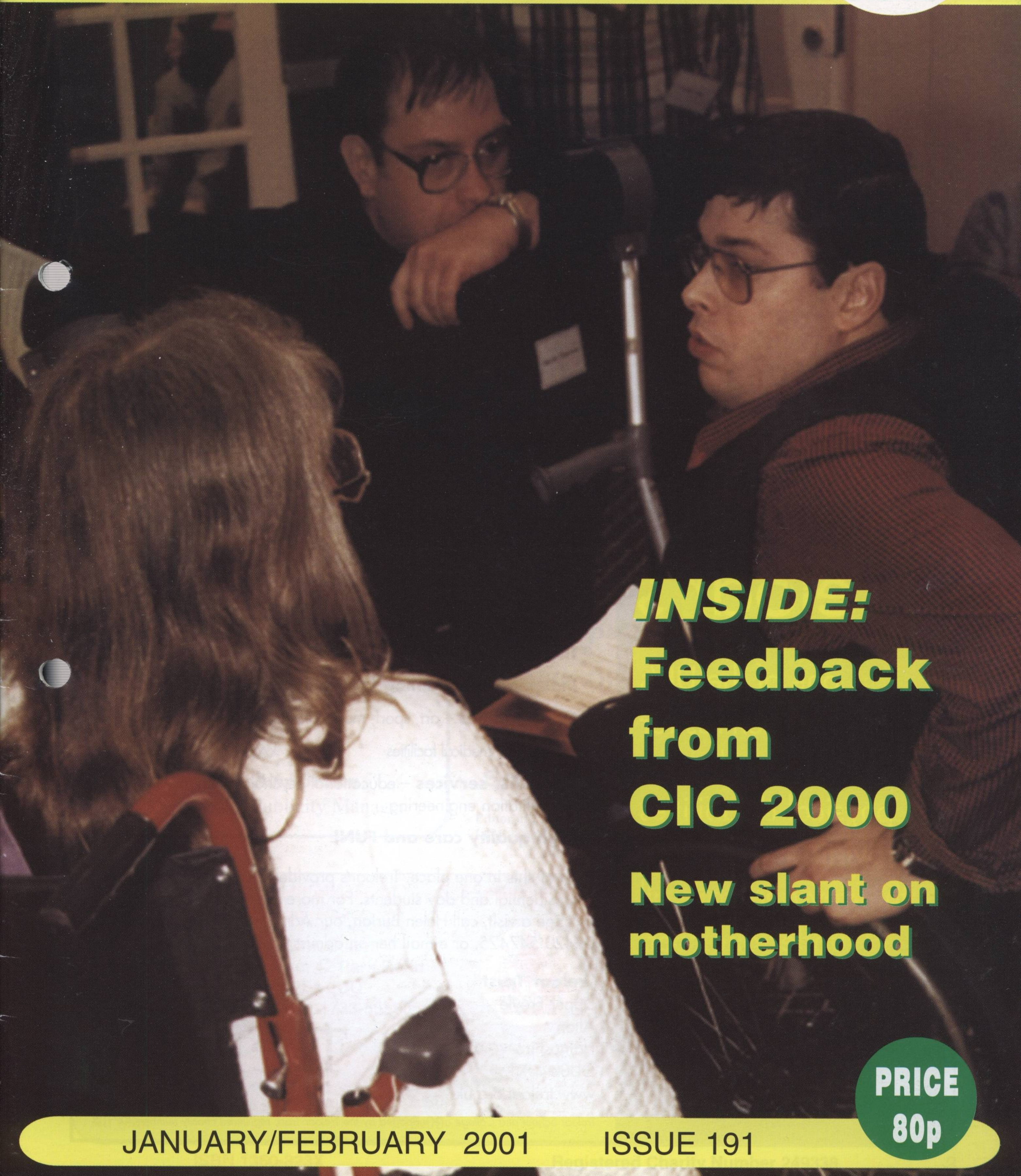
LINK

The magazine for people with Spina Bifida and / or Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS
ASBAH



INSIDE:
Feedback from CIC 2000
New slant on motherhood

JANUARY/FEBRUARY 2001 ISSUE 191

PRICE 80p

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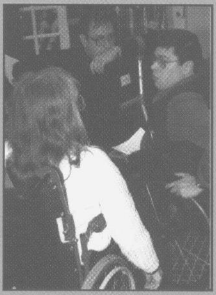


Cover photo: What was so engrossing these three at the Your Voice CIC 2000 conference? Turn to pages 10–11 to find out.

Editorial

Dear Readers

A happy New Year to you all!

Link would like to make it a busy start to the year, too, by giving both parents and people with hydrocephalus and BIH opportunities to communicate your views on matters of importance to key doctors and scientists.

The Society for Research into Hydrocephalus and Spina Bifida wants parents to let them them know what you think of the controversial surgery to repair spina bifida lesions while babies are still in the womb *(see story on opposite page)*.

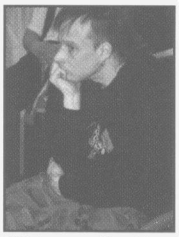
And, if you live near Addenbrooke's Hospital in Cambridge and have hydrocephalus or BIH, doctors there would like to know what it's really like to live with the conditions *(see page 15)*.

Listening to what we really think! It's a good start to 2001. Please do what you can to help.

Tony Britton

Tony Britton
Publicity Manager

contents



CIC ● pages 10 – 11

People ● pages 12 – 13

Babies ● pages 16 – 17

Fundraising ● page 19

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ASBAH exists to provide advice, support and advocacy to people with spina bifida and/or hydrocephalus, their families, and their carers.

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

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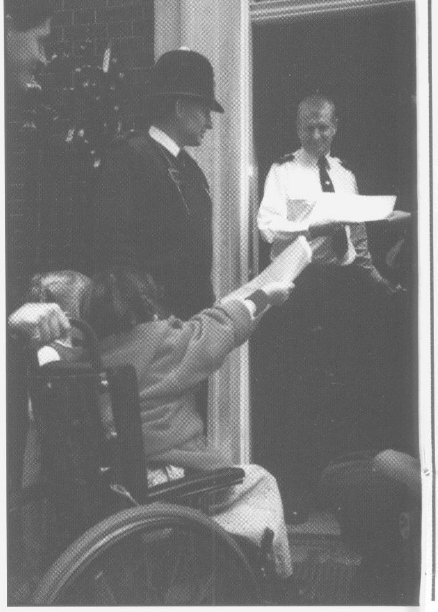
ASBAH hands in letters to No 10



ASBAH joined a lobby outside 10 Downing Street in October. We were among representatives of children with disabilities who asked the Prime Minister to re-think government plans to remove crucial advice on school statements.

Education adviser Petrina Noyes, six-year-old Gabrielle Gibbons *(pictured)* and her mum and dad, Pauline and Tim, joined a delegation from umbrella group Action on Entitlement. The group complained that a proposed new Code of Practice on SEN undermined the long-standing legal entitlement of some of Britain's most vulnerable children to a good education.

