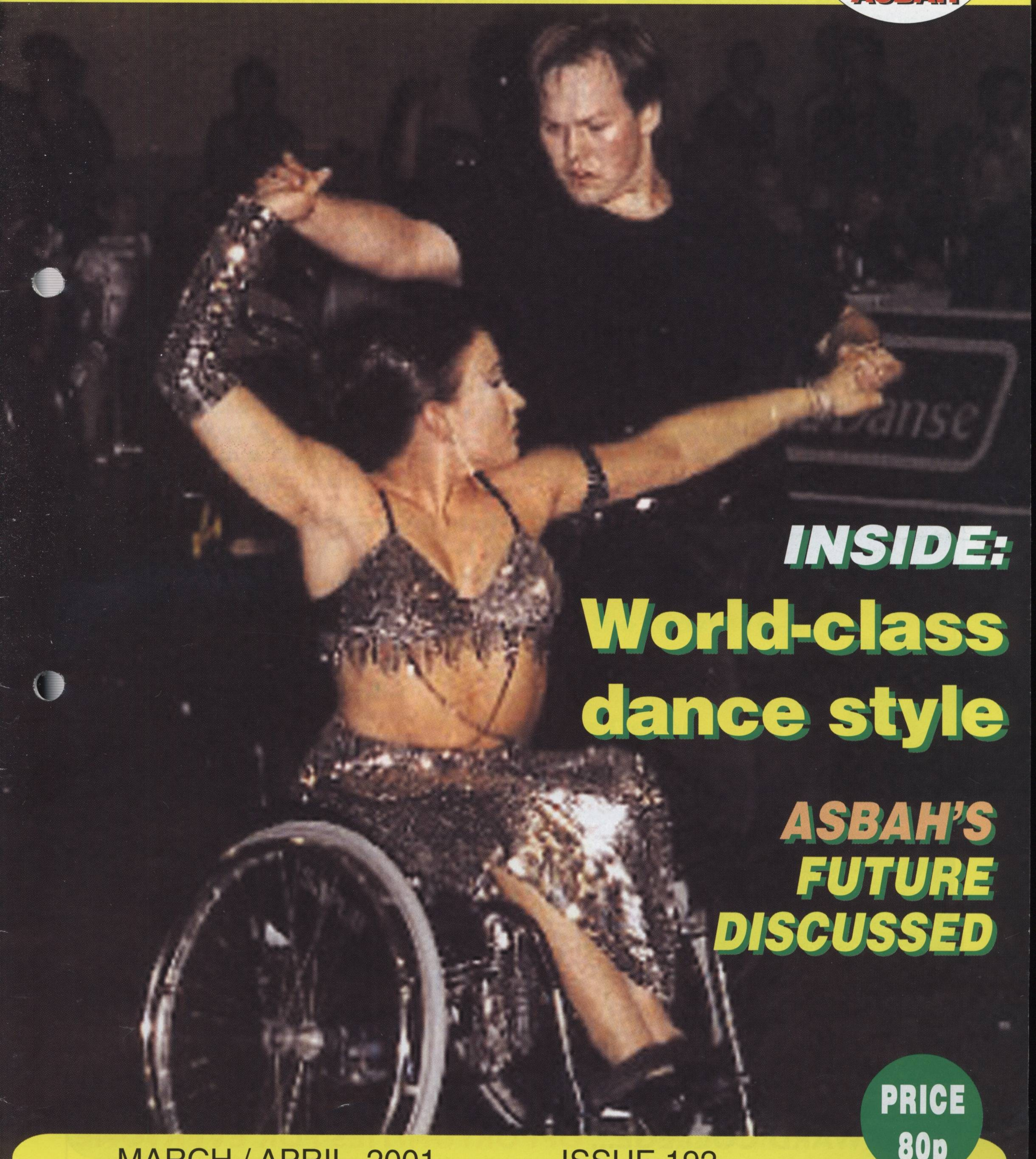
LINK

The magazine for people
with Spina Bifida and / or
Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS
ASBAH



INSIDE:

World-class dance style

ASBAH'S FUTURE DISCUSSED

PRICE 80p

MARCH / APRIL 2001 ISSUE 192

Treloar's

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LINK

Cover photo: Stunning picture coverage of the British-born girl making it big in the world of ballroom dancing. See page 13.

Editorial

Dear Readers

It's been great working with Charles Harper on his launch of a new local Association in Devon, which he has done with great aplomb. We have also helped the Alexander family with their revival of an ASBAH support group in Gloucestershire, and their next big event on 24 March.

ASBAH's new draft strategy plan proposes that we work towards a radical shift in focus over the next few years. It includes communicating and working as one with local ASBAHs; in unity, there's strength, that's the idea – with everybody contributing their own particular talents and strengths.

Which brings me to our second annual ChairAbility Challenge in October. If more of us can work together, this will be an awareness day to be proud of! This can be the wake-up call we all need so much.

Tony Britton

Tony Britton
Publicity Manager

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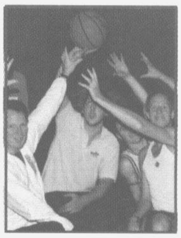

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ASBAH exists to provide advice, support and advocacy to people with spina bifida and/or hydrocephalus, their families, and their carers.

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

postmaster@asbah.org
www.asbah.org

Continence services – time to have your say!

VOLUNTARY sector watchdogs are so concerned at failures to improve continence services locally that one of them has launched a consultation to find out what users really think.

North London-based Incontact is rallying the resources of 18 national organisations to obtain as wide a variety of views as possible – with a view to drawing up a Manifesto for Continence to be sent to politicians. ASBAH has pledged its support to the campaign.

To have your say, get in touch with InContact *(details at end of story)*. You will be sent a reply-paid postcard for your views.

The consultation follows complaints from Continence Foundation director David Pollock that there have been very few improvements in local services since the publication nine months ago of new government guidelines.

"Now is a crucial time for stirring up discontent if you are not satisfied with a particular service," said Mr Pollock. "Our strategy at the moment is to put as much ammunition in the hands of people locally – both service providers and service users – to put things in motion. We want people to ask questions."

Mr Pollock, who retires this month (March), left these parting shots:

- Despite a guideline that continence directors be appointed locally, none had yet been.
- Patient care groups were flouting the guidelines by failing to identify everyone with incontinence and offering assessment.
- Carers were getting little specialist support and information.
- Access to specialist services had not been improved.
- And nurseries, playgroups and schools were still excluding children because they were incontinent.

The Continence Foundation has produced its own report to help continence specialists and individuals lobby for improved services in their own area. Under its new director, Judith Wardle, it will also carry out extensive monitoring to check how the introduction of the government guidelines is progressing.

● *For a prepaid postcard on which you can have your say, contact: Jolyon Rose, Manifesto for Continence, c/o Incontact, United House, North Road, London N7 9DF, tel: 0207-700 7035, fax: 0207-700 7045,* edu@incontact.org

Your views are sought

THERE'S still time for parents who would like to express views about the development of surgery on babies in the womb to repair spina bifida lesions to receive a short questionnaire from the Society for Research into Hydrocephalus and Spina Bifida.

Only five parents have called ASBAH to request the form, since details of the survey were announced in the last *Link*. The research society is surveying parents' views in Canada, Sweden and Spain as well as Britain, and will relay these opinions to its next meeting in Sweden in June.

● *If you would like to be sent the questionnaire, contact Information at ASBAH, tel: 01733 555988,* gillw@asbah.org

Saves that stretching!

A DEVICE which enables mains water supply to be turned off at the flick of a switch has gone on the market for around £25 plus the cost of plumbing it in.

It can be found in many DIY warehouses and hardware shops.

The makers say the SureStop water switch can be located above a kitchen worktop – which would make it far easier to reach than the stopcock.

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Making the child No 1 at school

SAFEGUARDS which protect the legal rights of children with special needs to the best education seem to have been preserved, following a lengthy campaign which involved ASBAH in doorstepping 10 Downing Street.

There had been fears that a proposed revision of the Code of Practice for special needs education would lead to a weakening in the position of children in school – with schools and education authorities being allowed to get away with vague statements.

Education Secretary David Blunkett agreed that statements of special educational need, required by many pupils with spina bifida and hydrocephalus, should continue to specify the provision they require. Failure to provide specifically what has been promised can give parents grounds for appeal.

