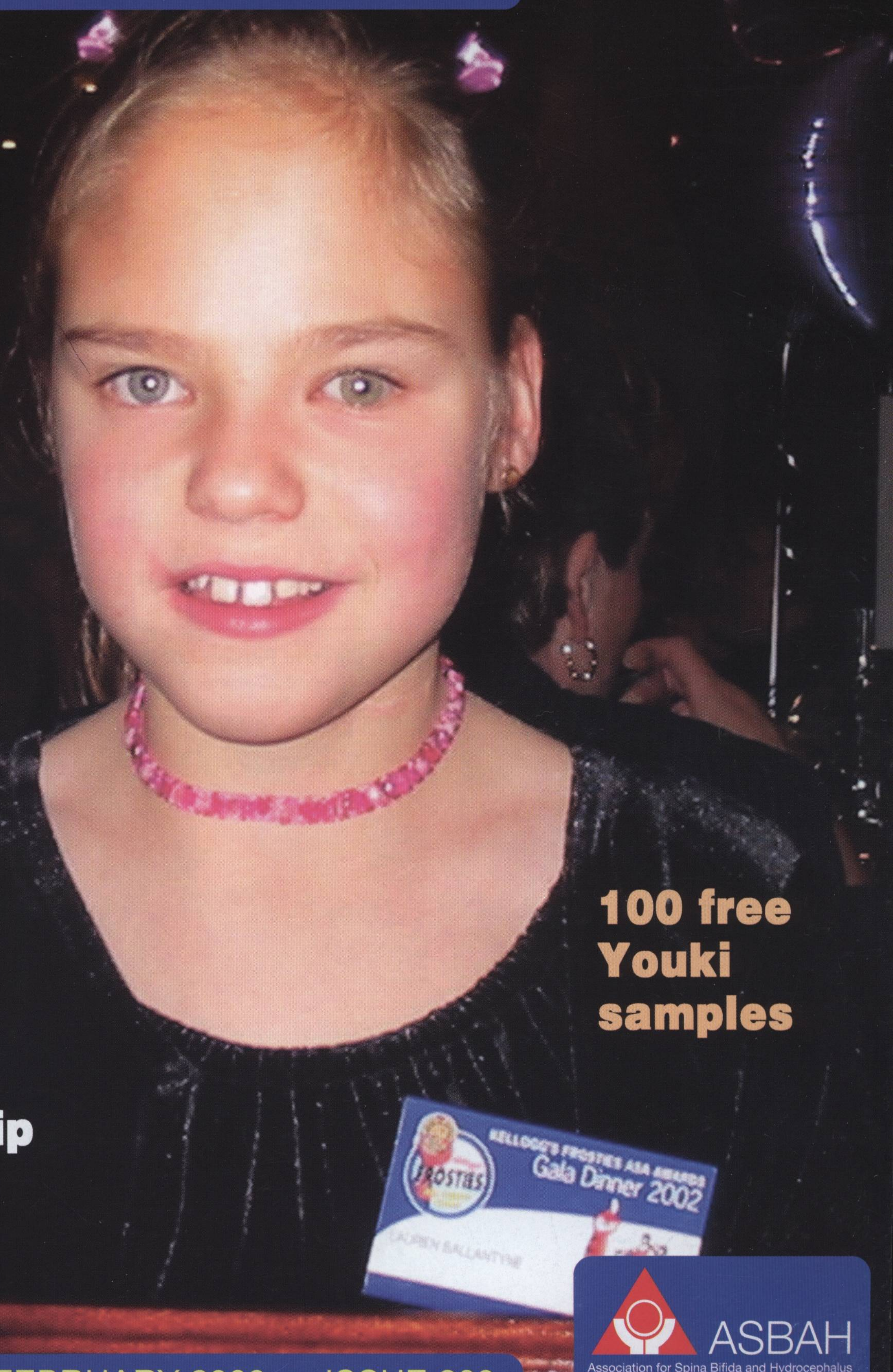
Link

The magazine for people with Hydrocephalus and Spina Bifida



Lauren makes a splash

Sports award

Boxing Day dip

100 free Youki samples

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JANUARY/FEBRUARY 2003 ISSUE 203

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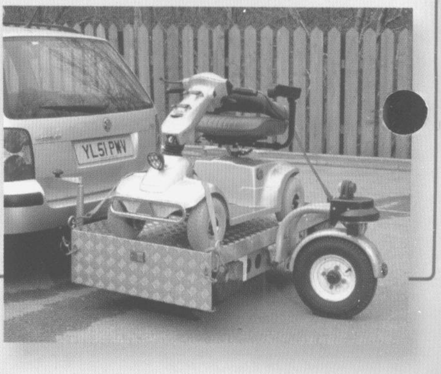

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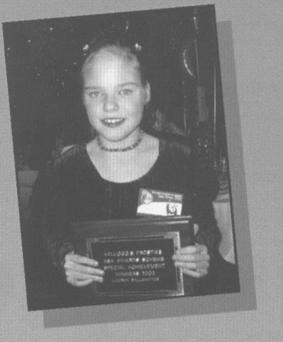

Cover: Lauren Ballantyne (8) won an award from the Amateur Swimming Association (ASA) after years of determination, effort and stubbornness. Story on page 16.