Action on Entitlement said the proposed new code watered down disabled children's entitlement to have their specific needs clearly stated in their Statements of Special Educational Needs – legal documents which at the moment help to safeguard rights to a good education. The new code proposes to remove this specificity, but this detail has never been flagged up for debate by the DfEE.

The group, Action on Entitlement, said: "If statements are vaguely written, parents will be unable to judge whether the extra help for their child will be sufficient or approprate, or whether a particular school is able to make the necessary provision.

"The school will be unsure about the help the child needs and parents will be unable to judge whether a school is fulfilling the statement."

The group asked for the introduction of the new code to be delayed for a year so all interested parties can be consulted. They also accused Schools Minister Estelle Morris of back-tracking on a promise not to change the legal framework affecting children's entitlement to education.

● *A grin from Gabrielle as she leaves No 10*

Extra money in the pocket

A £200 million package of extra financial help for carers and disabled people was announced in November.

Three benefits will rise above the rate of inflation. They are:

- **Carer Premium**, increased by £10 on top of the normal uprating – from £14.15 to £24.40 per week.
- A £7.40 per week rise in the **Disabled Child Premium**, paid with Income Support, Job Seekers Allowance income-based, Housing Benefit and Council Tax Benefit.
- **Disability Income Guarantee (DIG)** starting level will rise by £14 to £142 and £186.80 per week for singles and couples respectively.

Disabled Child Premium and DIG will also receive equivalent increases within Working Families' Tax Credit and Disabled Person's Tax Credit.

Keeping it on the RADAR screen

CASH crisis charity RADAR is to merge with the Hampshire-based Enham Trust before April to avoid closure.

The new charity will provide services for disabled people and also campaign for their rights.

The Enham Trust is also planning to merge with Disability Scotland.

RADAR is Britain's leading umbrella charity for disability groups. Enham provides training, employment and accommodation for around 400 disabled people a year.

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LL57 4BL
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Survey for parents on fetal surgery

THE WORLD'S top scientists and doctors in our field are inviting parents to let them know what they think of the controversial surgery to repair spina bifida lesions while babies are still in the womb.

The Society for Research into Hydrocephalus and Spina Bifida (SRHSB) has opened up the debate to *Link* readers who are parents. Parents can express their views by completing a short questionnaire available from ASBAH.

This unprecedented move follows the development of fetal surgery for spina bifida in two centres in the United States. The procedure has already attracted massive media attention – fuelled by a photo of an unborn baby's fist protruding from an incision in the womb, seen in newspapers round the world.

The questionnaire asks parents whether they would expect the operation to be carried out and, if they did, what would make the operation a success – or a failure – from the baby's point of view?

Parental views are also wanted on whether their decisions to continue with or terminate pregnancies would be influenced by the knowledge that this operation is now possible.

Fetal surgery for spina bifida is not yet available in the UK, and no centre here has yet declared that it will carry it out.

SRHSB last year expressed caution over the procedure, which they said was still in its experimental stage, with insufficient information appearing in the medical journals. They now say that the neurosurgeons involved are sharing more of their results.

Carole Sobkowiak, SRHSB secretary, said: "We have taken a cautious approach so far. There are risks for both mothers and babies, and we are not yet convinced of the long-term benefits."

Link readers taking part will not be identified. Their opinions will be collected for presentation at the SRHSB's next full meeting in Uppsala, Sweden, in June. These will be considered alongside parent views from Canada, Sweden and Spain, as well as the latest medical and scientific information.

● To obtain a questionnaire, contact: Information, ASBAH, tel: 01733-555988, email: gillw@asbah.org

Members wanted in Devon

DEVON, without an ASBAH adviser for five years, is in line for a new local ASBAH. Charles Harper, a former chair of South Thames ASBAH, wants people interested to contact him as soon as possible.

Mr Harper (49) recently moved to Paignton. Please contact him on tel: 01803-522256; mobile 07946-018111; email cpharper@talk21.com or write to: 23 Sturcombe Avenue, Paignton, Devon TQ4 7EB.

Obituary: Jan Saunders

JAN SAUNDERS, who helped build Essex ASBAH into one of the largest local ASBAHs in the country, died suddenly of a brain haemorrhage in Spain on 24 October. She was aged 59.

Mrs Saunders and her husband John, a former electronics engineer, had made a real go of ex-pat life in the Alicante area of Spain since moving from Rayne, near Braintree, Essex, eight years ago.

"They were enjoying their retirement but always kept themselves busy, with voluntary work for ex-pats, teaching wheelchair skills, keeping an eye on people in hospital, fundraising for local causes, translating and interpreting," said daughter Katrina Grounsell, a member of ASBAH's executive committee.

"Mum was the life and soul of the party, and always got on well with people. She didn't suffer fools gladly. She had multiple sclerosis but didn't let her disability get in the way of anything she wanted to do. Several people have already commented how much I've grown to be like her!"

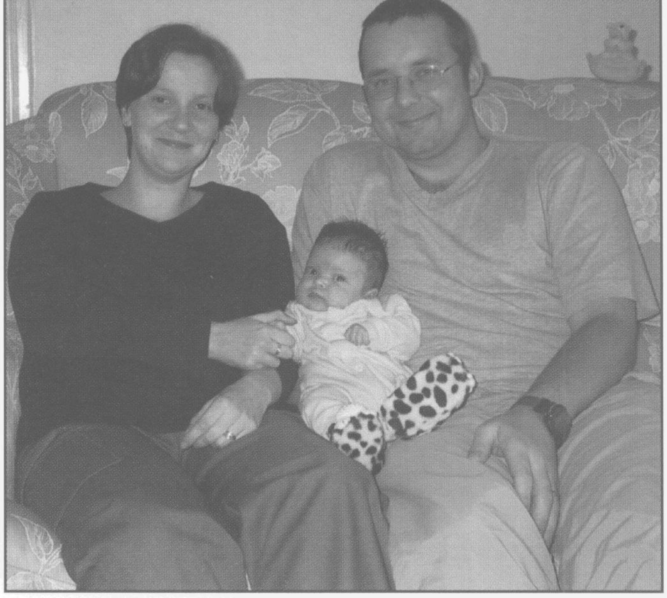
Mrs Saunders joined Essex ASBAH soon after the birth of Katrina, who is now 38. Her husband served 18 years as an officer of the association – becoming its secretary in 1963 and then chairman in 1977.

In her mid-30s, Jan gained a degree and then became a junior school teacher. The couple adjusted their horizons again after the onset of MS, moved to sunny Spain and devoted themselves to each other and their new community.

The couple had three daughters – Katrina, Beverley and Juliet – and five grandchildren. A memorial service was held in Rayne in November, with a collection for ASBAH and the MS Society.

Anthony Quinn & Co: a correction

IN THE November *Link*, there was a story about how parents of children with severe learning disabilities can make financial provision for these children in their wills. Anthony Quinn & Co, who publish a booklet on the subject, have asked us to point out that they would prefer readers not to make contact them directly for the booklet but obtain it through ASBAH. Our information department once again has a small stock of this free booklet.