This was after ASBAH had joined Action on Entitlement (AoE), an alliance representing 16 voluntary organisations representing parents of disabled children, in a five-month campaign against weakening of the Code.

In a statement, AoE welcomed the minister's apparent change of heart but said he now needed to back up his words with statutory guidance which also preserved the right to specify quantity of provision.

They said that, unless he did, education authorities will continue to ignore the law and routinely write statements which do not state the amount of help the child should get.

"If Mr Blunkett means what he said, he should actively pursue better statements across the board – for all who are disabled or who have special needs, not merely those who are able to fight for their rights."

● *Mum's fight for daughter at school. See page 8.*

Our window on the world

ASBAH'S Information Sheets, Education Topic Sheets, and much else besides are available for downloading from our website – which is now www.asbah.org

The website was visited 66,462 times in 2000. Most 'hits' (1,849) occurred in the week ending 17 March.

Surfers from 52 countries accessed our website during the year, including several from Lithuania, Turkey, Iceland and Ecuador, and one or two from Zimbabwe, Venezuela, Guatemala, Sri Lanka, Taiwan, Slovenia and Russia.

By far the most known hits were from the United States (1,300) and it is thought that a significant number of the 'unknowns' (16,500) derived from the US also.

Most of the remaining hits came from the UK (1,291), Canada (697) and Australia (213).

Cornish rescue for Churchtown Farm?

A RESCUE package which could safeguard the future of Cornwall's well-known Churchtown Farm activity centre is to be put to Scope, following the charity's decision to axe funding for the centre at the end of this month (March).

The deal – which involves using an undisclosed amount of funds put up by Cornish businessman Terry Johnson – would involve transferring the freehold of the property to the Friends of Churchtown Farm, with the management being taken over by another charity, the Winged Fellowship.

Centre manager David Owens said the businessman, who runs the St Merryn Group of food companies, wanted to get involved after he had enjoyed 10 years of rapid business growth in Cornwall.

Mr Owens said that he hoped Scope would agree to put back its deadline for the centre closure until September to improve the chances of the rescue bid being accepted.

He added that the Friends had already received bid pledges and actual cash totalling over £100,000.

Links were also being explored with further education colleges with a view to developing programmes at Churchtown which would benefit students with learning disabilities.

Scope has put Churchtown Farm at Lanlivery, near Bodmin, on the market through an agent in Exeter. This followed a review of its priorities following problems with cash flow and a drop in income from its charity shops, which has been eating away at its reserves.

The centre is popular with ASBAH staff and service users. Rosemary Batchelor, our senior health and policy issues adviser, said it was one of the few places she booked for residential courses in which she had total confidence.

Obituary: **Mrs Joyce Cockings**

A FORMER secretary of a local ASBAH has died after a long period of ill-health.

Mrs Joyce Cockings was secretary of Northamptonshire ASBAH for more than 15 years years until current secretary Alison Walter took over the post in 1997. She was 53.

She became involved after the birth of her son John, who had spina bifida and who died while still a child.

Members enjoyed the fruits of her formidable organising skills in their annual outings. Mrs Cockings also made sure that everyone was remembered at Christmas when they received a gift voucher from the association.

Mrs Cockings, who died in January at Kettering General Hospital, is survived by husband Roy, daughter Tracey and two grandchildren.

BBC apologises for Tanni error

THE BIGGEST number of complaints to BBC1's *Points of View* programme was received after a studio design error resulted in Britain's most famous disabled athlete being unable to get on stage after she was voted third in the BBC *Sports Personality of the Year* contest.

Wheelchair track athlete Tanni Grey-Thompson – winner of nine Paralympic gold medals, including four at the Sydney Paralympics – was unable to join non-disabled winner and runner-up, Steve Redgrave and Denise Lewis, on stage because the set designer failed to provide a ramp for her wheelchair. Instead, the award was handed to her in the audience.

The BBC apologised unreservedly for its mistake on *Points of View*. The show received over 500 complaining phone calls, faxes and emails.

ASBAH joined the chorus of complaint, describing the BBC's treatment of the 31-year-old athlete as "outrageous." We said the set designer needed an urgent course in disability equality awareness.

Tanni was more forgiving. She told *Points of View* that she was so excited at receiving the award that she did not realise the BBC had blundered.

Healthcare tips from a mother

A TEENAGER'S life has been transformed, thanks to her parents doing their homework.

Professionals were puzzled how 16-year-old Caroline Murgatroyd, who had breathing problems, survived with such high carbon dioxide levels but had drawn a blank on treatment.

So parents John and Sue searched for an answer on the internet and found the Nippy – a non-invasive pressure ventilator which forces a good breath of air through the mouth into the lungs. Caroline's oxygen levels more than doubled.

Mrs Murgatroyd said: "Caroline took to it so well, she wanted to be on it all the time at first. Now she only has to wear it at night and she is feeling so much better. You can use it abroad and in the car so it means you can travel."

Their daughter also had pressure sores. A nurse showed them how Actisorb – a dressing made of charcoal and silver – quickened the healing of sores on Caroline's back and under her bust.

The skin covering her meningomyelocele had been thin and weeping for years as breathing difficulties means she has to sleep on her back. The sore area under Caroline's bust is caused by scoliosis.

The combination of dressing the sore areas with Actisorb and placing pillows under the natural arch of Caroline's back, resulted in almost complete healing.

"We had tried everything and nothing worked but Actisorb has made a tremendous difference," said Mrs Murgatroyd.

● Editor's note: If you think the Nippy might be right for you, ask your consultant to send you for a trial. Actisorb is available on prescription – speak to your practice nurse to see if it's suitable for you.

Cool water

A CAMPAIGN to enable and encourage pupils to drink four glasses of fluid during the school day is underway.

Water is Cool in School wants more child-friendly drinking facilities in schools and for pupils to be given regular opportunities to drink.

Headaches, urinary tract infections and constipation are some of the health problems associated with low fluid intake. Physical and mental health and performance can also be affected.

The campaign has been mounted by ERIC (the Enuresis Resource and Information Centre). ERIC is lobbying the Department of Education and Employment and sending out information packs to health professionals.

● **Campaign packs from: ERIC, 34 Old School House, Britannia Road, Kingswood, Bristol BS15 8DB. Tel: 0117-960 3060;** info@eric.org.uk

MMR vaccine

ASBAH urges parents to follow the advice of their GP or paediatrician in respect to the controversial MMR vaccine.

The vaccine for measles, mumps and rubella (German measles) is normally given when a baby is 14 months old, followed by a pre-school booster.

Parents became anxious about the vaccine after reports that one paediatric consultant linked the combined vaccine to autism and bowel disease. Most other paediatricians disagree with his findings.

As far as anyone knows, children with spina bifida and/or hydrocephalus are at no higher risk of reaction to MMR than any other children.

Having each vaccine separately appears not to be an option now in the UK.

LETTER

PRECOCIOUS puberty in children with spina bifida is fairly well known but I wonder how common is acute PMT in teenage girls?

My daughter Caroline is 16 years old and, while she was ill with severe breathing difficulties, her periods stopped altogether. Nine months later when they started again we noticed mood swings two weeks before her period was due.

I would be interested to hear from other parents of teenage girls with spina bifida who have problems as they go through the monthly cycle as I don't think any research has been done in this area.

Sue Murgatroyd, 34 Honeyhill, Paston
Peterborough PE4 6DR

Editor's note: Many teenagers have PMT but we're unaware that girls with spina bifida, who have had precocious puberty, are more prone. Evening Primrose oil or Vitamin B6 can help.

PAULINE GIBBONS shares her experience of statementing

A person, not a number

THE decision to send our daughter to mainstream school was difficult asshe had had so many health problems – seven shunts and uncontrolled epilepsy at the time. Only parents can decide as you know your child best and whether you would cope as you will need to be more involved in the mainstream.

The statementing process started rather late for us. Gabrielle *(pictured),* who has spina bifida, hydrocephalus, hemiplegia, speech impairment and epilepsy, was four before we asked for an assessment, though she had been at a special school since she was two and a half. It's important that you request an assessment rather than other agencies because if the local education authority (LEA) refuses, only a parent can take this further.

