare workers and certain groups of patients. At the present time there are no authoritative statistics which indicate the extent of the problems in the UK healthcare setting or in the general population.

From our own experience in the Royal Liverpool Children's Hospital over the last six months we have documented at least one episode of a major hypersensitivity reaction in a young female patient with spina bifida undergoing corrective spinal surgery. The condition was recognised and she has made a full recovery.

The increased incidence of this sensitivity is thought to be related to the general increase in the use of latex products, particularly gloves, by healthcare workers and also to the incorporation of tube products with a higher latex content. Patients with neural tube defects and congenital urogenital abnormalities seem to be particularly at risk probably because of the increased number of surgical procedures they are exposed to involving equipment containing latex. Latex is present in many different types of material within the operating theatre set-up including surgical gloves, urinary catheters, surgical drains, disposable syringes and IV fluid giving sets.

Latex itself is a cloudy white liquid which comes from a rubber tree, *Hevae brasiliensis.* Once the liquid has been tapped from the tree, chemicals are added to it which provide the strength, elasticity and dimensional stability characteristic of many rubber products. Natural rubber latex is therefore composed of proteins and added chemicals, some of which would be removed during the later stages of production. The reactions that can occur in an allergic response to latex can range from mild irritation of the skin to more serious general manifestations of anaphylaxis or major shock.

In this country it is clear that more work needs to be done to identify the potential problem so that we can reassure our service users involved in repeated forms of surgery. This also involves increasing awareness among healthcare professionals as well as those service users susceptible to latex hypersensitivity. There are at present tests which are freely available to assess the sensitivity of the individual to latex, the commonest of which, I believe, is the RAST test which is a blood test. It is also possible to perform skin testing to latex allergy.

It is clear that more work needs to be done before we are able, in this country, to give a clearer picture of the true incidence of this apparently relatively rare event in service users undergoing frequent surgical procedures in the UK.

FOODS WITH A CROSS-REACTIVITY TO LATEX

RESEARCH has shown that proteins found in certain foods show similar immune system reactivity to the proteins found in latex.

So, if your mouth itches when you eat any of the foods listed below, you could be allergic to latex as well.

Foods which have been identified as having cross reactivity include:

Bananas
Avocados
Kiwi Fruit
Potatoes
Tomatoes
Mangoes
Chestnuts

MAKES OF LATEX-FREE PRODUCTS

Continence sheath – *Clear Advantage* from Depuy Healthcare. Freephone 0800-590916.

Condoms – *Naturalamb* from Lamberts (Dalston) Limited, Dalston House, Hastings Street, Luton, Beds, LU1 5BW. Tel: 01582-400711. Fax: 01582-400646. This is made of a non-latex natural membrane which will help prevent pregnancy but does not protect against HIV infection (AIDS) and other sexually transmitted diseases. Natural skin condoms can be worn under latex condoms (if male is sensitive to or at risk from latex) or over latex condoms (if female is sensitive or at risk).

Disposable gloves – *N-dex Nitrile EMS gloves* from Sentinel Laboratories Ltd, Mitchell House, The Mardens, Crawley, W Sussex, RH11 0AQ. Tel: (01293) 526457. Fax: (01293) 517870. Contact: Brian Smith.

A list of more household and hospital products made from latex and suggestions for latex-free alternatives has been produced by the Spina Bifida Association of America. Copies are available from: Rosemary Batchelor, Co-ordinator, Specialist Advisers, ASBAH, 42 Park Road, Peterborough PE1 2UQ. Please enclose an SAE.

Hydrocephalus Network News

WINTER 1996/97

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS
ASBAH, 42 Park Road, Peterborough PE1 2UQ
Tel: 01733 555988 Fax: 01733 555985
Reg Charity Number 249338
Network Co-ordinator: Rosemary Batchelor

THE INSTITUTE of Child Health wants families to take part in a project aimed at finding out the genetic basis of some forms of microcephaly. They would like to hear from families with children affected by the so-called 'autosomal recessive' type of microcephaly. Questionnaires are available from Lynn Thomas, tel: 01733-555988.

Thank-you ASBAH

TWO little girls with hydrocephalus presented a cheque for £605 to their area adviser, Julie Turnbull.

Kylie Pratten, aged eight, did a sponsored tricycle ride and Charlotte Gabittas, aged seven, did a sponsored swim to raise the money.

The girls, who live in Cleethorpes, North East Lincolnshire, do something every year for ASBAH. They appeared on the front cover of the Oct/Nov '94 issue of *Link* magazine doing a sponsored tricycle ride around a local park.