Bundle of joy arrives on TV

A COUPLE agreed to be filmed for a TV documentary while they were expecting their baby with spina bifida because they wanted to get across a positive message about disability.

Rachael and Richard Speirs, from Burnley, took part in a *Born To Be Different* film which features families with disabled children under a year old. It will go out on Channel 4 in January.

Rachael (25) said that she and her husband were just pleased their baby would survive after a 48-hour period during pregnancy when it was suspected that Emily had Edward's Disease, a chromosome disorder incompatible with life.

"When we found out that Emily just had spina bifida, we weren't that bothered as long as she'd live," said Rachael.

The couple admit that they knew nothing about spina bifida but were supported by their consultant neurosurgeon and found ASBAH's website on the Internet. Our adviser for their area, Angela Lansley, was also on hand.

The Ricochet Films team filmed Rachael in labour though not delivery as an emergency Caesarean had to be performed. Footage was taken again the next day when Emily's lesion was closed and then a few weeks later at home.

"Emily is fantastic," commented Rachael. "We wanted to show people that it's not all doom and gloom – people with disabilities do have a good life."

Latex used in scratch cards

OUR mobile phone story *(Put your mobile to the other ear!, September 2000)* reassured one *Link* reader but she has warned of another equally serious problem.

Latex allergy sufferer Laura Gear cringed when she saw she needed a scratch card to top-up her 'pay and go' phone.

The 25-year-old, who carries an Epi pen at all times in case accidental contact with latex causes anaphylactic shock, had previously learned that the ink used on National Lottery scratch cards is latex-based.

This explained why her eyes became swollen on visits to her grandmother as scratch cards from newspapers were usually lying around.

Laura said: "I phoned BT Cellnet and they confirmed the ink used on their top-up vouchers is latex-based."

"As there is no warning on any scratch cards that the ink used is latex-based, I thought I should bring this to *Link* readers' attention."

So far, Laura, from Brislington, Bristol, has resorted to asking mum to scratch the top-up card – out in the open air and well away from her daughter.

- BT Cellnet told *Link* that an alternative would be for customers to credit money to their account by pressing a special button on the mobile to get through to the payment centre, then enter a Switch or credit card number *(details of this are given in their mobile phone user guide).*

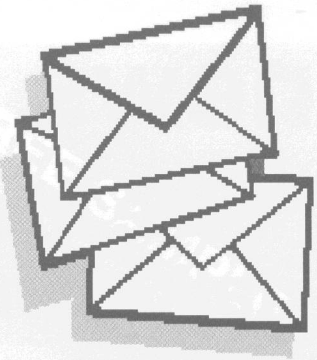
MY DAUGHTER Kirsty was born in 1989 with a very large encephalocele, joined at the back of her neck, which had part of her brain inside. The sac was removed when she was four days old and then a shunt was fitted.

Now Kirsty cannot walk unaided and her learning ability is slow.

I would like to hear from any parents whose child was born with this condition and would like to know if it was diagnosed before birth and how.

Kirsty's condition wasn't diagnosed even with a scan at 39 weeks.

Manda Puffer
1 Jersey Way, Barwell
Leicester LE9 8HR



WE would like contact with families with a child of about 3–4 years old with spina bifida and hydrocephalus.

Our daughter Greta is two years old and has sacral spina bifida level 5 and has had a 3rd ventriculostomy for her hydrocephalus.

We have started catheterising every three hours.

Greta seems to be near enough of normal intelligence and hopefully she will eventually be mobile and walking.

At present she is under an orthopaedic surgeon and has splints up to her knees.

We hope that families in similar circumstances will get in touch as it would be nice to know what the next few years may hold for us.

Sally Tapping
Monserrat
Kiln Close, Prestwood
Bucks HP16 9DJ

I AM awaiting an operation to release my tethered cord associated with mild spina bifida. The thought of it fills me with dread. Are there any readers who can give me answers to the following:

- **More information about the operation itself, how did you feel before and after?**
- **Post-operative experience, "intimate care" (for a woman);**
- **Pain from the operation and its relief – is it an ache, a stabbing pain, or sciatica pain?**
- **What sort of pain relief were you offered?**
- **How long until you felt much better, and got rid of the usual leg and back pain?**
- **Any complications (eg re-tethering) that you have heard about from others, CSF leakage, meningitis possibilities?**

The TCS is a pain (figuratively and physically) and I really need to get my head round it to make an informed decision.

Ms N Bunton, 98 Hambledon Road
Worle, Weston super Mare BS22 EG

Fine start to our talks on strategy

ASBAH's new draft strategy plan will soon be put out for full consultation – after an invigorating three months spent getting it into shape.

Three focus groups have discussed what issues they think should be involved, and there have been a large number of meetings with various stakeholders.

"We had a 26% response rate by the deadline given for replies to an initial questionnaire which has helped us set the agenda for a formal consultation in 2001", said Linda Hams, assistant director (policy and marketing), who collated the replies.

"Several extra questionnaires were considered after the deadline", she added.

The first results will be considered by ASBAH's trustees in January before the next phase of even wider consultation.

"We had an excellent response. It has become obvious that many people want ASBAH to raise its profile, do more lobbying and market and publicise itself more strongly.

"There has also been very strong support for our services, with lots of opinions expressed by stakeholders about where we should focus our work in the future."

Contact Linda on 01733-555988 if you want to be involved in the next round.

An audience with ASBAH

ASBAH had its first ever audience with Northern Ireland Assembly members on 11 October.

At a reception sponsored by Assembly member Eileen Bell, regional manager Margaret Young *(both pictured above)* stressed the high incidence of neural tube defects throughout Ireland. She also urged members to think disability and what was needed to make a difference to our service-users.

Joining us in the Long Gallery, Parliament Buildings, Belfast, were representatives from local associations, statutory services, and health and social services trusts.

Edward Evans, chairperson of our Northern Ireland Services Advisory Committee, also spoke.

Margaret said: "For the NI Region, it provided an excellent opportunity to begin raising ASBAH's profile in the corridors of power."

The text of Margaret's presentation has been sent to all Local Assembly Members, and more detailed information to members of the Committee for Health, Social Services and Public Safety.

Folic acid campaign rolls out throughout Ireland

IRISH health chiefs from both sides of the border launched a new folic acid campaign on 3 November.

The TV, radio and press campaign aims to cut the number of pregnancies affected by spina bifida and other neural tube defects.

In Northern Ireland, two babies every month are born with an NTD. Seven Republic babies are affected each month.

The six-week campaign uses material first seen north of the border in an earlier campaign in 1998. It targets women and highlights the major role played by folic acid in the prevention of spina bifida.

The campaign advises all women who can become pregnant to take a daily 400 mcg supplement, irrespective of whether or not they are planning for a baby. It points out that folic acid is safe to take over prolonged periods of time and is available in tablet form from pharmacy counters and health food shops.

Higher doses for women who have already had an affected pregnancy and where there is a family history of NTDs can be obtained on prescription.