Our first proposed statement failed to quantify the support Gabrielle would need. In brief, she would receive 25 hours support. A physiotherapist, speech therapist and occupational therapist would see her termly to review her programmes and monitor. Nowhere did it refer to her receiving hands-on therapy from a qualified therapist which we believed she needed.

After a meeting with the LEA, a further proposed statement, a final statement, a meeting with the conciliation officer (at our request) and us producing an independent assessment quantifying Gabrielle's needs, it seemed the LEA did not want to negotiate so we decided to go to an educational tribunal.

In preparation for the tribunal it was essential to have a good knowledge of the Code of Practice, Education Act, Gabrielle's assessments, and what a statement is and how it is supposed to be used. We also wrote down a brief history of Gabrielle, what she could and couldn't do and where she was at now. The questions we prepared for the LEA were clear, to the point and not clouded emotionally. We took a photo of Gabrielle so the panel could see she was an ordinary little girl, not a number.

We did not take a legal representative but if you don't think you could cope alone, it would be useful to take one.

We became very stressed waiting for the tribunal. But we knew our case backwards which really helped.

Before going to tribunal, you need to check the facts the other side will be presenting, for example, we were told the speech therapist would go into school weekly for the first half term but on checking with 'health' we found the therapist might see 10 children in a morning and Gabrielle might be last. This kind of information was useful to point out to the panel.

The tribunal hearing was straightforward and informal and the panel appeared to be fair. They wanted to hear the facts and could see behind the LEA's prevarication. Luckily for us, the LEA was not well prepared and had no witnesses but this will not always be so. It is important to take notes and challenge anything you don't agree with or that is incorrect; your witnesses will help – in our case an OT and a speech therapist.

The decision arrived two weeks later. Feeling sick and shaking, I opened the letter. The panel had found in our favour and ordered that Gabrielle needed at least weekly physiotherapy, speech therapy and occupational therapy. At times following surgery, this may have to be increased. It was great to have won after months of fighting and worry.

Gabrielle has started mainstream school and her support is in place (not without numerous phone calls to the LEA which was slow to implement!) The transition has been quite a culture shock to all of us but with support Gabrielle has coped really well and the school has been very supportive.

Already she has made great progress and enjoys school and her confidence is increasing. We know we made the right choice and it has all been worth it.

ASBAH's future

Draft plan proposes radical shift in focus

A RADICAL shift towards high profile lobbying and campaign work is included in ASBAH's draft strategic plan – which goes out for consultation with our stakeholders at a series of regional meetings starting this month (March).

While the plan stresses that ASBAH will be the only voluntary organisation which continues to stick up exclusively for people with spina bifida and hydrocephalus, it says that ASBAH can no longer claim to be all things to everybody with spina bifida and hydrocephalus, their families and the professionals who work with them.

The plan, when finally approved by ASBAH's board of trustees later this year, will set the framework for our work for the five years from 2002 to 2006.

New fundraising strategies will be employed – in an increasingly competitive world – to significantly increase ASBAH's annual income.

Until that increase happens, our overall spending on services will be kept to its present level. This will not preclude bids for project work funding.

The plan recommends where we should concentrate our direct services. Broadly, these are: support to new parents; educational matters; specialised healthcare support; helping young people with SB/H to find services which enable them to have more control of their lives; and responding to the needs of adults and older people with SB/H.

In many cases, this will mean using other agencies – once they are properly informed and adequately trained – to work with our service users. We shall aim to provide "exemplary new services", but only where no other agency is doing so.

The draft plan outlines the legal, social and financial imperatives which now form the backdrop to our work and which require ASBAH to re-order our priorities.

We should keep abreast of human rights policy and practice, meet the growing expectations of disabled members for full participation both in ASBAH and society at large, keep up with developments in medicine and technology... and remember that ASBAH, as at present set up, has for some years found it difficult to break through a fundraising barrier, which is stuck at £2m a year.

Executive director Andrew Russell commented:
"The people most affected will be those individuals and families who have had what amounts to a key worker service from ASBAH. But we can't pretend that this is what everybody has been receiving, or that we can provide this type of direct service as the norm.

"We have already had a wide consultation among members and other stakeholders. All our stakeholder groups want us to have a higher profile and raise our capacity to lobby and campaign effectively – so that we can change policy and practice as it affects service users in the wider society."

The plan confirms ASBAH's intention to complete regionalisation in England, Wales and Northern Ireland. It also stresses the importance of communicating and working as one with local Associations and other bodies. In unity, there's strength, particularly when the statutory services are being approached to fund Advisers and other services.

MEETINGS to discuss strategy with members

REGIONAL meetings are being arranged to discuss the draft strategy with ASBAH local Associations.

Dates proposed at the time of going to press are given below. These will be clarified when the invitations are sent out. If you would like to be involved in the consultations, please phone ASBAH publicity on 01733-421316, tonyb@asbah.org

9 March – Midlands Region
10 March – Eastern Region
22 March – South West Region
29 March – Northern Region
31 March – South East Region
5 April – ASBAH Cymru Committee

AFTER more than 40 years of pain and being told by doctors that his headaches were caused by alcohol, drugs and a nervous breakdown, my husband was finally diagnosed with hydrocephalus.

True Story

Agony of Barry's 40-year wait for correct diagnosis

by Linda Duffin
Selby, North Yorkshire

Barry was born with hydrocephalus in 1946. He was nearly four years old before he could walk and at school he had problems with quite a few subjects, for example, PE and reading. He had headaches and balance problems but was told his headaches were a 'Duffin's complaint.'

We married in 1971 and, on a few occasions, Barry would be poorly with 'vertigo' – or that's what our GP called it.

Two years later, our first son was born. He lived only two days, dying of a cerebral haemorrhage. Our lives were to change from then on.

Barry was admitted to a psychiatric hospital because his headaches were so bad. He used to say it felt like the top of his head was about to blow off. A nervous breakdown was diagnosed and he received shock treatment but he became worse after two sessions, falling over. Then he went to Sheffield for a scan. On the way, he said he would not be able to get his head in the machine as it was too big and this proved to be right. So from 1975, Barry was treated for his nerves and given pills.

He used to say the pain was so bad, if he had a gun he would have killed himself. He would go to bed covering his head with the bed clothes.

From 1946–79, Barry was under the same panel of doctors in South Yorkshire. Then we moved to Selby and GPs were aware of Barry's large head but always thought it had been checked.

In 1987, Barry had an accident at work – a high pressure hose came off while he was hosing down precips at a power station. Hydrocephalus was not to blame but the company would not pay compensation because, after examination, they said Barry's illness had been present from birth.

After all those years of pain and unnecessary suffering, Barry went for more tests at another hospital in 1988.

The CSF pressure was found to be so great, they wanted to operate that night but Barry wanted to spend the weekend at home.

Things started to look up after his first shunt operation. This was short lived as it became blocked and stopped working. Then we had problems making the neurologist understand there was a shunt problem. I was described as a neurotic housewife.

In the end, we 'went private'. After this consultation, Barry received his second shunt. At this hospital we were to meet a gentleman who became our friend until he retired. Barry has had three further shunt operations.

Sometimes Barry has very bad days but we make the most of the good ones. We started going to our local Scope shop to help one morning a week and it was there that we met a lady who told us about ASBAH. Now Barry is not alone with his condition.

As a wife and carer, I hope no one has to endure such pain and suffering. I feel Barry was let down very badly. And I hope no one has to fight for their loved one as I have had to for him.

CALLING all local ASBAHs, wheelchair basketball players and anyone who's ever cared about the rather low profile we've had in the media in the past couple of years!

Help us do something about it. Put the date of ASBAH national awareness day in your diary, and join us in organising our second annual ChairAbility Challenge.

Last year, on 3 October, MPs in Kent , Bournemouth, north Wales, Manchester, Northampton, and Birmingham got into wheelchairs to take part in demonstration games of wheelchair basketball.