Editorial

THE START of a New Year – with new hopes, goals and challenges. We start 2003 with a number of changes. Tony Nero, our designer, has been working on the design of ***Link*** to make it brighter and more modern. Hopefully you will agree – do please let us know what you would like to see more of – and perhaps less of too! It is the magazine for all of ASBAH and we do try to cater for all of our readers – but do let us know how we can improve it.

A team of seven – including parents, advisers, local association committee members and service users – have all volunteered to form an editorial panel, offering guidance and ideas of new areas which ***Link*** might cover.

Amidst all of these positive signs it is with sadness that editor, Liz Cawthorne, who has been involved with ***Link*** for eight years, is leaving us. Liz has done an excellent job, with very little resource, in moving the magazine forward and reporting informatively on a plethora of issues affecting many of your lives and sharing with you your achievements, sadness and challenges. I am sure that you will join with me in wishing her every success in her new role.

A happy new year to you all, please keep sending your news and views – photos are especially welcome.

Best wishes

Pete

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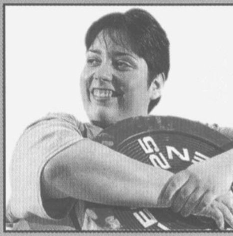

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Flight to the USA ● Page 16

Teach 'em young ● Pages 19–2

Goodbye 'Mac' ● Page 28

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ASBAH's vision is a future where everyone with spina bifida or hydrocephalus can get the most out of life.

ASBAH's mission is to work with people with spina bifida and/or hydrocephalus, their families and carers to promote individual choice, control and quality of life.

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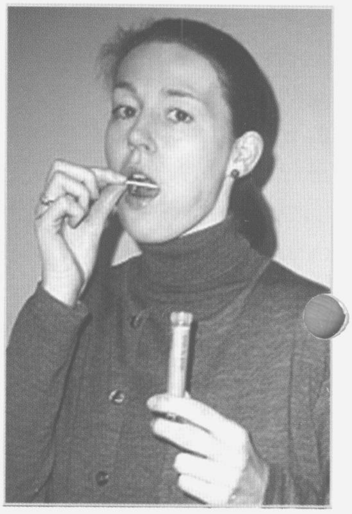
ASBAH
Association for Spina Bifida and Hydrocephalus
Getting the most out of life

New 'risk gene' identified by Irish and American researchers

AS reported in *Link* last year, researchers from Ireland and the United States are conducting a study on the causes of spina bifida. Their research has previously identified how a certain gene interacts with folic acid.

New results, in Ireland, have identified another genetic risk factor for spina bifida. The researchers have found that a genetic variation in a folate-related gene is associated with an increase in the risk that a woman will have a baby with spina bifida or another neural tube defect.

These findings, which help to explain the protective effect of folic acid, have been made possible by the cooperation of families like yours taking part in the study.



Your help needed

By including ASBAH members in England and Wales, the researchers will be able to verify if the same genes are involved throughout the UK, and identify further risk factors. So the potential for further understanding of spina bifida is tremendous. Identifying the genes that affect the metabolism of folic acid will improve our understanding of how spina bifida arises, and ensure that better guidance and nutritional information is available for families at risk and mothers-to-be.

Therefore, ASBAH would very much encourage you to take part in the study, which asks individuals with spina bifida and, if possible, their parents to collect their own DNA by taking cheek swabs using a home-testing kit. The study requires very little work for the volunteer. It is simple, painless and can be done in your own home. All information given will be held in the strictest confidence.

So far, 582 ASBAH families have agreed to participate in the study and 364 families have returned their samples. We would hope the remaining families to return their samples by courier as soon as possible. If any family has misplaced any items from the pack, the researchers will send you a new one.

Remember – the more families who take part the greater the chance of finding an important result.

● For more information, freephone 0-800-1699050, or email Gill Winfield gillw@asbah.org for an application form.

Further information on the research can be found in *American Journal of Human Genetics* (reference: Am J Hum, Genet 71: 1207-1215, 2002).

Health talks for better services

ASBAH'S staff in Wales and several service users and carers met with the director of the Specialised Health Services Commission for Wales (SHSCW) in November to discuss the standards and care pathways needed to enable children to obtain the best possible service from the NHS in Wales.

Elin Ifan, manager of ASBAH's service in Wales, said that all those who had taken part felt the day had been very worthwhile, and Dr Gillian Todd, director of SHSCW, commented afterwards that the day had been a real 'reality check.'

Participants have now received the draft 'Standards and Care Pathways' from Dr Todd for further comments.

The draft includes service principles, the key to which was the need for specialist service co-ordinators to ensure that service users received a planned, effective, person-centred service from the NHS in Wales.