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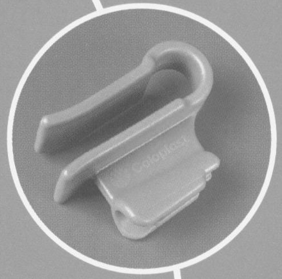

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CIC 2000, conference on Choice, Independence and Control, Hilton Hotel, Leicester, 17-19 November 2000

Choices, choices – what democracy is all about!

THIS WAS Your Voice's main event of the new Millennium and one of the Association's biggest gatherings of the year.

CIC 2000 achieved all it set out to – bringing people with spina bifida and/or hydrocephalus together to talk about what was important to them, and to have a good time.

Choice, Independence and Control is what CIC was all about and this was reflected in the dozen workshops on offer in the plush setting of The Hilton International Hotel in Leicester.

Thirty-nine people attended from as far away as Cumbria, Sussex and South Wales – despite problems with floods, petrol and the railways.

A third of delegates hadn't been to a Your Voice event before, even though our Disabled Users' Group has now been up and running for almost eight years.

This time the spotlight came down on: the Jubilee Sailing Trust (including a video of people with spina bifida/hydrocephalus from Ireland aboard the TS Lord Nelson); the Disability Discrimination Act; Relationships; the Human Rights Act; Information Technology; Your Voice; Working in Disability Rights; the Uphill Ski Club; Access to Higher Education; Life Plans; and Housing.

Speakers from the Your Voice steering group took their places with others from SKILL, a housing association and a member of The Outsiders' Club.

Apart from illuminating discussions which allowed people to share experiences, realise that others were in the same boat and go away thinking they could try something new, there was time to relax and enjoy the hotel's excellent food.

Although accessibility was far from perfect, delegates were impressed at the reaction of hotel staff when fire alarms went off during lunch.

One of the CIC organisers, Carole Armour, commented: "Staff moved tables and opened doors very fast to enable us to get out, but didn't evacuate because the alarms didn't continue. They were very helpful."

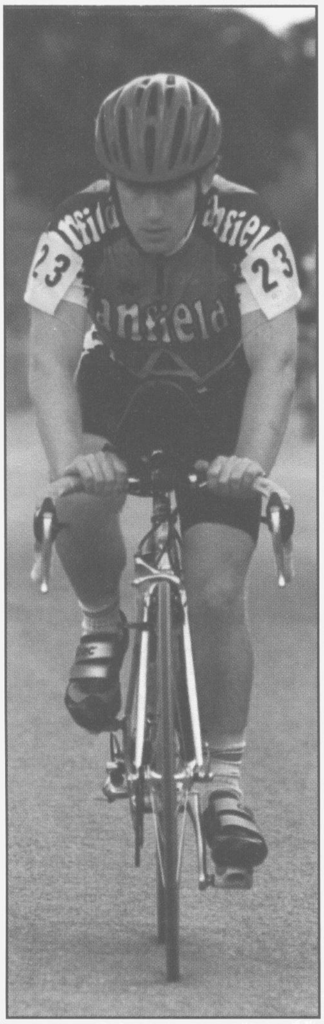
Rounding off the weekend, ASBAH executive director Andrew Russell explained about the wide consultation

process taking place on ASBAH's future which, according to Your Voice chair, Angela Waring, was appreciated by delegates.

Thanks to organisers Jon Burke (co-ordinator of Your Voice), Angela Waring (Your Voice chair), Janet Waugh and Carole Armour (Your Voice steering group members) and Rachael O'Brien (ASBAH Northern Region secretary). They ensured that everything ran smoothly during the weekend.

For details about Your Voice, contact Jon Burke, tel: 0113-255 6767, jonb@asbah.org

Pictures show:
Mary King and Rachael O'Brien, deep in discussion (above); group photo (left) and, (below from left) the Your Voice committee; relaxing during CIC 2000; wheelchair skills exercise; a group workshop; and Kevin Towner, deep in thought.
Photos by Sam Tanner



Geraint takes on the toughest of life's challenges

CYCLIST Geraint Catherall completed a demanding cycling season with a gruelling series of races – including a 24-hour marathon.

Now living in Leicester, where he works as a hospital plaster technician, his cycling is split between finding new routes in that area, and 'at home' with his club around North Wales and Cheshire.

Geraint, who has hydrocephalus, said: "I had a team of people from my cycle club and my father following me with food and drinks, and clothing and lights."

Geraint completed the national, 24-hour championship event with a distance of 366.29 miles – 43 miles less than the winner.

The next day his muscles were treated to a much-needed massage but he was fit enough to compete in a 100-mile time trial a week later; then 190 miles in a 12-hour race the week after that and, finally, a 25-mile time trial and hill climb up the Horseshoe Pass, Llangollen.

Carole moves on from Darlington

PHYSIOTHERAPIST Carole Sobkowiak retired this summer after 21 years as superintendent physio at Darlington's Child Development Centre. But she remains hon secretary of the Society for Research into Hydrocephalus and Spina Bifida, and is heavily involved in planning their next annual meeting which next year will take place in Sweden.

Carole trained as a physiotherapist in Sheffield and, in 1967, she worked at Sheffield Children's Hospital with Professors Lorber, Zachary, Sharrard and Emery which stimulated an abiding interest in spina bifida and hydrocephalus.

It was while she was running the physiotherapy department at a children's hospital in Edinburgh that she undertook groundbreaking research on hand function in young children with spina bifida and hydrocephalus. This proved that hydrocephalus could affect the upper limbs.

In 1996, she was honoured by her professional colleagues by being made a Fellow of the Chartered Society of Physiotherapy. She is looking forward to spending more time at her cottage in Swaledale.

Rock solid leadership

WARM FAREWELL to Margaret White, who has provided rock solid leadership to Sussex ASBAH for the past 25 years.

Margaret *(pictured below)* retired this summer as county organiser.

During her remarkable stewardship, SASBAH has grown to become the strongest, best supported local ASBAH in England.

She never talked much about herself, and enjoyed being photographed even less.

But Margaret is credited with being the driving force behind the success of SASBAH's housing project at Grand Avenue, Worthing – which was opened by the late Princess Diana – and the clinic for young adults with sb/h at Chailey Heritage.

Tanni – a true sports legend

TANNI Grey-Thompson, newly flame-haired, became the most successful track athlete in Paralympic history at Sydney this year.

She matched her four-times gold medal record set in Barcelona eight years ago. The 31-year-old athlete with spina bifida has now taken nine golds in a Paralympic career spanning 12 years.

Tanni, who hails from Cardiff, has had to take fame in her stride. On her return to Britain, she was met by fans who had camped out at the airport, was stopped by dozens of people on her way home in Teeside and has done dozens of interviews, TV and radio shows.

She told *Disability Now* that her sheer grit was due to her upbringing: “My parents were really positive. Their support influenced all my attitudes. They told me ‘if you want to do something you can do it – we’re not treating you any differently’.”

Good luck to Tanni who, after a well-earned holiday, will be setting her sights set on the Commonwealth Games and the Disability World Championships.