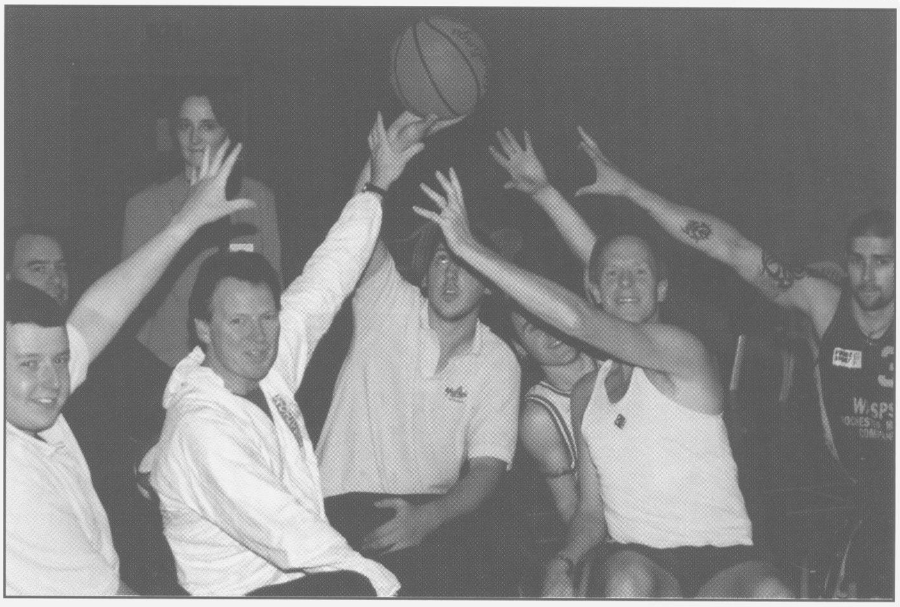
The result was newspaper and radio coverage in practically every venue for a strong, positive message about the power of disabled people – with saturation coverage occurring on Kent, where Kent ASBAH fielded five MPs on the same day.

This year – on Saturday, 13 October – we want to give you the opportunity to join us. And, if you run a local Association, you can have a fundraising event to run alongside ChairAbility.

Invite your MPs to take part, and add a bit of extra spice (and a chance of TV coverage) by gettng your favourite celebrity crowd-puller to take part as well. The idea is simple. What's more we have proved it works!

By working together, right across the contry, we can make much more of an impact this year.

ASBAH needs a wake-up call on media awareness, and on working together. ChairAbility can provide just that.



A scene from one of Kent ASBAH's ChairAbility Challenges last year. Photo courtesy of the Gravesend Messenger.

ChairAbility Challenge

Saturday 13 October 2001

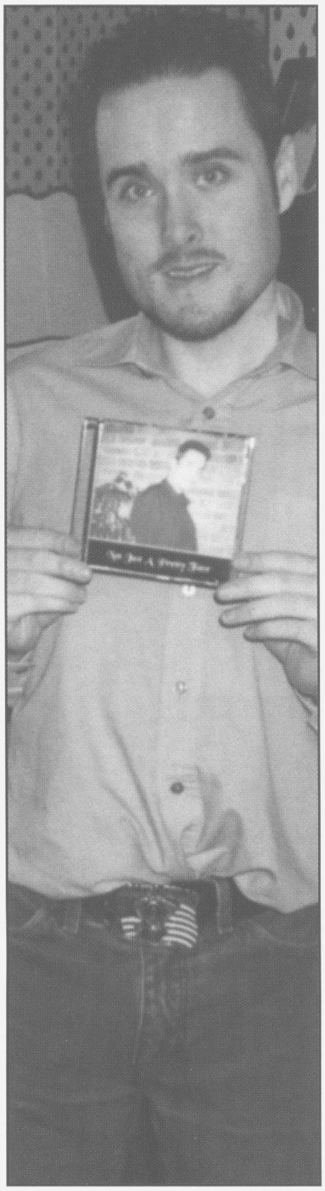
Please join in. To express an interest, or simply check out what to do, phone any of of us on the central steering committee below.

- Linda Hams, asst director, National ASBAH, tel: 01733-555988
- Fiona Godfrey, development officer, Kent ASBAH, tel: 01797-366894
- Jo Francis, SE regional manager, ASBAH, tel: 0208-449 0475
- Tony Britton, publicity manager, ASBAH, tel: 01733-555988.

Helpful checklists, cheerful people!

WE'VE got a checklist and model invitations to help you plan the event, T-shirts for your players and a helpline to help you organise your event. Simply phone ASBAH publicity on 01733-421316 any weekday during office hours to talk things through. The key concept is to get MPs and/or celebrities into wheelchairs, and then get them to play wheelchair basketball – either one-on-one or as part of a team game. Book your basketball court for 13 October. Make sure it's wheelchair-friendly. And remember it's a fun event – so keep on smiling!

people they make us tick!



Cormac cuts CD tracks to grab a performing future

CORMAC BURNS is a singer/songwriter making a bid for stardom with his second CD and a couple of TV appearances.

Not Just A Pretty Face, a demo of four songs, was put together in a recording studio in Newry, County Down, and is now being sent to record companies and other singers.

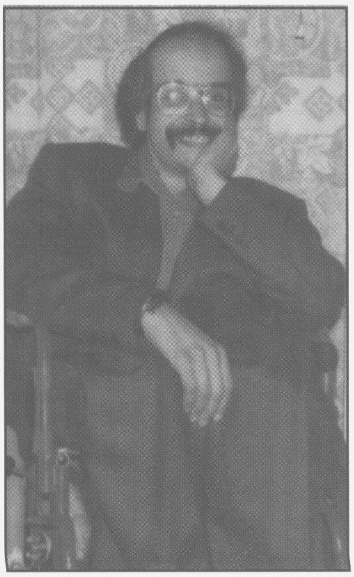
At the end of January, the 27-year-old guitarist performed a couple of numbers on a digital TV show.

Cormac, who has spina bifida and hydrocephalus, hails from a Crossmaglen with loads of musical talent.

Cormac discovered his own abilities at the age of nine when, at the age of nine, he got up on stage and sang at his parents' 25th wedding anniversary. Now he and two of his sisters, Dearbhla and Helena, sing at local weddings.

He said: "A lot of disabled people don't realise what they can do and have their confidence undermined. I was lucky enough to win a scholarship to the States a few years ago and I heard disabled musicians there who were as good as any on *Top Of The Pops.*"

Balbir goes e-mail global



BALBIR SINGH, who had a suit made to fit his exuberant personality on television last year, has come up wth a designer-label way of using new technology to beat the stresses of everyday life. He wants to set up an e-mail network so people with similar interests can get to know each other and keep in touch.

The 41-year-old from Penge, south London, says: "Sometimes we get together at ASBAH events and chat. Then we go to our homes scattered round the country, and lose touch."

He added that the great joys of e-mailing were that it gives time to gather your thoughts and make corrections before sending messages.

If you're connected, then set the ball rolling by messaging Balbir on bsingh2@cwctv.net

Honour for a pioneer

A FORMER nurse beat a million other staff to receive the first NHS Nye Bevan Award for outstanding work.

Jenni Thomas, founder director of the Child Bereavement Trust which ASBAH has supported since its launch in 1994, was employed for years in a special care baby unit where she met many grieving parents.

After training as a counsellor and as a facilitator who herself could train groups of medical professionals, Jenni set up the CBT.

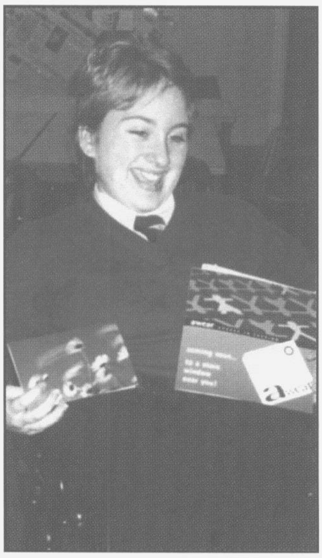
"I am still proud to work for the NHS, which has vision in Buckinghamshire, where I see bereaved parents. Our work is not just when a baby dies but it could be when a child loses a parent," she said.

Lauren's one of the Big Shop winners!

LUCKY Lauren Lewis looked forward to splashing out on a 'new look' after winning £100 in a prize draw run in connection with The Big Shop survey.

The 13-year-old *(pictured below)* was among the many who completed a nationwide survey into the experiences of disabled people when shopping for clothes.

The Big Shop survey, organised by disabled people's fashion charity **awear**, asks for disabled people's opinions about store accessibility, service in store and changes in the shopping environment.