Photo courtesy of Grimsby Evening Telegraph

Kylie's mum, Gill, said: "I would like to thank Mrs Turnbull for her support. It's so nice to have someone to turn to when needed."

Shunt blockage in France – one family's experience

FOLLOWING your article – *Are you insured? Check before you travel* – I thought you might be interested to know of our holiday experience.

This summer we went on a Eurocamp holiday in France. We just took out the usual family insurance and did not feel it necessary to mention our nine-year-old daughter Victoria's condition as she had been free of surgery for six months.

Four days before setting off, we saw her consultant who gave me a letter saying Victoria was fit to travel but she did have this condition.

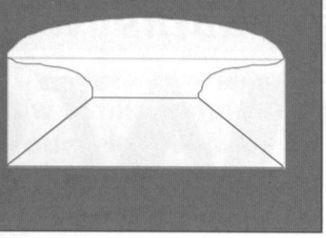
Half-way through the holiday in Royan (SW France) Victoria had headaches and vomiting. We took her to the nearest hospital in Royan for a CT scan but were immediately transferred by ambulance to the neurological hospital in Bordeaux. That evening Victoria had her shunt replaced. After a short spell in intensive care, she was transferred to her own room.

Meanwhile my husband and other elder daughter were booked into a small hotel just five minutes walk from the hospital while I stayed with Victoria. As usual, Victoria made a quick recovery after surgery and just four days later she was allowed to return home to the UK.

The consultant in Bordeaux would not let her do the 24-hour car/ferry/car journey so Eurocamp flew myself and Victoria home to Manchester and then a taxi brought us to the door.

continued on page ii

HN NEWS letters



HAVING read the Spring issue of *HN News*, I was astonished by its contents. I felt the article by Chantel Briody regarding her experience was informative, but in a newsletter which is read by people with hydrocephalus and their relatives, it portrayed a very pessimistic point of view and would put the fear of death into anyone.

I was diagnosed as having hydrocephalus at six months old. Since then I have had shunt renewals and each time I have had the best standard of hospital care. At six months and six years old I wasn't really old enough to remember much about what happened, but it was only last April that I had to get a new shunt fitted because I had outgrown the previous one and it became blocked. At the time I was sixteen and although I was older I still felt quite apprehensive but my hospital stay was very comfortable and the staff were extremely caring and efficient.

Throughout my life with hydrocephalus I have lived a very normal life. Although I have been perhaps a little slower at things such as Maths I have never let it hold me back.

I have been to mainstream schools and gained standard grades at a general level. I was awarded a place at Edinburgh's Telfors College and I started an NC in Office Technology in August.

I decided to write my experience to show that you can lead a normal life and that having hydrocephalus is not a problem, it's a challenge.

Kirsty Service
South Queensferry, Edinburgh

I AM the proud mother of a four-year-old son who has hydrocephalus caused by a polercephalic brain cyst. My son's condition was detected when I was three months pregnant with him.

Before he was born, the outcome of his arrival into the world was very bleak indeed. Well, I can assure you that all is not bleak.

My son attends a nursery school that caters for mainstream as well as special needs children. He is an inspiration to us all. He is bright, happy and so very clever that we think he has been here before.

If I had believed all that I was told by the so-called specialists, then my son would not be with me today.

Although my son has certain needs and problems, these are far out-weighed by the joy and love he showers on us.

So if you, like us, have a child with whatever extent of hydrocephalus, do not give up hope. There is always light and love at the end of *any* dark tunnel.

Mrs M Pitts
Beckton, London E6

Shunt blockage in France – one family's experience

continued from p i

During the four traumatic days in Bordeaux we were in constant touch with Alpha Assistance which covered the medical insurance and Eurocamp sent down from Royan a courier to act as an interpreter. The treatment Victoria had at the hospital was superb and their quick reaction to the situation, ie treat now, sort out payments later, was excellent.

To this date we have not had to pay for any hospital bills. I dread to think just what our final bill would have been – probably into tens of thousands!

Victoria has now fully recovered. However, the whole experience has left us feeling that, although life has to go on as near to normal as is possible, we will not dare to go abroad for some time, and I don't think Eurocamp will want to hear from the Keelers again!

Mrs Ann Keeler, Sheffield

Under pressure

Fiona J Rowe explains Benign Intracranial Hypertension in response to a number of inquiries on the subject to ASBAH Services staff

Fiona Rowe DBO, CGLI Teacher's Cert, is senior clinical teacher and research orthoptist at Addenbrooke's Hospital in Cambridge. She is responsible for the clinical placements of students in the orthoptic department and in addition undertakes the post graduate teaching of ophthalmologists and other health professionals. She has many research interests relating to clinical practice, her current primary project being the assessment of visual function in benign intracranial hypertension.