● Congratulations also to Anthony Peddle from Northampton and Emma Brown from Pontypridd who gained gold medals in powerlifting, a sport making its Paralympic debut at Sydney.

Don’t forget the human touch, says Michael

MAKE equal opportunities mean something by backing it up with the human touch – this was the message to employers and college authorities from Michael Davis, who spoke so well on behalf of ASBAH at a fringe meeting of the Liberal Democrat Conference in September.

Michael spoke about the discrimination he had faced in jobs even though he had explained his needs in interviews.

His life had changed at the age of 21 when he was diagnosed with hydrocephalus – half-way through a law degree and after 10 years of success in athletics and football.

The 37-year-old, from Wokingham in Berkshire, told MPs: “I have learned that people with hydrocephalus have different issues to contend with. I have learned by default what are my own personal needs.

“As a student, there was plenty of literature to help me with study skills etc but this doesn’t come close to the human touch. Colleges need more staff to support individuals.

“At work, in a number of jobs, I was treated very unfairly as managers either failed to understand my condition or, in practice, didn’t consider my needs which they had previously accepted.”

Dennis’s straight bat!

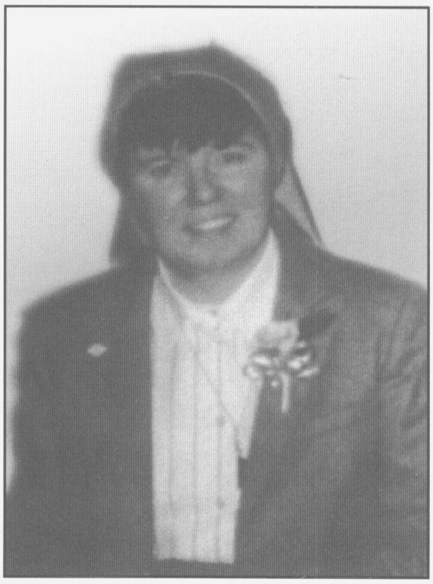
KENT ASBAH’s cricket book, *Playing Away,* racked up modest sales at first class matches this summer.

“We must have sold about 100 at the county grounds – most of them going to people who wanted to help a charity,” said village cricket fan Dennis Paul *(pictured right)*. “It’s about a fictional cricket club, the Brickfield Wanderers. Although the author changed the names, I knew all the characters. They were from my old club!” If you’d like a copy, a fiver to any committee member at Kent ASBAH will secure one for you.

Your View

So what did happen to the old Network News?

by Sr Valerie Malone FMM
St Joseph's, County Dublin



CONGRATULATIONS on *Hydrocephalus and You* – it is a remarkable book and a great achievement. And the new-look *Link* is more eye-catching, and holds my interest. The colour pictures are great. I am all for touches of humour, occasional cartoons and so on. The stories are inspirational, to say the least.

However, I am wounded to the heart that *Hydrocephalus Network News* no longer exists.

I suppose this is difficult for people who don't have the condition to understand. After all, it was just a few pages four times a year. Nor can one say that it was the best thing ever published. True.

But it was ours. Hydrocephalus is an awful thing. After my fifth shunt revision in 15 months – in addition to months in bed, severe sickness and pain like I couldn't believe – the neurosurgeon said to me: "Valerie, you are going to have to slow down your life completely and forever, or you will never get off the slippery slope of shunt surgery."

Because of the accumulative experience of the preceding 15 months, I could believe and understand what he was saying, especially as I had severe, persistent headache. So I slowed down. Writing, in many forms, is my central activity now. I make the absolute best of my lot, but it's not particularly exciting.

I am just one person with hydrocephalus.

I write this not to complain but to illustrate that life for people with hydrocephalus is not particularly rosy.

To compound the situation, hydrocephalus treatments are rather the 'poor relation' in neurosurgical wards. Indeed, it could be classed as a 'poor relation' in terms of general medicine.

How much money and resources has been poured into cardiac and cancer research? Relatively speaking, is there much research into hydrocephalus?

Spina bifida and hydrocephalus are often mentioned together. I did not know hydrocephalus could exist without SB until my own private revelation.

It is my experience that medics see people who complain of shunt malfunction as a nuisance: irritants with overactive imaginations.

For instance, the aforementioned 'months in bed' were due to unimaginable headache. I literally could not stand up and was frightened with the pain.

Yet, because scans were 'fine', doctors repeatedly sent me home, head bowed. After four months of this, they decided on another test. Instantly, they saw the shunt was not working. This was just one in a series of such incidents.

No one seems really interested in our plight.

Then, out of the darkness, popped *Hydrocephalus Network News* – such a beacon, bringing light, hope and care to us, a minority, even within minorities. ASBAH was meeting real needs head on (pardon the pun) yet again!

Why was publication stopped? I'm afraid I missed the consultation about it.

I sincerely hope I am not the only 'moaner in the pack.' Please can we have our 'own publication' back? Or at least a bit more space within *Link*?

● Editor's note: We've put the lot into *Link*, including plenty for people with hydrocephalus alone. And it appears six times a year, instead of quarterly!

Data – our promise

A NEW Data Protection Act has come into force which applies to information held on paper as well as computer files.

As recommended by the Data Protection Commissioner, ASBAH has published a Data Protection Statement to reassure service-users that information about them is stored and used correctly.

It reads: "The new Data Protection Act governs what information can be held on an individual and how that information can be used.

Like many voluntary organisations, ASBAH holds information about our service-users: including names and addresses, disability details and records of our contact with you.

Our main reason for holding this information is to enable us to provide a service to you.

All the information given to ASBAH by you, and held in paper or computer files, is strictly confidential. We will NOT disclose any information to any other organisation or individual outside ASBAH, without your prior consent.

Statistics gathered from our records may be used anonymously to monitor trends in the use of ASBAH's services. Statistics can also help ASBAH in its aim of lobbying for improvements in statutory services for people with spina bifida and/or hydrocephalus.

Holding the information also enables ASBAH to ask relevant service users if they would like to take part in particular research projects."

To find out more about data protection and how it affects you, see *The Data Protection Act 1998: An Introduction*, free from the Data Protection Commissioner, tel: 01625 545700.

Or phone the Data Protection Information Line on: 01625 545700 or visit the website at www.dataprotection.gov.uk

Finding out what it's really like to have it

A NURSE researcher and a leading professor at Addenbrooke's Hospital in Cambridge are trying to find out what it is really like to live with acquired hydrocephalus or benign intracranial hypertension (BIH).

Leslie Gelling and Prof John Pickard believe this study will help professionals to care for people with these conditions.

They want to hear from people over 18 years old with acquired hydrocephalus or BIH living in or around Cambridgeshire, or anyone visiting the Cambridge area. At present, people with spina bifida or congenital hydrocephalus are not included in the study.

If you take part, Mr Gelling will conduct a tape-recorded interview of about 30 minutes. This will take place at a time and in a location convenient for you.