Lauren chose £100 worth of New Look vouchers to spend at her local store in Merthyr Tydfil, Wales.

She was presented with her prize at her school, St Cenydd in Caerphilly, where teacher John Humphries took this photo.

To learn more about the Big Shop survey or about the work **awear** is doing across the UK, phone 0115-9530439, www.awear.org.uk

World class style for British-born ballroom dancer

A TALENTED dancer, who started out training in her cellar, represented her home country in the International Paralympic Committee's first World Championship in Wheelchair Dance Sport.

Ann-Karin Smith and partner Tor Erik came eighth in the Latin American section and ninth in the Standard.

The prizes were presented by Princess Martha Louise, patron of the Norwegian Sports Association for the Disabled, who Ann-Karin met afterwards *(pictured top left).*

Ann-Karin, from Asker in Norway, added glamour to the contest by wearing glittering dresses, created by mum Karina, who has encouraged her daughter to dance since she was 13.

A dance-floor was built in their cellar and Mrs Smith ran training sessions for three wheelchair-users and their friends.

She persuaded the local council to sponsor a trainer and they later moved to training rooms.

For more expert training, Ann-Karin now trains in Oslo at studios used by non-disabled dancers who, she says, are a great inspiration.

The 20-year-old, who was born in Harrogate, is a medical secretary and hopes to become an OT. She said: "I'm happy when I'm dancing, I forget all sad things and all pain ... I'm like a new person!"

This year, she and Tor plan to compete twice in the Netherlands including the European championships.

TV setback for family

CHANNEL 4 has put back for a year the showing of their *Born to be Different* film featuring new parents Rachael and Richard Speirs, of Burnley.

Ricochet Films, which made the programme, said C4 has now commissioned them to make a follow-up film, as a two-part documentary. Emily, who was born last August, has spina bifida.

Big slate of candidates in an 'historic' first election to committee

DEMOCRACY rules OK for *Your Voice*, ASBAH's Disabled Users Group.

After years of confining the election of officers to the central steering group, *Your Voice* gave power to its members last September when, for the first time, everyone could vote members on to the committee.

A total of 34 candidates stood in the historic direct elections to the 15 seats on the committee. Ballot papers went out to the 250 people who had registered an interest in *Your Voice* and had been put on the mailing list.

Encouraging returns resulted in several 'new faces' on the steering group, bringing a range of experience and fresh ideas.

Those elected were:

- Carole Armour (Leicestershire)
- Alan Bernstone (North Yorkshire)*
- Lisa Cain (Essex)
- Geraldine Ferry (North Yorkshire)
- Cora Jones (Birmingham)
- Mary King (Manchester)
- Christine Mannion (West Yorkshire)
- Wendy Mitchell (Liverpool)
- David Nicholson (Northumberland)
- Zem Rodaway (Humberside)
- Beverley Rowe (Sussex)
- Kevin Towner (Sussex)
- Angela Waring (Hertfordshire)
- Janet Waugh (West Yorkshire)
- Paul Zickel (London)

*Alan Bernstone has since had to stand down. His seat on the committee has now been taken by Gerald Everness (South Wales), who received the next highest number of votes.

Lottery support in N Ireland

OUR user-involvement work in Northern Ireland can continue seamlessly, thanks to Lottery funding. The National Lottery Charities Board has awarded our Northern Ireland region an extra £52,612, spread over three years, to support the post held by Helen Clarke.

In her first three years with ASBAH, Helen has uncovered an "information gap" stopping many adult service users knowing about mainstream opportunities.

Over the next three years, Helen will work on an information service for people coming into the office, emailing or using the Internet. She will also help bring the Belfast Users' Group towards self-management and, with colleagues, see if there is similar demand elsewhere in the Province.

Motoring onwards

CLASSIC car enthusiast Paul Zickel is one of the new faces on the *Your Voice* steering group.

Paul (45) works for the Department of Education and Employment in the standards and effectiveness unit of the schools division in central London.

He also benefits from being on the Cabinet Office's leadership development programme – a mentoring scheme for civil servants with disabilities.

"This has been the highlight of my time as a civil servant, due to the generosity of spirit and commitment of my mentor, a senior civil servant at the National Assembly for Wales," he said.

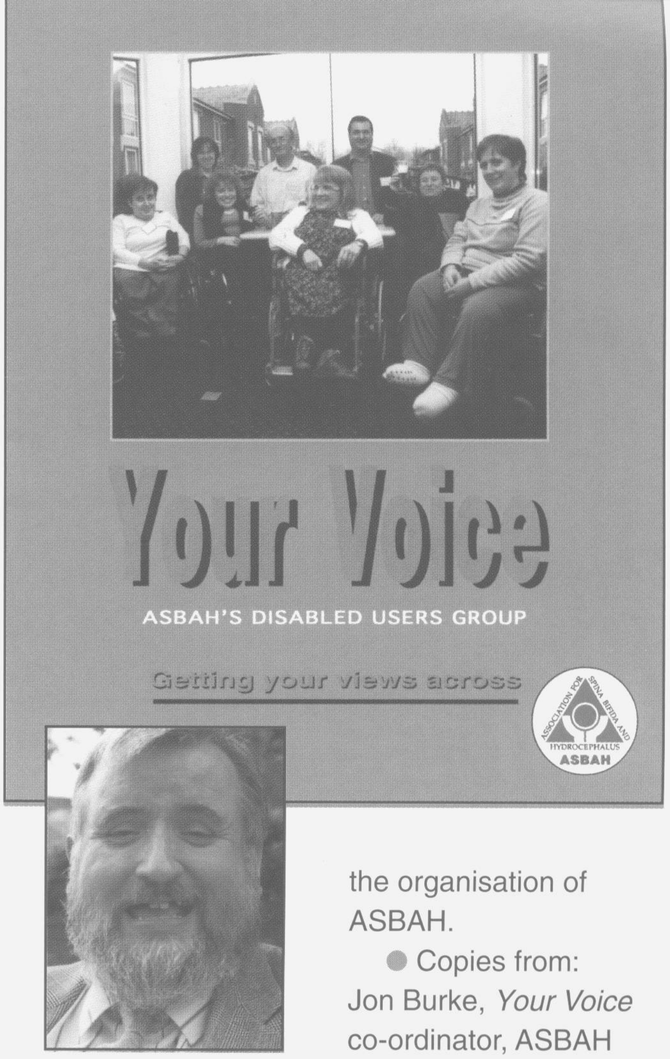
He hopes that both the leadership programme and the Civil Service Disability Network, which he helped launch, will expand.

His interest in classic cars dates from the discovery 20 years ago that he had spina bifida.

He learnt that the seating and layout of the 1962 Rover 110 was excellent for posture and ergonomics and, as he was having severe problems driving, he went out and bought one.

"I could not afford the alternatives which were Volvo or Mercedes!" he said.

Book tribute to a pioneer



THE MEMORY of Terry Denyer, one of the pioneer practitioners of user involvement in ASBAH, has been honoured in the publication of a new full-colour booklet dedicated to him – describing the work of *Your Voice.*

Terry *(pictured, inset),* one of the first chairmen of *Your Voice,* died in 1997 at the age of 52.

The 20-page booklet carries reports on user-group participation so far, testimonials from people who say what inspired them to join, plans for the future, and a photo spread from their last big event in November 2000 – its CIC 2000 conference in Leicester on how to obtain Choice, Independence and Control.

Your Voice was formed almost nine years ago, with the active support of ASBAH's board of trustees and management. Nowadays, well over 250 ASBAH members ask to receive regular mailings about its activities, and organise their own programme of events and training sessions. It is an integral part of the organisation of ASBAH.

● Copies from: Jon Burke, *Your Voice* co-ordinator, ASBAH House North, 64 Bagley Lane, Farsley, Leeds LS28 5LY, tel: 0113-255 6767, email jonb@asbah.org

Angela sets elective chair rotating!

LOCAL government conveyancer, Angela Waring *(pictured below),* was first to bite the bullet when she became *Your Voice's* first elected chair, a position this year being occupied in turn by several steering group members.

The idea behind having a 'rotating chair' is to give more people the opportunity to lead our Disabled Users' Group, which aims to give disabled people a bigger say in ASBAH.