New Year's honour

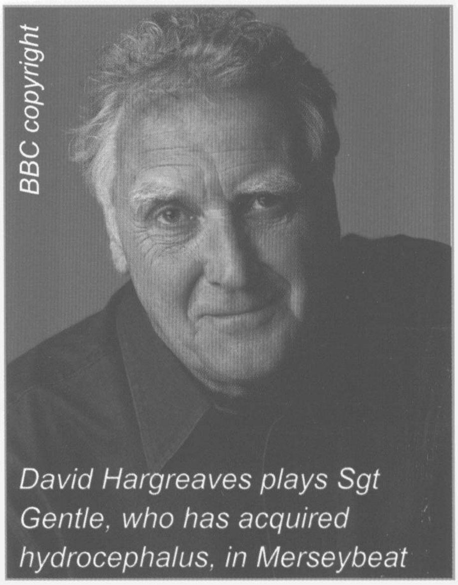
A FOUNDER member of Northern Ireland ASBAH and the Mid Ulster branch has been awarded the MBE.

Jimmy Rippey, of Cookstown, (*pictured*), is absolutely delighted although he regards the honour as not for just him alone, but for others he has worked with as well.

Two BBC drama series feature hydrocephalus and spina bifida

THERE'S been a boost in the general public's awareness of hydrocephalus, and spina bifida, thanks to portrayals in two popular BBC drama series this winter.

Researchers from BBC 1's *Merseybeat* and *Holby City* consulted ASBAH on how the conditions should be treated and how the storylines about the characters concerned should be developed.



BBC copyright

David Hargreaves plays Sgt Gentle, who has acquired hydrocephalus, in Merseybeat

And, so far, ASBAH service-users have given the thumbs-up to the treatment of hydrocephalus, which was acquired by *Merseybeat* character Sgt Bill Gentle.

In the last series, Sgt Gentle (played by David Hargreaves) kept putting off going into hospital for an operation, because he wanted to help in the search for a rapist.

In the end, he got a knock on the head as he was trying to make an arrest and collapsed. He was rushed to hospital and was going to have an emergency operation but he 'flat-lined', due to drug reaction, and had to be resuscitated.

In the current series (Mondays at 9pm), we found out that Sgt Gentle is fine, and had some time off work to recuperate. He eventually returns to work after recovering well. From nuances in the script, viewers are being made aware that work colleagues are making allowances for some of the effects of his hydrocephalus.

Unfortunately, ASBAH felt the *Holby City* portrayal of Lucy, who has spina bifida, was a missed opportunity. The episode was screened in early January.

Lucy, a wheelchair-user, had been in and out of hospital all of her life. Her mum, Denise, walked out on the family when she found out that Lucy had spina bifida. Denise still loved her husband, Clive, and wanted to be there for her daughter but didn't think she could be. Denise didn't know if Lucy would ever be able to understand why she left. Dad Clive was having a heart bypass and his main worry was Lucy. He was worried in case anything should happen to him in surgery – who would look after his daughter?

Dr Margaret Borzyskowski

Malgorzata Borzyskowski MBBS FRCP, known as Margaret, was a distinguished Consultant Neurodevelopmental Paediatrician at Guy's Hospital, London.

As a student she won scholarships and qualified with Honours from the University of Newcastle-upon-Tyne in 1971. She gained Membership of the Royal College of Physicians in little over two years after qualification and was subsequently made a Fellow. In 1986 she was awarded the prestigious Ronnie MacKeith Prize.

As a junior doctor Dr Borzyskowski worked in Newcastle, Oxford and Great Ormond Street. She became a Paediatric Registrar in 1975 in the Guy's Health District.

In 1978 she became an Honorary Senior Registrar at Guy's Hospital and went on to become a Consultant in 1990. She was very involved with the care of children with disabilities and carried out developmental assessments. Her expertise in children with spina bifida led to significant research into the neuropathic bladder. She had experience of child psychiatry at the Maudsley Hospital and had a special insight into the psychological problems of incontinence. For the past seven years she was a member of ASBAH's Medical Advisory Committee.

She lectured widely and had many international publications to her name as a leading expert in the management of the neuropathic bladder. She contributed enormously to the Society for Research into Hydrocephalus & Spina Bifida (SRHSB) and served on the Executive Committee. Margaret was truly talented and well liked by her colleagues and patients. She faced a long illness with enormous courage until her death in October and will be remembered as a very special person. She is survived by her husband Professor Jonathan Webb and two sons.

Good news for Motability drivers

A RISE in mileage allowance and the elimination of worries about wheelchair damage are among a package of improvements being made to vehicle hire scheme Motability.

The changes, from 1 February, coincide with a new structure for the scheme to help streamline service delivery.

The fresh approach includes:

- Eliminating worries about wheelchair damage – any genuine damage to cars from mobility equipment will now be included as normal fair wear and tear.
- More miles – all new contract hire agreements will include a 25% increased allowance to 45,000 miles; all miles above this cost 10p a mile.

For agreements which started before 1 February, customers can drive up to 38,000 miles without extra charges.

- Contract hire customers may be able to buy their cars after their contracts end, subject to certain conditions.
- Better HP packages will give a more attractive way to buy a new/used car.
- Partial refunds of advance payments will be simpler to obtain. Applications will now also be approved even when a customer's allowances fall up to six months short of the three-year agreement period, without the need for an extra deposit.
- Correspondence will be friendlier and easier to follow. Customers will deal with Motability Operations.

medical update

Reader offer

100 Youki trial size bottles and creams to *Link* readers

LAST issue, we ran a story about the success the Bennetts family had had healing 17-year-old Will's pressure sore with Youki – a spray derived from natural sources.