Afterwards you will receive a transcribed copy of the interview so you can check for mistakes and add any comments you may have forgotten during the interview.

All postage will be paid and you will not be expected to travel to Cambridge to be interviewed. Your identity will be protected and all documents connected to the study will be treated as strictly confidential.

- **More details from: Leslie Gelling, Nurse Researcher, Box 167, Addenbrooke's Hospital, Hills Road, Cambridge CB2 2QQ, tel: 01223-216146; email: lhg23@medschl.cam.ac.uk**

Message of hope in new book from a mother

HOPE and inspiration are offered in a book written by a mother about her daughter whose positive attitude and love of others enabled her to live her short life to the full.

My Shining Star is a tribute that aims to encourage new parents of disabled children; to help change people's misconceptions of disability and be a comfort to those who have recently lost someone.

It is available for £6.50 (including postage and packaging) from Mrs June Tanner, 41 Cavendish Avenue, Churchdown, Gloucester GL3 2HW.

Watch your back as you raise that loving handful!

“A LOT of non-disabled mums ring me saying they can’t cope. I say it’s easy being a mum. They say it isn’t.”

As I watch mother-of-two Kirsten Battle sit patiently in the driver’s seat as her wheelchair is slowly lowered beside her, out of a box on the roof of her car, I think having so many hurdles in life perhaps makes you more patient than most.

Though she shares tasks with her husband Mark and has a good deal of support from her parents, Kirsten knows she is a very good mum.

Yet, despite having confidence in what she does and the grit to fight against personal discrimination, it would be easy to have been daunted by passers-by continually asking: whose children are they? and by professionals who assume she is not fit to be a parent.

“No woman should be scared of pregnancy or having their child taken off them by social services,” says Kirsten, who lives in Leeds with Mark and their children, Abigail and son Matthew.

“I have heard that any child born to a disabled parent is automatically put on the ‘at risk’ register. I refuse to have anything to do with social services for that reason: they have this image of disabled people not being able to do things.”

Even though Abigail is almost five, Kirsten still watches her back when out.

“ I don’t feel able to discipline Abigail in public because I feel I’m being watched,” she said.

There are other hurdles like the lack of positive role models and a local network, and the absence of accessible mums and tots groups. But Kirsten, who is involved with an organisation called Women’s Health Matters, hopes to tackle these with the creation of a new, local support group.

Kirsten said: “The group will be for any disabled woman who has or wants children either naturally, by IVF, adoption or fostering.

“It can be a lonely job being a mum anyway but when you are faced by discrimination it is even harder.

“The group will do our kids good too – a bit like a counselling session for them. It must be strange to have a disabled or long-term ill mum.”

Her pregnancies with Abigail and Matthew (now a year old) were very different. With Abigail, there were the usual problems of sickness in the early stages and mobility later on.

With Matthew, she suffered acute contraction pains at 21 weeks, while at a meeting at our regional centre in Leeds and was rushed by car to hospital.

Drugs helped but spells of Braxton Hicks contractions – which felt to Kirsten like the real thing – kept recurring.

“I got to 34 weeks and I couldn’t move. was relying on Abigail to help me get dressed, which was OK, but one time I nearly fainted and fell on her so I phoned the hospital and told them I couldn’t cope at home and that I wanted them to get this thing out of me.

“I was told to come in and have a rest, and they would try to take me to 35 or more weeks. That was on the Friday; the following Wednesday I was preparing myself for a Caesarean."

Abigail and Matthew were born four and five weeks early by Caesarean because Kirsten's 'pelvis was too small for a normal delivery.'

Plans to 'be awake' during delivery of Matthew were thwarted as spinal block equipment was withdrawn but, as the next best thing, the hospital took the unusual step of allowing the operation to be videoed and photographed and allow Mark to be present.

Matthew recovered in a 'Transitions Unit' – almost special care but for babies well enough to be out of incubators.

In the maternity wing, there were no special facilities for disabled mums: Kirsten brought in her own cot and had to operate at three levels – the raised bed, cot and wheelchair right down low.

"I had just had a Caesarean which is hard when you're non-disabled but when you have legs that don't work and a tummy that's sore, you think the hospital could have thought a bit harder."

No adapted toilet was simply got around by Kirsten befriending the group of mothers she found herself with, who willingly co-operated with her needs.

Breastfeeding was short-lived with both babies, particularly with Matthew as Kirsten had been poorly for much of the pregnancy. He was a hungry baby and was consuming solids at two and a half months old.

Well before the day of his birth, Kirsten and Mark thought carefully about how Matthew could be eased into the family circle. On that day and for days after, there were gifts and cards for Abigail, countersigned or hand-printed by her baby brother, which kindled a belief that the new addition had gone out shopping between her visits.

"Both have been really close since they set eyes on each other."

Having children has undoubtedly changed Kirsten's life for the better.

"I find if easier to cope with two than one, or even me on my own. The amount of motivation for my life has gone though the roof since I've had these two."

● Words by Liz Cawthorne

Photos show:
ABOVE – Kirsten introduces Abigail to her new little brother, Matthew, in hospital.
BELOW – Matthew growing up to be a strapping toddler.
OPPOSITE – Kirsten pictured with her first-born, soon after Abigail's birth almost five years ago.

We can visit this place only once!

A SMALL but successful support group took its members to The Dome *(pictured below)* to foster togetherness and allow families to go somewhere that otherwise they probably wouldn't be able to get to.

Around 25 people associated with the Luton and Dunstable Support Group travelled by coach to the big Millennium attraction on a trip organised by group founder member Valerie Bottoms and funded by the Vauxhall Employees Charities Committee.

Although members could find nothing for children under five to explore or play on, most found the show in the main arena breathtaking – so much so that some families watched it twice!

Access for disabled people was considered very good, but baby-changing facilities seemed to be inadequate.

Luton mum Sharon Taylor said: "It was a very tiring day, especially with bored two-year-olds but a good time was had by all. It was an opportunity that we would not have missed and certainly one that we could not repeat."

MID WALES ASBAH decided to celebrate the Millennium by inviting the three other Wales associations, plus ASBAH staff, to a Millennium Munch and activity afternoon.

Local Association members from Llanelli, North Wales and South Wales – along with ASBAH in Wales manager, Elin Ifan – had the chance to meet and chat to friends from all over Wales.

The afternoon included a buffet lunch, tombola and raffle. Everyone enjoyed it so much that Mid Wales ASBAH may make it a regular event.

Flats, not bedsits

A HOUSING project run by a local Association – 5 Grand Avenue, Worthing – has been refurbished.

It now contains six self-contained flats, each with bedroom, bathroom, kitchen and living room. There is also a communal laundry and office for Sussex ASBAH, who manage the property, which is owned by North Downland Housing Association. It used to contain nine bedsits.

SASBAH president Sir Michael Checkland officially re-opened the house.

fundraising

Hair-raising – that's our Mo!

PASSERS-BY watched in horror as Maureen Hornby coolly ordered a 'Number One' from the hairdresser beside her, poised with a razor.