What is benign intracranial hypertension?

Benign intracranial hypertension, (sometimes called idiopathic intracranial hypertension or pseudo-tumour cerebri), is a rare condition in which there is raised intracranial pressure without evidence of a tumour or other intracranial disorder. The patient is alert and healthy but usually aware of symptoms relating to the raised pressure, most commonly headache and disturbed vision.

The incidence of the condition is 1 or 2 persons in every 100,000 and most frequently affects females and only occasionally males. The usual age of occurrence is mid-twenties but has been reported in children and later generations.

What causes this condition?

The cause is unclear but three factors are implicated:

1. An abnormality in absorption of cerebrospinal fluid thereby leading to a build up of this fluid.
2. Increased blood volume around the brain with a secondary rise in cerebrospinal fluid.
3. Swelling of the brain.

The condition may be due to any one or a combination of these factors.

How is the condition investigated?

Patients are usually reviewed in both Neurology and Ophthalmology (Eye) departments. Investigations include lumbar puncture to measure the degree of raised intracranial pressure and brain scans to exclude obvious intracranial problems which would cause raised pressure.

As loss of vision may occur with this condition, routine follow up in an Ophthalmology department is recommended which enables assessment of vision and the peripheral field of vision in each eye.

What does management involve?

The management varies according to each patient as individual responses to the various treatments available must be responded to. Water reduction tablets may be used as part of the medical treatment and Acetazolamide (Diamox) is most prescribed. Where raised intracranial pressure persists, a lumbar shunt may be inserted to divert excess cerebrospinal fluid into the abdomen and therefore relieve the raised pressure. In circumstances where loss of vision has occurred despite the use of a shunt, an operation involving the nerve at the back of the eye may be considered. This involves making a slit or opening in the outer layer of the nerve to allow excess cerebrospinal fluid to drain away from the nerve.

Complications of treatment usually relate to blockage of a shunt or to infection of the shunt. This requires further operation to adjust or replace the shunt and with infection, antibiotics are necessary.

Patients with benign intracranial hypertension are frequently overweight and calorie-controlled weight loss is recommended under the guidance of a dietician or the patient's general practitioner. This benefits the patient.

The final outcome for patients with benign intracranial hypertension is considered very good. There are, however, some for whom management proves more difficult.

Life with Benign Intracranial Hypertension

Donna Draper with her dog Ikka

IT IS now five years ago since I came home from my holiday in Greece and was subject to a violent bout of viral meningitis. I recovered well only to be left with a permanent headache and morning sickness!

For two years I was treated like a hypochondriac and told it was 'migraine, stress, depression, teenage tantrums,' you name it, I was told I had it. Gradually my sight became affected with double vision and photophobia and I began having blackouts. As time progressed so did the collapsing episodes until I ended up in Addenbrooke's Hospital where I was finally diagnosed as having benign intracranial hypertension (BIH).

I was fitted with a lumbar peritoneal shunt but had a whole range of problems with blockages and over drainage. I was eventually fitted with a cysternal shunt which for nine months transformed my life. I was back to my old self, fit, healthy and headache-free. But it was too good to last. The CP shunt began blocking intermittently so a revision back to an LP shunt was made which gave me a further eight months of 'healthy' life! But the over drainage problem re-emerged and I am currently undergoing further treatment to rectify this.

Three years since diagnosis and 24 operations later, my experience of BIH has been very frustrating, frightening and tough but I am very aware that the outlook for the majority of patients with BIH is extremely good and I hope in a couple of years' time I will be able to put this experience behind me.

Having wonderful friends, an ever-supportive family and an extremely understanding medical team have been the key ingredients to an ever positive attitude and has provided me with the strength to carry on my life and fight this condition!

Donna Draper
Little Yeldham, Essex

What's in a name?