Mrs Sharon Bennett, of Cornwall, said: "We never would have believed the pressure would have healed in 10 weeks. We had been told it would take 3–6 months."

When the surrounding skin looked healthier, Youki Skin Repair Cream was applied and once the sore closed, this cream was placed on the sore itself.

The manufacturer, Depeche Mode Laboratories, is now giving away **100** Youki trial size bottles and creams to *Link* readers, on a first come, first served basis.

Just send your name and address to: ***Depeche Mode Laboratories, PO Box 2365, Maidenhead, Berks SL6 8WJ. To qualify for a free sample, please mention* Link *in your letter.***

- ***By featuring this offer in* Link *is not an endorsement of Youki by ASBAH.***

Keep 'em on you

TRAVELLERS are being warned to keep medical supplies and/or medical records in a handbag or pocket after hand luggage belonging to one ASBAH service-user was refused at a security check.

Now that security has been tightened up at airports, ASBAH medical advisers suggest that essential items belonging to service-users are kept about their person.

Gill Yaz, specialist adviser (medical), based at our South-East Regional Office, said: "In these days of heightened security, you don't know what will be refused on a flight. We suggest you keep essential items in your pocket. Bulky medical equipment should be labelled 'Medical Supplies – Urgent' and you should see that it is put in the hold. If it is refused at security, you should make a fuss about it and see that it gets on board."

Well Away

By Clare Heyland
ASBAH's Independence Adviser
Northern Ireland

EIGHT young people from across Northern Ireland enjoyed an ASBAH weekend at the Ballinran Centre close to the Mourne mountains, County Down.

The aim was to help young people improve self confidence and self esteem through being away from home in a group situation. In addition, the weekend focused on team work and communication skills.

Young people tapped into their creativity to explore co-operation and negotiation, through art and drama. When the weather permitted, everyone enjoyed a variety of energetic games outside.

There was also free time for music, television, chat and snooker. A highlight of the weekend was a fun-filled challenge in which precious points could be built up to postpone bed time and lights out.

Feedback from those participating, and their parents, has been very positive. The weekend was funded by Right Fit (a Glaxo SmithKline/Barnardo's initiative). We now have to find further funding to continue running these valued aids to achieving independence.

Sporting life

By Marshall Thomas

AS 2002 drew to a close, the annual round of sporting awards celebrated a highly successful year for Britain's athletes. The British Wheelchair Sports Awards, run by the British Wheelchair Sports Foundation, was held in Reading at the end of November.

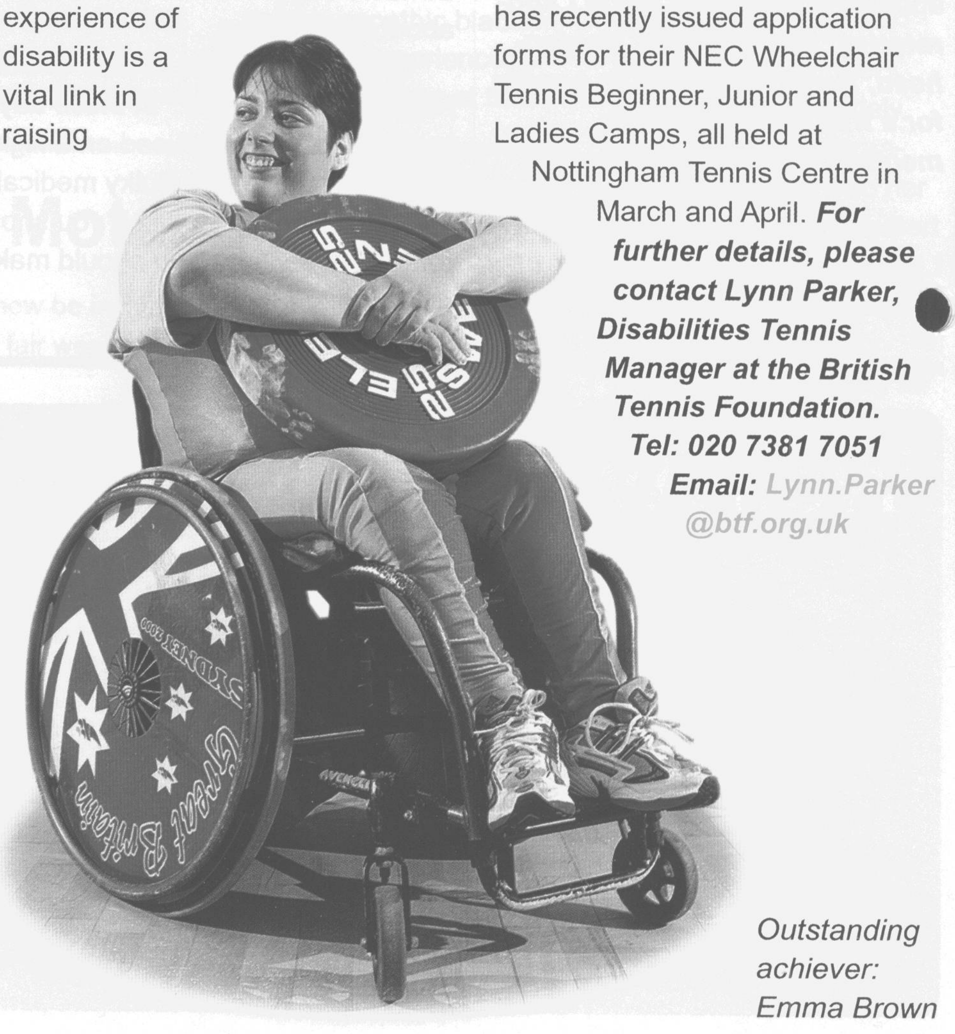
The award for Outstanding Individual Female Achievement was won by Emma Brown (*pictured below*), from Pontypridd, Wales. After twice breaking the world record to win Gold at the 2000 Sydney Paralympics, Emma was seriously injured in 2001 and required surgery. In fighting back from injury, she had to change her technique as she returned to competition and full training, but her comeback was completed in August when she competed in the World Powerlifting Championships in Kuala Lumpur, winning the gold medal in the 82.5 kg class. On all four of her lifts she set new World Records finally breaking the existing standard by 9.5 kg to set a new level of 135 kg. Emma has won many awards, including Welsh Woman of the Year and is a great ambassador for wheelchair sport.