Considered brave by her friends and co-organisers of a fun day, Maureen brushed the stunt off as a way of raking in the money for ASBAH.

She had persuaded The Jolly Brewer, in Broadgate, Lincoln, to hold its Bank Holiday fun day for ASBAH in exchange for having her head shaved.

She wanted to raise money for us as her 40-year-old sister acquired hydrocephalus as a baby after contracting meningitis.

The 52-year-old's daring inspired two other male pub regulars to join in the fun and the money-making by having their heads shaved too.

Mrs Hornby sported a temporary Mohican before that too went under the chop. She said: "Although there weren't a lot of people there, money was flowing and I had collected £180 in sponsor money at my sister's birthday the week before. We all thoroughly enjoyed ourselves."

A magnificent cheque for £700 was presented to Sue Mason, our Lincolnshire adviser.

For a fortnight afterwards, Mrs Hornby went out wearing a head scarf but then even that was discarded. "After all, everybody knew I'd had it done," she said.

Now her hair is growing back nicely but nothing will persuade her to give a repeat performance. "I've done it once; someone else can do it next year," she says.

PHOTOS show: *top – Maureen sporting a fabulous green Mohican on her way to the complete chop; below – what she looked like at the beginning.*

Blackpool e-appeals and Essex antiques

EMAIL appeals to companies making promotional goods have pulled in some 300 extra prizes for our annual tombola at January's Pigeon Show of the Year.

Small but useful items like biros, key rings, desk organisers, silk ties and cuddly toys will take their places beside more expensive prizes such as jackets, clocks, crystal decanter and glasses and a lawn mower.

A total of 900 prizes have been collected by ASBAH fundraising staff, Ian Morley and Jane Ayres, for our money-spinning stand at the two-day show at the Blackpool Winter Gardens, 20-21 January.

The event is run by the Royal Pigeon Racing Association – ASBAH's all-time, best-ever supporter.

● DONATIONS of £1,200 have come over eight years to ASBAH from clubs and societies grateful to an ex-policeman for giving them insights into the world of antiques.

Robert Cameron, who runs Penny Farthing antiques in Leigh-on-Sea, Essex, gives six to eight talks a year to Women's Institutes, Rotary Clubs and Probus groups.

In exchange, Mr Cameron, who has a niece in her 30s with spina bifida, asks for a donation to be sent to ASBAH.

And we at ASBAH thank Mr Cameron for choosing us to reap the rewards of his entertaining evenings out on the road. Every gift helps!

dates for your diary

Put your date on this page

A LOT happens every month in which *Link* readers will be interested – but quite often we are not told about it until it is too late.

If you would like your event to be included on this page, please let us know well in advance.

The magazine appears at the beginning of January, March, May, July, September and November.

So please notify us – at the latest – by the beginning of the month preceding the issue in which you would like your event to appear.

And, if you have a yearly programme of events, send that to us for inclusion.

Send details to Publicity, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, email: lizc@asbah.org

We cannot guarantee to include your event each time, but will do our best to draw it to our readers' attention.

Help with move to adulthood

THERE'S help for parents with the transition from childhood to adulthood at an ASBAH day in Llandudno, north Wales, on Saturday 3 February *(see opposite)*.

Our adviser, Peter Bennett, has put together a programme, which also includes an information update on welfare rights.

Upcoming events

Leeds drop-in

Wednesday 3 January, Leeds
Northern Region drop-in, ASBAH House North, 64 Bagley Lane, Farsley, Leeds. 10–noon. *Details: Bernadette Baldwin or Rachael O'Brien, tel: 0113-255 6767.*

Dunstable meeting

Monday 8 January, Dunstable
Monthly meeting for parents/carers of children/young people with spina bifida and/or hydrocephalus, organised by the South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. *Details: Valerie Bottoms, tel: 01582-605749.*

Bromley coffee

Monday 8 January, Bromley
Coffee morning organised by South Thames ASBAH, 10–noon, United Reform Church, Bromley.

Fun Day

Saturday 20 January, Gloucestershire
Family Fun Day organised by the Gloucestershire Support Group. *Details: Julie Knight (ASBAH area adviser) 0117-924 5077.*

Pigeon Show

20–21 January, Blackpool
ASBAH at the British Homeing World 'Show of the Year' (organised by the Royal Pigeon Racing Association), Winter Gardens, Blackpool.

Adventure lecture

26 January, Leamington Spa
Legless But Smiling, lecture by disabled mountaineer Norman Croucher OBE, 7.30pm, Spa Centre, Leamington Spa. £4. *Contact: 01926-613 142.*

Llandudno Day

Saturday 3 February, Llandudno
Study / Information Day on welfare benefits and the transition between childhood and adulthood. 10.15–3.30, Ysgol Gogarth, Llandudno. £5 per booking (lunch included). Closing date for bookings 12 January. *Details: Peter Bennett (ASBAH Adviser) 01978-852 254.*

Bromley Coffee

Monday 12 February, Bromley
Coffee morning organised by South Thames ASBAH, 10–noon, United Reform Church, Bromley.

Dunstable meeting

Monday 12 February, Dunstable
Monthly meeting for parents/carers of children/young people with spina bifida and/or hydrocephalus, organised by the South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. *Details: Valerie Bottoms, tel: 01582-605749.*

Family Weekend

2-4 March, Morecambe
Residential programme for families who have a young child with spina bifida and/or hydrocephalus, with parallel programmes for parents and for siblings. £60 adults, £30 for children over 5, under-5s attend free. The ASBAH Family Weekend is sponsored by the BBC Children in Need Appeal. *Details: Rita Duell, Services Department, ASBAH National Centre, 42 Park Road, Peterborough PE1 2UQ, tel: 01733-555988, ritad@asbah.org*

DAVE'S DIARY

david.fulford-brown@ntlworld.com

IF you read this and it makes sense, it means the pills are working, my head isn't going to explode, and I've been scaring myself and the family silly for nothing. OK, the exploding head bit is a slight exaggeration but that's what I felt like for most of this weekend!

Some time last Friday I started feeling a slight itch, just behind my ear, exactly where my shunt is. Well, I scratched it but didn't think anything of it at the time. I've never had a problem with my shunt or thought about it all that much. It was put in at birth, extended a few months later, and packed up some time later when I was a kid.

I was always one of those kids who, if they got a sore, wouldn't 'leave it alone' and 'don't pick it.' Messing with things I should leave well alone is a habit I've kept as an adult. So, sure enough, after a couple of days of being prodded and poked, what was just an itchy area had turned into a flaming torment.

Because the ache was over the shunt area, I managed to convince myself and the family the pain was because of my shunt! So I made an appointment to see the doctor first thing (very first thing!) on Monday.

My mood on Monday wasn't helped much by the arrival of *Link!* By an amazing coincidence there was a two-page story about the pain and trauma of shunt problems. Not really what I wanted to see right then! I'm always happy to fill more space in *Link,* but not as the centre of a future piece about brain surgery, thanks very much!