I'm angry, cross, annoyed
At a very misguided man
The one who names diseases
With inappropriate, ill suited titles.
Benign Intracranial Hypertension is the label
That doctors place on me.
If I met that man face to face
I would demand that he justify that name.
And tell me what's benign:
I find the word an insult to my suffering.
It implies it's OK, harmless, curable,
Slight, superficial, easily treatable.
I know it's not life-threatening
In a mortal sense,
But it's killing my living.
I haven't worked for months
In the job I love,
Had countless lumbar punctures
And needles in other parts.
Operations with tubing and valves
Inserted in unsymmetrical patterns around my body.
Symptoms too numerous to list.
My marriage is under constant strain
And my children suffer,
That really hurts.
Will I be home next week or not?
I want to get on with living,
Have a routine or normality.
Yes, I'm angry all right.
What right did he have to label all this benign.
I have a right to be exasperated, infuriated
With his lack of imagination and understanding.
Surely he could have come up with something,
Something just a little more grand,
Something to portray my distress,
To evoke a little understanding in people standing near,
To induce a little sympathy for me.
Come on someone please,
Start now with this disease
Let's have a renaming ceremony,
But please, remember, invite me.

Liz Galfskiy
Winchester

Tuppence for me

Learning to walk at physio group in Motherwell, aged two

THE FIRST IN A TWO-PART SERIES BASED ON THE AUTOBIOGRAPHY OF **JON WILSON**, A MEMBER OF THE SCOTTISH SPINA BIFIDA ASSOCIATION

THE THING about being a twin is you see what the other is doing and want to copy. But it didn't take long before I realised this was not going to be easy.

My first attempts at moving around unaided were those of 'swimming' across the carpet and stretching up to shelving made by my father for my toys. He also made wall bars in the living room for me to hold on to which enabled me to try and pull myself upright.

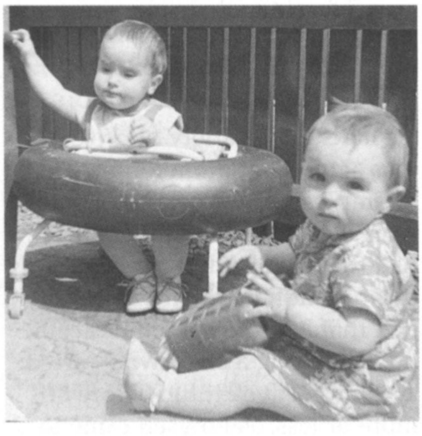
As Donald developed, I continued to follow. This became gradually harder to do, but I was determined to keep up. I was put in a baby-walker with my weak legs touching the floor. An inflated inner tube was placed round the walker to protect me from injury as I tried to make myself move by leg power.

In an attempt to learn to balance myself upright, I remember my mum putting a rug outside the back door and propping me up against the wall. I would collapse down on to the rug and then get up again to lean against the wall. At the same time, dad made a tiny pair of crutches for me. With these I learned to move forward and let my legs, which were pretty useless, drag along.

Soon I was wearing knee-length callipers and using crutches. A wheelchair too was part of my aids and appliances and at first I was very enthusiastic about wheeling myself about, but later on I could be lazy and expect to be pushed.

At some stage I thought I could walk without using crutches. I imagined I would then be seen to be the same as everyone else although in the end the manner of my walking probably made me stand out even more. But I was determined to try. I soon saw that once I started moving there was no way I could stop without leaning on someone or standing by a wall. Also my back ached and the distance covered was minimal. In

continued on page 22



Jon and Donald, aged one. Dad's idea for encouraging Jon to move safely

JON WILSON was born one of twins on 16 April 1964. There were already three brothers and two sisters in the family and the twins were an unplanned pregnancy.

The boys – Donald and Jon – were born at home but on finding that all was not well with Jon, both babies were taken to the local hospital. Donald was returned home in a day or two with Jon transferred to the Royal Hospital for Sick Children in Glasgow.

Such was the introduction of 'lumbar myelomeningocele and hydrocephalus' to the family which started Jon's father (a pharmacist) and mother (a former medical secretary) on a quest for more information.

At this time in Scotland the number of babies born with spina bifida had reached a high level. The hospital asked Jon's mother to found a counselling group for parents and by 1965 this had developed into the Scottish Spina Bifida Association. Elsie Wilson was awarded the MBE in 1987.

In 1981 Jon was nominated by his school for a Junior Disabled Scot of the Year Award. The scroll speaks of 'determination to lead as full a life as possible despite severe disability.' Determination, Jon says, is the name of the game!

He says: "What motivates me is to get over problems that stand in my way, no matter what. Eventually the majority of people will have to cross some kind of barrier. The thing to do is to ignore any adverse remarks, get on with life and enjoy yourself."

'Tuppence for me,' from page 21

the end, I discovered that I presented myself better using my crutches and this also meant that I was more independent.

Donald and I had lots of early tests of strength against each other. I used my shoulder strength and he used his skill with his arms and feet.