Also among the award winners were GB Men's Wheelchair Basketball team, who won silver in the Gold Cup, the sport's world championships, with talents of Jonathan Pollock, featured in the last *Link*, given particular mention in the team's citation for the award. The basketball team were also joint winners of the Disabled Sports Personality of the Year award at the Sports Writers Association Awards in London.

The British Wheelchair Sports Awards also honours an individual journalist each year who makes an outstanding contribution to the coverage of wheelchair and disability sport in the media and the important role this plays in raising the profile to a wider audience. The winner of the 2002 Award was Rikki Singh, who works for BBC Sport and whose own passion for sport and personal experience of disability is a vital link in raising the profile of Britain's disabled athletes.

Although nominated for the Outstanding Individual Male Achievement award at the BWSF Awards and also for the Lawn Tennis Association's Disabled Player of the Year award, Jayant Mistry was beaten to both awards. However, the British Men's No 1 wheelchair tennis player did end the year on a high, as he was one of four top international players to take part in a wheelchair tennis exhibition match at the Davis Cup Final between France and Russia in Paris.

The British Tennis Foundation has recently issued application forms for their NEC Wheelchair Tennis Beginner, Junior and Ladies Camps, all held at Nottingham Tennis Centre in March and April. ***For further details, please contact Lynn Parker, Disabilities Tennis Manager at the British Tennis Foundation. Tel: 020 7381 7051 Email:*** ***Lynn.Parker@btf.org.uk***



Outstanding achiever: Emma Brown

A Constant Fight –

our survey of your views on services makes waves in the Department of Health

YOUR experiences of local health and social services provision – and the improvements that we believe would drastically improve the quality of life for families and individuals – are now being taken on-board by the Department of Health.

Researcher Sue Thompson recorded the views of 72 of our service-users (50 adults with a disability and 22 parents) to help ASBAH produce a document that would influence two National Service Frameworks (NSFs) being drawn up by the Department of Health.

Working under the auspices of Sheffield University, Sue also drew information from 28 ASBAH staff members and 16 non-ASBAH professionals.

Overall findings and a list of signposts on how services could be made better for people with SB/H, were presented as a published document to the Department of Health last Autumn.

The concerns raised by *A Constant Fight* – the need for accessible and co-ordinated services for children and adults with hydrocephalus and/or spina bifida – have already been taken on board by the NSF for All Children. Our Adviser for Manchester, Marcia Conroy, has furthered our representations to this National Service Framework team as a member of its external working group on disability.

There are also encouraging signs that *A Constant Fight* has been well received by the DoH team working on the National Service Framework for People with Long-Term Neurological Conditions.

Andrew Russell, ASBAH's executive director, said: "Although the NSF initiative applies to England, we believe the standards eventually published will be influential in Wales and Northern Ireland also, perhaps in modified form.

"We are very grateful to everyone who took part in this research as each individual viewpoint has contributed to a wider picture which ASBAH is using to shape the provision of health and social services for people with spina bifida and/or hydrocephalus and their families over the next few years."

As well as the Department of Health, copies of *A Constant Fight* have been sent to the Society of British Neurological Surgeons, the Association of British Neurologists, the British Society for Rehabilitation Medicine and other organisations.

Researcher Sue Thompson

"[You] have to start from scratch every time you have to see a doctor," (adult, 30s with SB/H, referring to the wide range of unconnected clinic appointments she must attend).

"You get to that stage where you stop asking, 'cos you lose heart: they won't come to you and suggest or offer anything," (mother of 14-year-old with severe impairments due to H).