It was back in 1997 that Angela first decided to get more involved in *Your Voice* after enjoying the first Choice Independence and Control (CIC) Conference, held in South Wales.

Since then, the 36-year-old has helped organise other weekends away and has been a vice-chair.

Angela was one of those elected as a *Your Voice* representative in September's ballot and was then voted in as chair by the other successful candidates.

Her three months were up after she chaired the January meeting. It was then the turn of Paul Zickel, previously vice-chair, with David Nicholson chosen as vice-chair – ready to take Paul's place in March.

In future, Angela sees *Your Voice* as getting more involved in the work of ASBAH and having more influence.

In the long-term she would like to see the group also become more effective outside of ASBAH.

Havant MP moves in his fridge!

PORTSMOUTH NEWS

AN ASBAH shop, which Havant MP David Willetts helped refurnish after it was flooded out, has reopened – after a frantic four and a half months getting it back into shape for trading.

After hearing how disaster had struck the shop in Havant's Leigh Park shopping precinct in September, Mr Willetts wheeled in a fridge from his home so shop staff could have somewhere to put their milk and butter.

"We'd only been open for two weeks before the drains at the back of the shop overflowed and six inches of water flowed in through the back door and out through the front," said Christine Cousins, ASBAH's shops co-ordinator.

"It was a real boost to morale to have the support of someone like Mr Willetts in turning the disaster round. We were drying out the shop until January, our insurance claim has now been settled and – although a new floor still has to be laid – we're putting a new carpet in temporarily so the place can earn its keep again."

Stock and shop volunteers are urgently needed once again. Liz Jervis, who manages the shop at 28 Park Parade, Leigh Park, is appealing in particular for spring clothing, bric-a-brac, books and small furniture.

Please phone 02392-450912 if you can help.

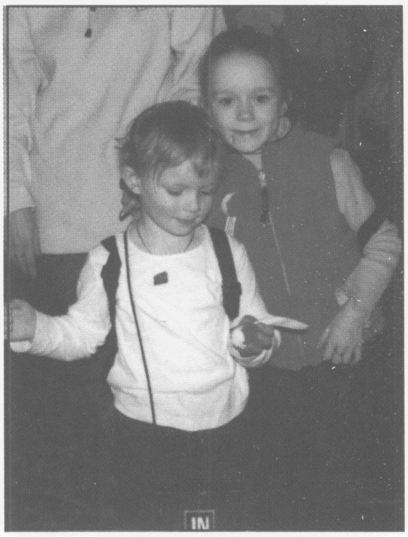
Pigeon
It's the

BRITAIN'S big pigeon racing extravaganza has once again turned up trumps for ASBAH.

The two-day British Homing World 'Show of the Year' at the Winter Gardens, Blackpool, in January presented us with a handsome cheque for £15,000.

This brings the total amount handed over by the event, over the 28 years that we have been associated with it, to a massive £365,000 – making the organisers, the Royal Pigeon Racing Association, the biggest ever donors in ASBAH's history.

And this year, we pulled off an extra fundraising coup – or should that be coo! – when our tombola on the

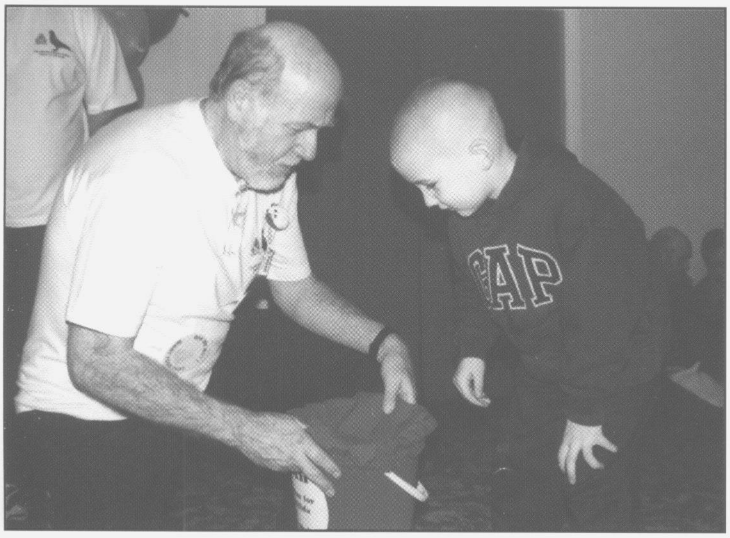


Show tops!

main stairs into the ballroom notched up proceeds of over £1,000 for the first time.

"We remain indebted to the RPRA, its general secretary Peter Bryant, and all the show's supporters for their continuing support," said fundraising manager Donna Treanor.

Photos include: ASBAH executive director Andrew Russell receiving the latest cheque from show chairman Alan Heath (above); show announcer Lesley tootling round on a scooter borrowed from the ASBAH stand; ASBAH adviser Anne Walton working our tombola pitch (right); and husband Reg (below) seen at his persuasive best.



dates for your diary

Great outdoors

SOME people shudder at the idea of sleeping in a tent but, at a site in Surrey, most people prefer a tent to sleeping indoors – at least for the week that a camp lasts.

The tents at Woodlarks Camp Site, Farnham, are roomy and waterproof with comfortable beds and a specially designed toilet block is close by. A mobile hoist can be used in one tent.

Camps run through the summer – some for teenagers but most for adults in various groupings. Outdoor activities are varied with the emphasis on making them possible, with help, whatever your disabilities. The heated outdoor swimming pool in a sun-trap valley surrounded by trees is a great attraction.

Your chances of getting a place on a camp are greater if you can persuade someone to come with you as a helper. Although most weeks cater for either male or female disabled campers, helpers can be of either sex. *Details: Sue, Woodlarks Camp Site, Tilford Road, Farnham, Surrey GU10 3RN. Tel: 01252-716279. www.Woodlarks.org.uk*

Address change

THE CHILD Bereavement Trust, which holds a conference in May for professionals, has moved.

Copies of its latest training programme and publication list from: Child Bereavement Trust, Aston House, High Street, West Wycombe, Bucks HP14 3AG, tel: 01494-446648, fax: 01494-440057; enquiries@childbereavement.org.uk

Upcoming events

Dunstable meeting

Monday 5 March, Dunstable

Monthly meeting for parents/carers of children/young people with spina bifida and/or hydrocephalus, organised by South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. *Details: Valerie Bottoms, tel: 01582-757745.*

Leeds drop-in

Wednesday 7 March, Leeds

Northern Region monthly drop-in on first Wednesday of each month, ASBAH House North, 64 Bagley Lane, Farsley, Leeds. 10–noon. *Bernadette Baldwin or Rachael O'Brien, tel: 0113-255 6767.*

Bromley coffee

Monday 12 March, Bromley

Coffee morning on second Monday of each month organised by South Thames ASBAH, 10–noon, United Reform Church, Bromley. *Peter Winterton, tel: 0208-462 3011.*

Family Fun Day

Saturday 24 March, Glos

Family Fun Day organised by the Gloucestershire Support Group. Civil Service Sports and Social Club, Estcourt Road, Gloucester. 10am–12noon. *Mrs Christine Alexander, tel: 01452-309946 (Gloucester).*

Dunstable meeting

Tuesday 3 April, Dunstable

Monthly meeting for parents/carers of children/young people with spina bifida and/or hydrocephalus, organised by South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. *Valerie Bottoms, tel: 01582-757745.*

Junior Tennis Camp

21–22 April, Gloucester

BTF/NWTA Junior Wheelchair Tennis Camp, The Oxstalls Tennis Centre, Longford, Gloucester. Open to juniors aged between five and 18, only 30 places – first come, first served. Coaching by top wheelchair players, demonstrations, set up and videos. Accommodation, Saturday only, at Longford Inn Beefeater. £15 with accommodation, £10 without accommodation. Parents can be accommodated, ask for rates. *Lynn Parker, British Tennis Foundation, tel: 0207-381 7051, email: Lynn.Parker@btf.org.uk*

Tennis championships

3–7 May

National Wheelchair Tennis Championships, Graves Tennis Centre, Sheffield.