Just seeing the doctor did a lot to settle my nerves. He calmly pointed out that I was right to keep an eye on my shunt (even if it was long dead). But if my head was about to explode, or there was any serious problem with my shunt, I really wouldn't be sitting there talking about it! The neurosurgeon he called after examining my head thoroughly agreed. I walked out of the doctors with some antibiotics for my skin and a big relieved smile on my face!

The pills are working, and I'm feeling much better now. But the doctor didn't just hand out pills. This morning I was sent to see the neurosurgeon, and pretty much got an 'all clear.' Even so, I'm still to see the doctor regularly until this thing clears up.

I can't express how relieved I feel right now, how much better I feel and what a prat I feel that I managed to panic and set all these alarms going because of an overgrown itch! But then, I realise I panicked because having a shunt is a serious thing and I think it is better to worry over nothing than do nothing about something. I'm very grateful the doctors did much more than something.

letters

We welcome letters for publication, which should be sent to: Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ. The Editor reserves the right to edit letters, so please keep them short.

Pen pals

I am 42 and have spina bifida. I work in an accountancy office doing clerical work three afternoons a week. I have a computer at home and have done many courses such as word processing, database, spread sheets and desk-top publishing. I don't mind whether my pen friend is English or Welsh, or comes from another country. They could be male or female, aged about 40 to 45. My interests include playing snooker, darts, computer games and water sports. Also I like going out for a meal or just a drink.

Jackie Roberts
Brecon Place, Porthmadog
Gwynedd LL49 9AA

I'M 33 years old and have spina bifida. I live independently in my own flat and would like to meet a lady with spina bifida around my age – preferably a non-smoker – if possible in South Wales. I enjoy most sports and serious kinds of music. Although I don't work, I attend a day centre three days a week which I love. If you would like to write, I would be happy to reply.

Gerald Everness
4 Irving Place, Barry
South Wales CF62 8EW

Trouble with the trains – again!

ISOBEL isn't the only person experiencing problems with trains *(Letters, Link, September 2000)*. We are, and there must be many more like us.

I will just use our last trip to London as an example. On the outward journey, the wheelchair space was double booked!

The return journey went well until we arrived at Leeds Station. No one appeared with the ramp. I got off and held the door, in the hope that the train would not set off.

The customer service manager from our train came past so we asked him for help. He went off to find the man with the ramp. The man came, but no ramp; "someone had moved it," he said. He asked the customer service manager to help him lift my adult daughter off the train. He refused saying he wasn't insured to do so. So, the man turned to me and asked me to help lift her off in her wheelchair. My daughter said: "No way is my mother lifting me off this train; she has a heart condition." The manager said: "Don't do it, love, because you're not insured either."

So the man went off in a huff to find the ramp.

Every journey has its problems – it could be the reserved seats or the ramps, often both.

I complained but did not get a decent reply.

Why do we have to set off on a journey wondering what will go wrong? How will my daughter ever cope on her own?

Joan Bowles, Halifax

Search for the hero inside yourself!

I am 28 and have spina bifida and hydrocephalus. Over the years, this has had its hard times due to the effects on daily life, as well as sadly losing some really good friends.

The loss of one of these friends hit me hard. She was so positive most of the time. I had to do something positive to cope with her loss and had some counselling. Then I decided to train to become a counsellor myself. I am now at the Advanced Diploma level.

The model they train you in is person-centered – it's about taking responsibility for yourself and making your own decisions. As most of us with a disability are aware, this is something which society does not often allow you to do. The course lets you really look inside yourself and face the challenges posed by yourself or by other people, your childhood and other factors. It enables you to change your ideas and thoughts about yourself and, when I qualify, I hope to make disability and its challenges one of my specialised areas.

I would like to thank ASBAH for its contribution towards my college fees – particularly Gill Yaz, one of the advisers, who was excellent at keeping me informed during my efforts to raise funds so I could continue with my course.

Karen Gibbs, 36 Douglas Road, Hornchurch, Essex, RM11 1AR

holiday lets

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

SELSEY, WEST SUSSEX (SASBAH)

Fully equipped, purpose-designed for wheelchair access, mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. *Details from: Julie Parks, tel: 01273-472298*

ISLE OF WIGHT ASBAH

Recently refurbished, fully equipped, two-bedroom bungalow. Sleeps six. Wheelchair accessible. Clubhouse, shop, local indoor heated pool. Beautiful area. Own transport advisable. Excellent rates: *Details: Mrs Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983-863658, www.iowasbah.i12.com*

BERWICK COTTAGE, EAST HARLING, SOUTH NORFOLK (CATEGORY 1)

Modern, purpose-built, self-catering cottage. Ground floor accommodation for up to 2 people (single beds) with disabilities. Scan 700 beds: Clos-o-Mat; overhead track hoist bedroom-to-bathroom, wheelchair shower and much more. Up to 4 carers/family/friends upstairs. Awarded Grade 1, Holiday Care. Open all year. Low rates Winter/Spring (£250 to £350 per week) – full centrally heated. Helpful caretakers demonstrate equipment, but otherwise total privacy in pretty village with accessible pub, GP, shops. Cottage brochure, Lin Berwick, (tel: 01787-882111). *Booking forms and full information, George Tickner, The Lin Berwick Trust, (registered charity), tel: 0208-595 7056.*

ORLANDO, FLORIDA

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

FOR SALE

ADJUSTABLE over-bed table, £35; Hine Pisces battery-operated bath lifter seat c/w battery charger, £375; Carmobility 90º rotating passenger seat (colour charcoal) – will fit Vauxhall Vectra but can be adapted to suit all 4/5-door cars, £490. All in excellent condition. *Lance Hams 01473-833325 (Ipswich), or mobile 07780-884313.*

HARRIER electric wheelchair. Three years old, vgc. Battery included. £1,250 ono, bought for £3,000. Genuine reason for sale. *Tel: 0121-777 5223.*

QUICKIE F75 electric wheelchair. Never used. Bought new with recharger for £2,800 in year 2000. Will accept £2,000 ono. *Tel: 01384-353 744.*

LARK 4 electric scooter with basket and charger. Good condition. Price new £2,100, asking £800. *Tel: 0121-459 3970.*

CAR MOBILITY 90º seat (fitted to Vauxhall Astra). Only 10 months old. £195 ono. Hand controls (brake/accelerator) £45. *Tel: 01366-384743.*

RENAULT Traffic van (carries two wheelchairs) 1996; white, vgc; 39,000 (services every 5,000). £6,000 ono. *Tel: 0131-440 3381*

Advert rates

- Classified Rates:

  £3.75 for 30 words max.
  £5.50 for 30-45 words
  £6.75 for 45-60 words
- Cheques and postal orders should be made payable to 'ASBAH'
- Classified adverts for the next issue of Link (March) should be submitted by Friday, 9 February.

  Please send to:
  Editor, ASBAH
  42 Park Road
  Peterborough PE1 2UQ
  Tel: 01733-555988.
  lizc@asbah.org
- Display rates on application from Publicity Manager, ASBAH.
  Tel: 01733-555988.
  tonyb@asbah.org