HERE are the main findings of ASBAH's report to influence the Department of Health as it draws up a National Framework for People with Neurological Conditions:

Health needs

People with spina bifida and hydrocephalus (SB/H):

- Have a wide range of health needs involving a number of different medical and health-related specialisms.
- Depend upon the provision of health services to meet crucial needs, eg continence care or mobility, in order to achieve and maintain independence and quality of life.
- Require health services which have a holistic approach and are able to work in partnership with the user.
- In addition to their specialist needs, require access to mainstream services such as family planning, mental health, women's health, etc.
- Require better access to health services by entitlement and without having to fight for them.

Social needs

People with SB/H:

- Need a service which supports their transition to adulthood and independence, where it is crucial that social, health, education, employment and emotional needs are covered in a co-ordinated programme.
- Need access to co-ordinated, knowledgeable support/advocacy to enable their successful negotiation of service access, especially with respect to accommodation, equipment, mobility, respite care, employment, etc.
- Require provision of accommodation appropriate to their independent living needs and without the risk of isolation.
- Need services which address the needs of a population with increasing life expectancy, in terms of accommodation, equipment, etc.
- Need services which adopt a holistic approach to provision of equipment including wheelchairs, rather than a narrow medically-defined assessment of need.
- Require adequate financial provision to meet the costs of living with disability.

Parents of children and young people, especially those with multiple impairments:

- Require accessible services which offer them the support they need as well as meeting the needs of the young people.

Meeting service needs

- **Service delivery** is often as important as the service involved – ease of access, continuity of personnel with knowledge and understanding and communication skills.
- **Co-ordination and continuity** of services within and between statutory services.
- **A holistic** approach focusing on user need and not availability of resources.
- **Realistic response times** which do not risk a reduction in user health independence or mobility.
- **Provision of information to users and providers.**
- **Co-ordinated support** for users in navigating the range of statutory (and voluntary) services.

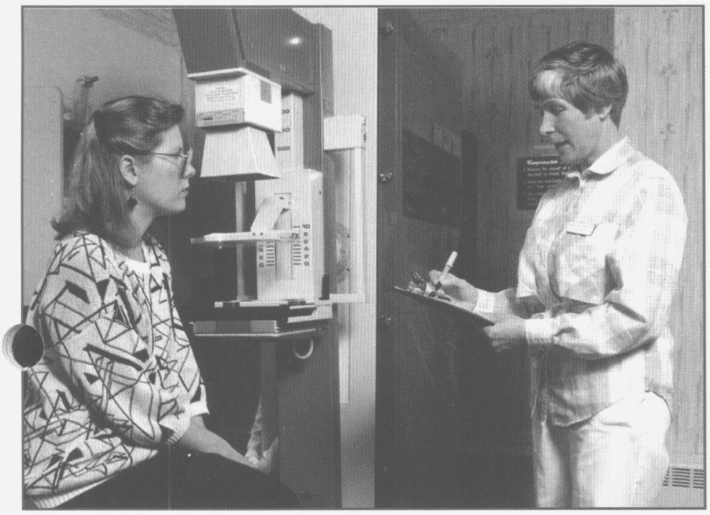
Signposts for the future

- A partnership approach between service providers and service users.

A woman with SB in her 50s contacted social services requesting help in the home. She found the staff variable in quality, constantly changing, and often failed to turn up at all without warning. She felt there was a constant emphasis on what they were not prepared to do rather than what they would do, and little regard for her needs: 'my needs seemed to come last.' She felt the service in no way met her needs but she still needs assistance, and now relies on help from friends whom she pays.

"You get to 16 and certain things are just cut off stone dead, like Physiotherapy – they think once you get to 16 you don't need them anymore," (adult, 20s with SB/H)

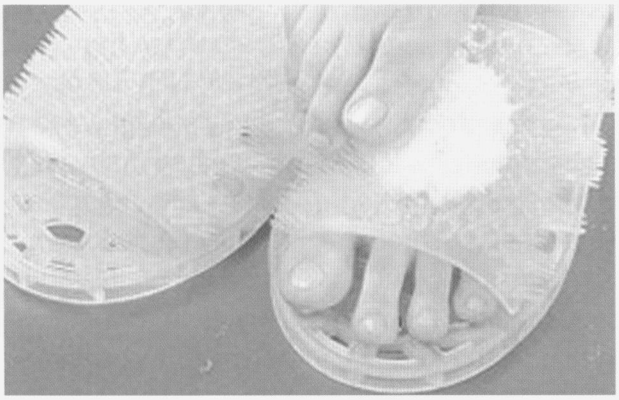
- A clearly identified Care Co-ordinator to operate with parents across the service divide, to offer support and advocacy where necessary and to maximise service use while sharing responsibility and control.
- Regional specialist centres with the knowledge and range of specialist skills to provide a holistic service to users through a co-ordinated approach under one roof, and including an outreach and information service.
- A transition service bridging the service divide and enabling young people to develop the skills necessary to adulthood and appropriate independent living.
- Planning for the future, including meeting the needs of those with hydrocephalus and those reaching older age.