Bereavement issues

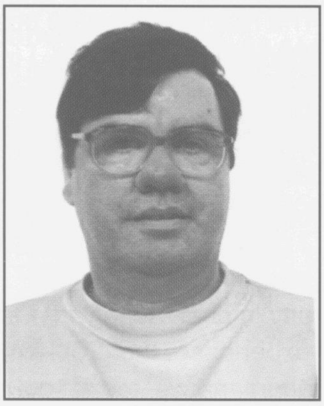
Tuesday 15 May, London

Baby and Child Death, managing the issues, conference organised by the Child Bereavement Trust. Theatre Royal, Drury Lane, London. Keynote speaker: Prof Liam Donaldson, Chief Medical Officer. *Conference Creations, tel/fax: 01491-419800, cbtinfo@conference-creations.com*

They're going for it in glorious Devon

PLANS to put spina bifida and hydrocephalus on the map in Devon took a big stride forward in January – with the formation of Devon ASBAH.

A dozen people turned up at an inaugural meeting in Paignton's St John's Ambulance Brigade HQ to lend their support to meeting organiser Charles Harper *(pictured)*. Another dozen from all over the county pledged their support by telephone.



"Since we publicised the meeting, I've taken calls from people who have never heard of ASBAH and from one man who knows nothing about his own spina bifida," said Mr Harper, who was elected first chairman. He is now supported by a full committee, including Tina Guy (secretary) from Tiverton and Julie Tock (treasurer) from Newton Abbott.

The new association is seeking charity registration before raising its own funds, and is planning a major county-wide awareness campaign. Mr Harper is a former chairman of South Thames ASBAH.

Prospective members should phone: 01803-522256, email:* *cpharper@talk21.com

Want to join your MP for a day?

EVERY year, RADAR organises an MP Shadowing Scheme to coincide with the International Day of Disabled People on 3 December.

The aim is to achieve a forum for a useful exchange of views. This will give disabled people opportunities to find out what really makes their MPs tick and for MPs to learn more about the barriers to full participation in society by disabled people.

The shadowing takes place in constituencies or the House of Commons, or a mixture of both.

Despite their current financial difficulties, RADAR expects to run the scheme again in 2001 – as close to 3 December as possible.

ASBAH has already asked for the following people to go on RADAR's waiting list for shadowing their MPs this year:

Hannah Sandford and Sarah Healey (Sussex ASBAH); Mike Lanning (Bournemouth and District ASBAH); Neil Lewis from Oswestry; Lyndon Fishwick from Telford; and our Herts/Beds adviser John Richards.

If you would like to take part, contact Tony Britton, publicity manager at national ASBAH, tel: 01733-555988, email: tonyb@asbah.org

Second West Country revival is under way

PLANS to revive our support group in Gloucestershire swing into action with a family fun morning in Gloucester on Saturday 24 March. The event will be held at the Civil Service Sports and Social Club, Estcourt Road, Gloucester, between 10am and noon.

The group started in a small way a year or so ago. Now it is being relaunched by organiser Christine Alexander, who wants the group to be a reliable self-help resource for the county.

Mrs Alexander, from Longlevens, Gloucester, said the group could lend a helping hand to parents and disabled people often left to cope on their own and who end up feeling very isolated. This could be distressing – particularly for parents with babies and young children with what nowadays are quite rare disabilities.

The mother-of-three, who has a young son with hydrocephalus, added: "We want to build on our small beginnings. Everybody with an interest will be welcome."

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'M 37 years old and would love to hear from females with hydrocephalus. I don't have spina bifida, but it would be nice to hear from people with this condition too. My hobbies are reading, writing to penpals and rubber-stamping.

Mrs Denise Reynard
9 Welbeck Road, Birstall,
Batley, W Yorks SF17 9QG

AMANDA Van Schagen, a nine-year-old wheelchair-user from British Columbia, Canada, would love penpals from the UK. Amanda has spina bifida. Write to her at:

No 55, 11355–236th St,
Maple Ridge, BC V3J 3R1,
Canada

Should have binned it!

AT THE end of last year, your mobility adviser, Linda Knight, wrote in *Link* (November 2000) advising wheelchair-users to keep their chairs clean and well-maintained .

I was surprised by the chair pictured, which had no cushion, a high back and armrests. The rear wheels were positioned so far back that the user could probably not get up a kerb. I imagine this is the cheapest and oldest model in the NHS range. It set me wondering how many people with spina bifida still have one of these chairs. The advice to keep the chair clean, so it moved more easily, was well intentioned but, unfortunately, no amount of cleaning would turn it into a chair that was easy to manoeuvre. I changed the photo caption from "Go on, give it a treat" to "Go on, bin it!"

Much of the difficulty in chair supply is put down to inadequate budgets. In my own experience, the problem is much more complex with poor communication and wasted resources. This was exposed in the Audit Commission report which was published shortly after my daughter got her excellent Bromakin chair.

I had to go to extraordinary lengths to get her a decent chair. I logged all the phone calls, made sure I noted who said what, and researched the subject. Not everyone is going to have the time, the skills or the determination and it shouldn't be this hard to get a chair that is going to aid mobility rather than handicap the user.

Let's hope the furore caused by the Audit Commission report leads to the improved service that the government promised. Maybe ASBAH should conduct a survey to find out whether members are satisfied with their current chair and use the results to lobby for action?

Chris Burgess, Stockport

Anxious rail journeys from Kent to London

ONCE I would have leapt to defend the railways as I have had several uneventful journeys from Exeter to Waterloo, whereby my daughter in a wheelchair and I were met at stations with ramps and escorted via their luggage buggy. However, these were pre-arranged journeys. But now I would like to jump on the *Link* bandwagon to complain about the lack of understanding for disabled travellers.

In August, I took my daughter and her little brother to visit their grandma in Belvedere, Kent. We planned lots of tourist things, including the Dome and the London Eye. Our main obstacle was getting onto the platform itself as Belvedere station has a stepped bridge over the railway line. This is the only entrance, unless you take a three-mile hike along a busy main road.

My 13-year-old daughter is no lightweight (sorry, Kelly) so I was exhausted before I had even bought our tickets and manhandled her onto the train (no ramps unless you book three days in advance). On several occasions, the doors were closing as we struggled on board.

There were no allocated spaces for wheelchairs on the trains we used. So Kelly had to sit in the doorways, being pushed and pummelled by baggage as other passengers entered.

On a lighter side, we had a wonderful day out at the Dome although Kelly did feel she missed out on a lot of things, as we could not get near them because of the crowds. The London Eye was brilliant, too, but difficult to get to as we had several flights of steps to go down from Waterloo Station – luckily my friend brought her strapping husband along for such eventualities, and no end of people stopped to offer help.

We now live in Cyprus, courtesy of the Armed Forces, where I will almost certainly pick up the odd tip on planning military manoeuvres for our next trip to London.

Jo Sheppard, c/o Mr A
Sheppard, Mercury Barracks,
BFPO 59, Cyprus

My progress in Zimbabwe

THANKS for sending me the colourful *Link* as it keeps me up-to-date and on track, like my wheelchair racing.

I have now found someone from the UK, living here in Zimbabwe, who is willing to help me to start up an Association here.

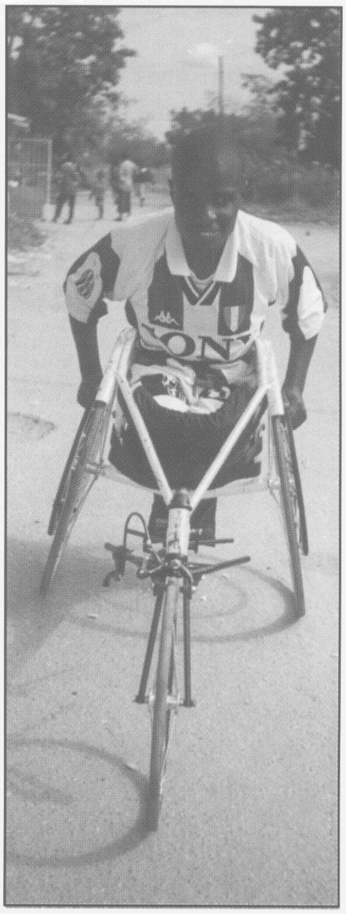
We are trying to find out how many people have hydrocephalus and spina bifida in Zimbabwe, and how many babies are born with these disabilities per week, month or year. My friend is going to help by translating information about hydrocephalus and spina bifida into our languages. It may take a long time but I shall let you know how we are going on with our plans.