We got up to mischief together. Now I was fairly mobile round the house, we both kept an eye on what was happening in the kitchen. Once, having been left there for a brief spell, we wanted to know what was on a high ledge which we could not see over. This was part of a cupboard unattached to the wall. We tried pulling ourselves up by using the edge of the work top and the whole lot came crashing down. Fortunately, only our pride was injured as we crawled out from under the mess.

As brothers we eventually settled for just verbally insulting one another on occasion. We are, in fact, the best of friends.

The main points to consider when you decide to try something new is that there will be problems. These can range from balance, mobility, other people's perception of what you can do, and what is the risk to yourself.

There are ways round the problems but most of us have to be very determined as children in being allowed to try new ways.

There is also the lesson to be learned that we have to ease up from time to time and reappraise what, in fact, we are hoping to achieve or, to use a very Scottish phrase, 'you'll scunner yourself and lose heart.' But like King Robert the Bruce's spider, which we were told about at school, 'Try, Try and Try again'.

Having to adjust to bladder management is not simple. From time to time, it was the major hurdle for me, completely blocking out other more serious aspects of the condition. Over the years an immense amount of work went in to protect me from difficulties.

The real breakthrough in bladder management came with my realisation that control of the condition depended on regular attention to detail to ensure urine flow is attended to while still of minimum amount. This can mean a reduced intake of fluid when on outings: to be balanced by corresponding increase in fluids, to ensure proper kidney functioning, when toilets are readily available. Self-discipline is vital in never allowing oneself to be lazy about such attention to detail.

When I was born with spina bifida, the medical profession found itself coping with a large number of survivors of the condition. This led to discussion in medical journals as to whether or not those babies with a severe degree of handicap should be encouraged to live or die. One such article showed the writer's criteria for survival and undoubtedly it would have meant that I would have been encouraged to expire at birth.

In my upbringing, my father, in a sense, was on the outside looking in while my mother was on the inside looking out. When she got upset about some aspect of the need to find alternative ways of dealing with my condition, it was dad who would arrive home, size up the presenting difficulty, and offer fresh ideas.

In our teens, I think that Donald's attitude to me was bound to be affected by me wanting to join in with him. He must have felt this to be a restriction on him. He was a stimulus to me but I must have seemed a bit of a drag. In the house we were good buddies and survived the growing-up spell as outside interests developed.

Left to right: Isabel (Donald's wife), Donald, Elsie, Laura (aged one), Jon (aged 32)

In 1990 I was best man at Donald's wedding to Isabel and what a wonderful day it was for everyone. Mum, dad, Donald and I had nine holes of golf at 6.30am, back for breakfast, into our finery, family members arrived for a snack lunch, before meeting up with Isabel's family and friends for the wedding service and reception.

My teens and early 20s were the ones which required the most determination to accept reality. Sometimes I would imagine myself dashing around like Donald, with an opportunity for a girl to choose me. But what can't be changed leads to acceptance and, as friends now have their own restrictions on their lives with mortgages, tending children, caring for others, this leads to a balance being achieved. Our meetings together are now ones where there is a lot of laughter and sometimes nostalgic talk. All our attitudes have changed.

As I tackled a variety of projects I was aware that mum felt that some attempts might show me up in a poor light. She had to learn that I had to be allowed to face disappointment or embarrassment and that I would sometimes come home looking a bit down-hearted. This protective attitude wore off, more or less, as I myself came to terms with things not always going my way.

Parents of children with special needs: is work an option?

By David Wainwright
Special needs campaign co-ordinator
Parents at Work

ALL WORKING parents will be only too aware of the difficulties of trying to combine employment with raising a family. But for families of children with disabilities or special needs the difficulties multiply, and solutions are more complicated.

Childcare is harder to organise; hospitals, therapists, education departments and other professionals automatically assume that a parent is available during the day; employers can be less than fully understanding of the pressures that parents are under. No wonder that fewer than one in five mothers of disabled children are in paid employment (nearly all part-time) compared to six out of 10 of all mothers!

Parents at Work, which works to support all working parents, is now campaigning to raise awareness of the particular needs of parents of children with disabilities and special needs.

Parents who do manage to combine work with bringing up a child with a disability or special need have done so by making 'the system' work for them; we want to enable more parents to make 'the system' work for them too.

In 1995 a *Parents at Work* survey of about 80 parents identified the need to develop and support a parents' network. We have now produced a directory of parents who want to be in touch with others in similar circumstances, and are publishing a regular newsletter so parents can share their experiences. In May 1997 we will be organising a conference at which parents will be able to meet and discuss their particular needs. A practical handbook on how to balance the demands of working and caring will be available at about the same time.