ASBAH advocates a partnership approach between service providers and service users. Go to www.asbah.org/report.html *for our full Executive Summary.*

> ***"Often when I'm an in-patient my general everyday care doesn't go well, despite what's in my care plan," (adult, 30s with SB/H)***

> ***"Everyone will sympathise and understand about the outside things that they can see, but not the inside things, memory and things like that," (mother of 12-year-old with SB and H).***



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A law unto himself

LAST issue we reported that an 18-year-old with a disability is only 40% as likely to enter higher education as his/her non- disabled counterpart. BEN EDWARDS, who has hydrocephalus and is at sixth form college, has high hopes for a place at a university to study law. We hear why and how he applied and what he thinks it's going to be like.

Q: How did you choose your course and why?

It has taken a lot of time researching universities, writing, and redrafting personal statements, but my UCAS form has finally been sent and now all I can do is to wait for the offers to come flooding in!

I decided I wanted to study Law after doing some work experience with a barrister. I am doing Law at A-Level and, last year, took part in the National Bar Mock Trial Competition at Birmingham Crown Court. I saw how cases were prepared by barristers and we had to present two cases which included cross-examining witnesses. It made me realise I want to become a barrister and I think I can do it!

Q: How did you set about finding the right university?

I first looked at the grades they wanted. Then I looked at where each one was and what there was to do around them, and imagined living in that place for three years! I ordered prospectuses from a lot of universities. If you can't make the open days, these are very useful. I didn't go to many open days which, perhaps, was a bad idea. It is always best to look around places before you apply.

I asked my form tutor for help in deciding where to apply as she teaches Law and could tell me where I could realistically get a place. I also asked friends for their opinions after they had attended open days.

Lastly, I looked at league tables as it's good to go to a place that is fairly highly ranked as it can be a deciding factor in getting a job.

In the end, I applied for Keele, Cardiff, Swansea, Northumbria, Exeter and Liverpool.

Q: Will you discuss your hydrocephalus at your interview with the tutors?

I mentioned my hydrocephalus on my UCAS form and I think it will come up in an interview. My hydrocephalus has been mentioned in my form tutor's overall reference and I think it is important they are aware of it as no one knows if and when I might fall ill.

They will probably ask me about the effect hydrocephalus has had on my studies. Through my A-Levels I have discovered that my verbal contributions in class and on a one-to one-basis are far superior to my written work – this could be due to my hydrocephalus; then again, it could just be me!

Q: Will you take a friend with you to help you recall what is said at the interview or don't you feel this is necessary?

I don't feel I need anyone to go with me to interviews, but if you have trouble remembering important information – as we all do at some point – then do ask someone to go along with you (a parent or a good friend).

Q: Maybe you don't regard your hydrocephalus as a disability or aren't aware of any subtle effects?

In some ways hydrocephalus is a disability in that I can't play certain sports or go on scary upside down rides at theme parks but that's all it stops me from doing. I would NEVER class myself as disabled and have had many discussions with friends and family (especially my mother) on this subject. My mum says I am classed as having a disability but I don't think I should be.

I do, however, find it hard to work when I suffer from a very bad headache as concentration becomes very difficult. When these headaches are bad, they are BAD and I find them very difficult to shift with Paracetamol. As I become older I suppose I am becoming more aware of the effects hydrocephalus has on my life – like not being able to express myself in written form.

I have also been told by friends that I amvery opinionated and find it difficult to accept another friend's point of view.

Maybe the problems I have are nothing to do with my hydrocephalus and I'd be self-opinionated regardless of whether I had hydrocephalus or not!

It did cause me major problems in 2001, at the time of my GCSEs, when I had to have three revisions. It beat me for a while as I had a lot of time off school as I couldn't work properly. I then realised that things can go wrong at any time. But I bounced back and did my GCSEs and am now doing my A-levels.

Q: Are you confident about looking after yourself or will you be living at home? How do you feel about that?

The only problems I will have with living in 'hall' or on my own is that my mum will not be there to do all my cooking, washing, ironing and generally keeping me in check!

I think it is important that I leave home and live in 'hall' as I will meet new people, have a good time and gain some independence as I can be lazy and allow too much to be done for me.

Q: Will you share with friends, go into 'hall' or live by yourself. Are you worried about being lonely?