My other reason for writing is to ask you to put me in touch with a top wheelchair athlete like Tanni Grey-Thompson as I would like information on training to qualify for the All Africa Games and the 2004 Paralympics.

I was delighted by the profile of Mr Graham Webb in the July 2000 *Link*. I would like to read more such success stories as I learnt much from his story.

Wilson Nyakoko, 18710 Unit L, Seke South, Chitungwiza, Zimbabwe *(pictured right)*

Editor's note – Good to hear from you again! I've asked Tanni to send you info on wheelchair racing.



Guard the future

WHILST broadly welcoming Pierre Mertens' statement on behalf of the International Federation for Hydrocephalus and Spina Bifida (IfHSB) and the statements from the conference *(Link Nov 2000)*, I urge caution before they are accepted as precedents in ASBAH's redefinition of binding principles.

How on earth can we promote acceptance of living with spina bifida and/or hydrocephalus whilst focusing on primary prevention via folic acid etc? The two concepts are diametrically opposed. The former emphasises the 'social model of disability' and the latter the outdated 'medical model', much beloved by the 'normalist' propagandists of the medical establishment.

It is up to those of us who are able to articulate our feelings on this matter to do so, in order that ASBAH truly represents us (those who have spina bifida and hydrocephalus).

The future of ASBAH needs to take into account the shift from prevention or cure to effective management that is not unnecessarily interventionist, but which is person-centred. We owe it to ourselves to pursue this new agenda vigorously, otherwise ASBAH will cease to have a reason to exist.

Chris Page, Letchworth, Herts

E-MAIL CONTACTS

CALLING all emailers! This is the start of a regular listing of contacts in the UK and around the world, especially for you. If you would like to get on the list, contact lizc@asbah.org

Ben Ashwell (25)	**ben.dynamite@talk21.com**
Valerie Bottoms (mum)	**valerie.bottoms@ntlworld.com**
Stuart Brown (32)	**stuart@browns87.fsnet.co.uk**
Neil Gray (26)	**n_gray64@hotmail.com**
Stephanie Meikle (23)	**steffy_m@yahoo.com**
Claire Mooney (30)	**clrmooney@yahoo.co.uk**
Sharon Murray (mum to three-year-old Sean)	**Sharon.Murray@btinternet.com**
Rachel Roberts (25)	**phabulass@aol.com**
Balbir Singh (41)	**bsingh2@cwctv.net**
Rachael Seymour (8)	**rachael@steveseymour.demon.co.uk**
Ann-Karin Smith (20), Norway,	**annkarinsmith@hotmail.com**
Bryan Stevens (15)	**bryanstevens@lineone.net**
LeeAnn Tacchi (20), USA,	**leeann13_@hotmail.com**

DAVE'S DIARY

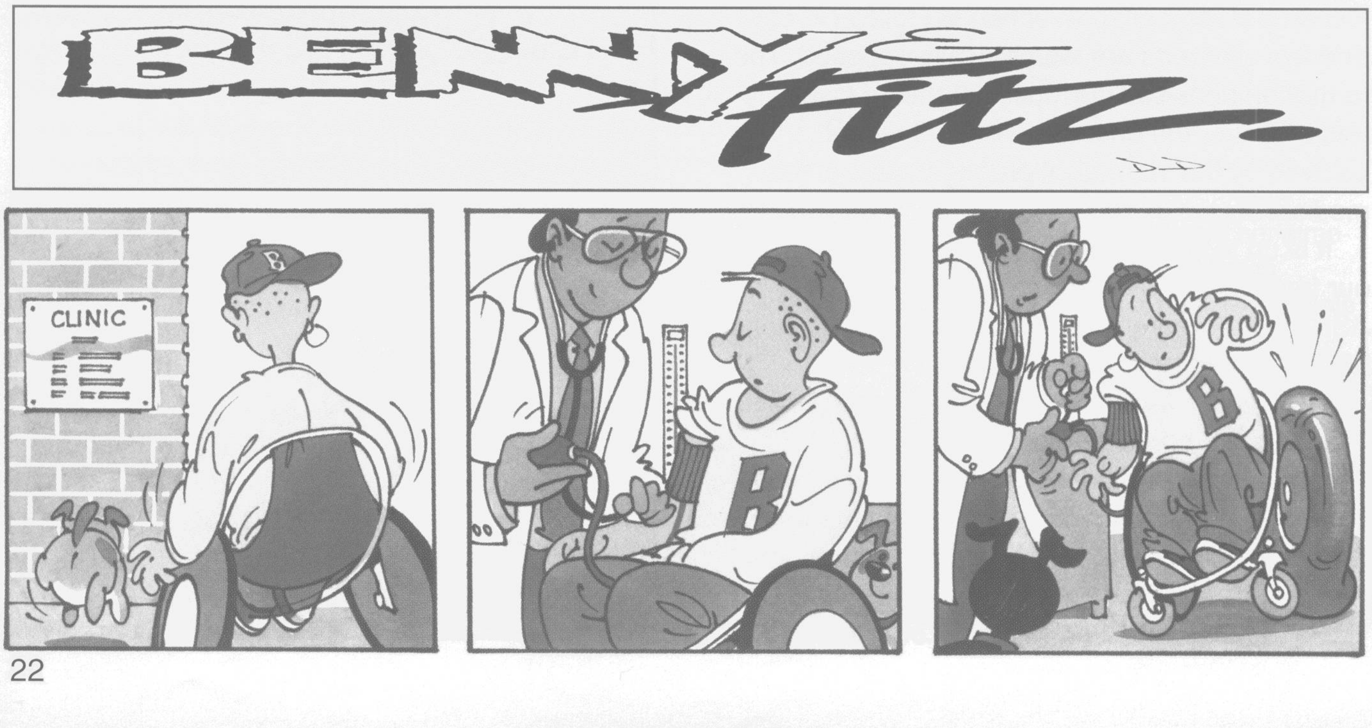
david.fulford-brown@ntlworld.com

Christmas and New Year are long gone, but I'm still weary from the combined flu and kidney infection I came down with before New Year's Eve. After days of bed rest, and taking antibiotic tablets the size of torpedoes, my New Year's Resolution was to keep a better watch on my waterworks.

Not that I have all that many problems these days, thank God. Not like when I was young. Back then I used to test positive for infections so often, and stuffed so many antibiotics down my neck, it's a wonder I don't still rattle. But the worst, the absolute worst, thing was being incontinent. Far from being the big joke some people make of it, being incontinent made my (and I think my family's) life an absolute misery. Only very gradually did things improve. First when I moved from the accursed and ancient reusable rubber leg-bags that used to chaff and itch abominably to the modern disposable gear, then when I went to Sheffield for an artificial sphincter op. Although initially it wasn't a total success, the operation has now improved my life so much I sometimes forget the past. I've had a couple of reminders recently.

Last Christmas I was vainly trying to get out of walking round shops by buying stuff off the Net and from catalogues. Flipping through a catalogue I was horrified to see the same sort of old rubber leg bag that had made my life so miserable, being flogged as an aid for old people. I just cannot believe that in this age of exercise regimes, drugs, surgery, catheters and modern disposable equipment, someone is still flogging this old stuff to people who may be too embarrassed to get professional help (and modern equipment). I wrote to the catalogue people but got only a vague reply about them trying to sell the new systems I suggested. I want to do more to stop people who don't know any better living in misery with old-fashioned equipment. I don't know much about the law but I'd dearly love to know the legalities of selling medical equipment in catalogues. And if you see these things being flogged, please let me know!

On a happier note, recently Channel 4 did an excellent programme all about incontinence. It was wonderful and disturbing. The people on it spoke of their problems with incontinence. It was wonderful to hear these things said. But as I listened, all the bad old memories came flooding back. I sat on the sofa nodding in agreement and muttering 'Yes' and 'Been there, done that'. I'd experienced everything they spoke about. But what really surprised me was that the people featured didn't have things like spina bifida causing their incontinence. In fact, it seems a staggering number of 'ordinary' people have to deal with incontinence at some point in their lives. But of course they couldn't possibly have spoken about it to friends or neighbours (some of whom probably had the same problem!). But now it *has* been spoken about. Hopefully people will realise they can talk about incontinence, they can get modern help. And they are not alone.



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