The parents' network will be vital in informing the campaigning aspects of our work. We will be explaining to service providers about the need to make themselves more accessible to working parents, and informing them about how to do so. We will raise with employers the need to provide more flexible working arrangements, so that parents can meet the needs of their children. And we will be adding our voice to the call for more daycare provision, particularly after school and during school holidays, for children with disabilities and special needs.

Of course, many parents positively choose to stay at home to care for their children, but those who want to work should not be discriminated against, or made to feel guilty. Work can provide a sense of worth, enables parents to maintain their own income, and can provide parents with a welcome break from home and caring. For those who cannot work, particularly if they are lone parents or where neither parent can work, inadequate benefits often condemn families to living in poverty.

The economic and social factors which prevent so many parents of children with disabilities and special needs from working leads to unnecessary hardship and stress, and probably contributes to family break ups. *Parents at Work* aims to banish the assumption that one parent *has* to be at home, and make work a realistic option for all those who want it.

If you want to receive a copy of our newsletter, join the network, or find out more about this project, contact David Wainwright or Janet Mearns at Parents at Work, 45 Beech Street, London, EC2Y 8AD. Tel: 0171-628 3565; fax: 0171-628 3591.

Editor's note: Is it possible to combine caring for a disabled child with earning a living? Send your views to: ***Liz Cawthorne, Link, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.***

Asking the right questions

FORTY of the commonest problems concerning special educational needs are addressed in a new book.

Taking Action – Your Child's Right to Special Education is produced by the Independent Panel for Special Education Advice (IPSEA).

Peter Walker, ASBAH specialist adviser (education), said: "Many parents who are experiencing difficulties regarding assessments, a satisfactory statement of educational need, an appropriate school and adequate resourcing for their child's particular problems would benefit from reading this book."

It is available from: Questions Publishing Company, 27 Frederick Street, Birmingham, B1 3HH, price £13.99.

LOCAL ROUND-UP

Please send your news items to: Liz Cawthorne, Link Editor, 42 Park Road, Peterborough, PE1 2UQ

GREATER Manchester ASBAH adviser Jean Black is pictured above (standing, second from left) with Tammi Gaynor, secretary of Trafford & Salford ASBAH (standing, first from left) at a buffet and games evening for Spina Bifida Week.

The event, at The Newbridge Centre, Stockport, was organised by Jean with Stockport & Tameside ASBAH . It was well attended by families and committee members from the two local ASBAHs.

A small profit raised on the evening was donated towards the costs of a study day in November at Oldham.

5 Grand Avenue's 10th Anniversary

by Margaret White
County organiser, Sussex ASBAH

FRIDAY 13th *can* be a lucky day! It was certainly a happy day for 5 Grand Avenue to celebrate its 10th Anniversary.

Past and present tenants, members of the original planning committee, friends from the Downland Housing Society, staff, friends, SASBAH members, our new vice president Lady Sarah Clutton, all gathered to drink a toast to the past 10 years and more importantly to the future. We had lots of lovely food (most of it prepared by the tenants) and a pale green cake.

The house opened in June 1986 but there was a lot of pre-history to this! It goes back at least to 1981, when the need for a house such as 5 Grand Avenue was raised by the SASBAH committee.

An open meeting held in Chichester in February 1982 attracted people with other disabilities and organisations representing them. A project committee was formed and we met frequently.

The breakthrough came when we met Downland Housing Society. They liked our ideas and got Housing Corporation funding. Then we had to look for a site.

The house was bought in 1983/4 then we had to wait a year until we had received funding for adaptions to the house.

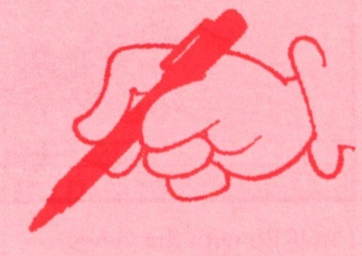
Once the building work and furnishing was complete, staff had to be selected and trained and a Community Programme of helpers put in place. The first tenants finally moved in in June 1986 – a full five years since we started!

We still feel proud of the house. A special appeal was headed by our then president Lavinia, Duchess of Norfolk, and we got a grant of £16,000 from the EEC – no one quite knew how! The Duchess also arranged for Princess Diana to come and open the house officially in December 1986.

Without any previous experience we had set up a major housing project. We had recognised and assessed the need, drawn up ideas for what was needed, negotiated with a major housing society, got funding, furnished a nine-bedroom house, set up a support system through the Community Programme, organised staffing and helped tenants move in. All this was done by a dedicated band of people, supported by the SASBAH Executive Committee and led in the early days by Tony Way. The chairman of the management committee for the last 10 years has been Tony Balsdon.

Ten years on, the house has seen 33 people (in addition to the present tenants) come and live for varying amounts of time. Where is everyone now? Nine are living independently on their own, seven are living with a partner independently, four have moved on to the SASBAH bungalows, eight are living at Downland Housing Trust or St Giles with some support, one went back home (planned), we have lost touch with two, and sadly two have died. A pretty good record for the 10 years.

Did you read about the new ASBAH area and specialist adviser appointments on pages 4 & 6?



Dave's diary

I'VE been reading about plans for 'the paperless hospital.' It's *never* going to happen! I hope not anyway. Who wants their arm removed because some overgrown PC has blown a fuse? Reassuringly, even at the newest hospitals I've been to, no-one has ever heard of a photocopier and I still get asked the same questions (age, address, etc) by three different people for three different forms.

Hospital food has been the butt of many a joke, but even that has changed. As a child I was fed brown 'gruel' but today I am offered a wide selection of dishes from my own personal menu. What a pity then that everything comes back as custard and chips, with turkey sandwiches on Sundays.

On the trip before last I was grateful to take whatever food came because I knew it wasn't going to be for long. I was having things down to my guts and was down for the dreaded 'bowel prep.' Taste requires that I omit the gruesome details of this procedure. Suffice to say that it generally involved a naso-gastric tube into my hooter and large quantities of Go-Lightly, the laxative from Hell, to be poured down my neck. I am ashamed to say that this procedure made even an 'old lag' like me crack up. Only on 'Absolutely Fabulous' could naso-gastric tubes be made funny!

Even today the thought of those wretched tubes going anywhere near my nose is enough to give me the screaming abjabs! And as for the hideously mis-named 'Go Lightly,' if I ever catch hold of the swine who created the stuff I'll fill a bowl with the filthy brew and stick his head in it till the bubbles stop coming up!

You may understand then, that it was actually a relief to go 'under the knife.' Of course the major reason for jubilation was the arrival of the pre-med. Within seconds of consuming the happy pills I was higher than the proverbial kite. Those few minutes justified the whole trip to hospital! Where else but a hospital can you get out of your head legally and for free?

Of course, as I was wheeled out of the ward my head was so happy on this hospital 'trip,' that I gave little thought to my dear (not so) old mum who would be left to wait for me – selfish swine that I am.

Patients, and, yes, perhaps even hospitals, should spare a thought for the poor old relative. If anyone needs doping to the eye-balls, it's them! For days they've popped in or been by your side to mop brows, feed you chocs, keep you up to date on the gossip and generally do the thousand and one things that bring comfort and support to people who are about to have their innards chopped about. Then, once the patient is on their trolley (and off it if the drugs have kicked in), what is there for friends and relatives to do but wait and worry?

In my mum's case she worries so much that she goes into a complete dream-world. The time before last she left the hospital while I was under the knife and wandered off to the local shopping mall. She returned later with the most hideously green slippers I have ever seen in my life. And no idea where or when she bought them! Last time she never even made it to the shops, but bent the car round a car-park post! Talk about keeping your eyes/mind on the road.

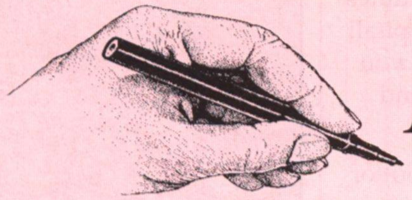
Something must be done! Patients, etc, need a guide book (or something) of hospitals providing facilities and support for those who wait. Write to me, c/o Link, with nominations for hospitals providing support.

By the way, my last trip was to replace a knackered implant. (I was going to put 'bust' but you might have had the wrong idea!). When I asked why it had gone wrong, I was told it was not to do with the machinery, but was *my* fault. Apparently, the bit of me the implant was attached to had spontaneously shrunk (or something), so it came loose. After the *years* I've spent trying to reduce my waistline, to have a part of me shrink spontaneously, a part moreover which no-one but a surgeon is *ever* going to see, well it's just adding insult to injury. I was gutted. And I've got the scars to prove it!

P.S.

Although I lost loads of weight in hospital I'm back on the diet. It is simple maths, really: loads of chocolates in, zero exercise out. Exercise is just not on my list of 'fun things.' So I do the Weightwatchers regime. They have a new one called '1, 2, 3 - success.' I've re-christened it '....4, 5,6 – total failure!' Oh well, back to the treadmill!

David Fulford-Brown



Letters

I AGREE with the views R N White expressed on the difficulty of finding good quality accommodation.

The discrimination does not end with landlords wanting a guarantor. On 1 January 1996 the government introduced measures to decrease the amount of expenditure on Housing Benefit.

In summary, the government has taken away the powers from local authorities to pay above a rent officer's decision in the case of vulnerable groups.

Local authorities now only have the power to pay half the difference between the rent charged by the landlord and the figure set by the rent officer.

The tenant is forced to either negotiate with the landlord, pay the difference or find cheaper alternative accommodation. There is a cash limited 'Exceptional Hardship Fund' which can be administered temporarily.

Indeed, it is ironic that the government is proposing to pass a Disability Discrimination Act to entitle disabled people increased access to goods, services and employment opportunities when it neither knows nor cares that recent Social Policy changes have a severe effect on some of the most vulnerable people in our society. Surely the policy makers should be looking at these problems in a more holistic fashion instead of instigating policies that contradict one another?

Sian Talbot
Poaslack
BN41 1FX

IN RESPONSE to the letter complaining about the wrong use on the television of the term 'water on the brain,' I completely agree.

I have found this problem to lie mainly with the Australian soaps, the most recent examples being *Neighbours* and *Heartbreak High.* In the past, they have used the term casually as a way of meaning that someone was thick or stupid.

My family and I eventually got fed up with it and we contacted the television programme, *Points of View*, but they didn't even have the courtesy to contact us further on the matter.

No one calls anyone a 'spastic' on the television anymore, so why are they still using 'water on the brain' as a way of insulting someone?

Kelly Jenno
Brantham
Essex

DATES FOR YOUR DIARY

7 – 8 February 1997

Scoliosis two-day medical and scientific meeting, open to members and the public, Courtauld Lecture Theatre, The Middlesex Hospital, Mortimer Street, London W1N 8AA. £12 per person per day. *Programme from Pauline Gray, Scoliosis Association (UK), 2 Ivebury Court, 323 Latimer Road, London W10 6RA. Tel/fax: 0181-964 5343.*

20 – 21 March

Independent Living exhibition, Whitchurch Sports Centre, Bristol. *Michelle Boland, Reed Exhibition Companies, tel: 01275-892609.*

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.

OUR son, Alexander, aged 20 months has hydrocephalus. We would like to contact other parents who have children of similar age, or slightly older, with the same condition.

Mr and Mrs Bowmer
Flat D, 11 Barkston Gardens
Earls Court, London SW5 0ER
Tel: 0171-373 6384

THIS poem was wriiten by nine-year-old Jessica Kelly, of Newport, Gwent, following a stay in hospital during which she had surgery for a brain tumour.

When I was in hospital
Anger was my name.
I didn't like the doctors.
When I had a bad day
I certainly wouldn't smile
And my mum would run a mile.
Then the doctors made me better
That's why I'm writing this letter.

I WOULD like a pen friend aged 20 – 30 years old. I have spina bifida and would like a pen friend with the same condition.

I enjoy swimming, going out for a drink and going to the cinema. I also like listening to music.

I work full-time as a receptionist/telephonist at Wrexham County Borough Council. I am 24.

Sarah Capper
13 Worcester Rd, Bangor-on-Dee
Wrexham LL13 0JB

I AM 34 years old and have hydrocephalus alone. I would like to advertise for a male pen friend who has hydrocephalus alone.

Melvin Crutchley
59 Moordale Avenue, Bracknell
Berks RG42 1TB

HOLIDAY ACCOMMODATION

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

NEW FOREST

Fully equipped caravan designed for wheelchair access throughout. Sleeps 5-6. Club house, indoor swimming pool, shop, sited at Bashley Park, New Milton, Hants. ***Contact Joan Searle, tel: 01705-376816.***

ISLE OF WIGHT ASBAH

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

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: 01621-785899.***

MOLD, NORTH WALES

Luxury, wheelchair-accessible bungalow. Sleeps 4/5. All mod cons. Two bathrooms, private south-facing garden. Ideal base. £280 weekly. ***Brochure: Mrs Dowling, 23 Gleneagles Road, Great Sutton, South Wirral L66 4NF (Tel: 0151-339 5316).***

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

MISCELLANEOUS

FOR SALE – Almost new (used twice) Traveller electric wheelchair. Cost £2,500 when purchased. Near offer appreciated. Mrs Rawles, 01323-482797.

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