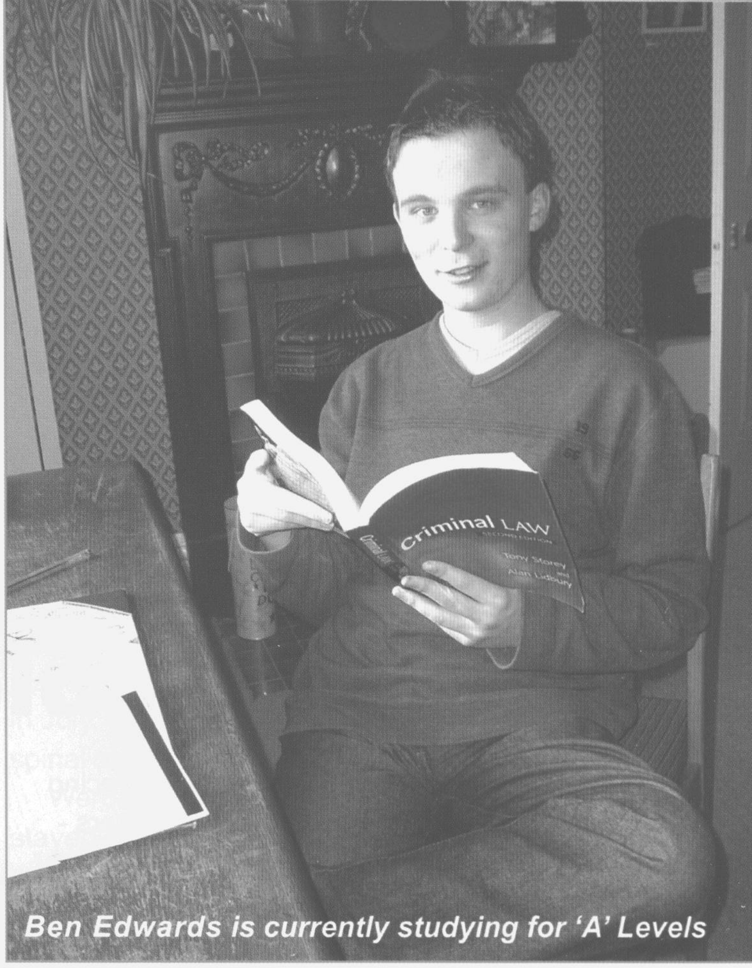
I will probably do what any university student does – live in hall in the first year, then a house with friends in the second year. At first, I might feel alone but gradually, through living in halls and attending social events, I will make new friends and have, I hope, a really good time.

Q: How will you ensure your work is handed in on time? Do you have any strategies for doing research? Do you worry you may forget important instructions, or is this not an issue?

I will have to time-manage and, maybe, do work early – and not leave it to the last minute!

To write essays, I make notes in class, use notes given out by teachers and search for relevant info on the 'net. Sometimes the problem can be having too much, rather than too little information.

I try and make notes on instructions given in class as I do forget what's been said. I don't worry about forgetting instructions – it is only natural: we're all human.



Ben Edwards is currently studying for 'A' Levels

Of course, I can always ask a friend what homework we had – this works just as well as writing it down!

Q: How confident do you feel about everything – ie do you have good reliable friends/family support to make a difference?

I feel very confident at the moment. I'm pleased I have applied to university for the course I want to do and, at the moment, I am on course to do what I WANT to do.

I have very reliable family – I realised how much they care when I was having all those problems in the run-up to my GCSEs.

The teachers are there to help, as they are for any pupil, but my tutor understands about my hydrocephalus and has said that if I end up in hospital again she will help, if needs be.

My friends are there for me, as I am for them. They were very supportive during my difficult time and this helped me to get through it all.

Q: How would you like to be treated?

I want to be treated like any other person and forget I have hydrocephalus. I don't want anyone to take it into consideration unless it is *absolutely* necessary.

Q: How will you handle drugs, alcohol or sex offers?

continued on page 14

from page 13

I have always had a bad view of drugs and will never accept any no matter how well I know the person or how ‘cool’ it may look. Why put yourself in danger with things we don’t understand?

I have smoked, as any teenage boy has, but it wasn’t until my trouble in 2001 that I realised it wasn’t worth doing voluntary damage to yourself.

As for sex offers, my short answer to that would be if there’s a good-looking girl and I like her – then YES please! We will have to see what happens. I will, of course, always practise safe sex but I don’t think sex will be a problem – just gotta find someone who I like and get along with.

I do drink alcohol and will continue to have fun and enjoy a quiet drink with a mate in a pub!

Q: What are your hopes for a job?

I hope to become a high-flying barrister and do really well in the legal world and become famous for my expert tactics in court and my taking part in high profile cases! Not too ambitious. I will succeed in becoming a barrister – whether I’m any good at it, only time will tell.

Disabled jobseekers

RICKY Gervais stars in a new, hard-hitting cinema advert aiming to challenge employers’ perceptions of workers with disabilities.

The commercial highlights one of the many problems facing disabled jobseekers - employers’ misconceptions about the types of role they can fill. Gervais stars as a David Brent-like character who expresses his willingness to hire ‘a disabled person’, but then finds ridiculous reasons why employees with disabilities would not fit into the workplace.

Gervais wrote and directed the commercial for jobability.com, the UK’s leading site for disabled jobseekers. He said: “I chose comedy for the jobability.com script because it’s what I do and it’s also a powerful tool for a serious message. To me, someone who you know is a bigoted idiot saying the wrong thing, does as much good as someone you know who is wise and fair saying the right thing. But the former is a bit more fun. Sadly, there is a bit of all of us reflected in Brent, and that’s the point.”

jobability.com research shows more than three-quarters of companies are unaware of the skills disabled people have to offer. Yet more than one million disabled people are unemployed, despite wanting to work.

jobability.com is run by totaljobs.com, the Leonard Cheshire charity and Microsoft. It offers a free vacancy advertising service to employers who agree to interview any person who matches the job specification – regardless of disability - and can source the best candidates from the CVs posted.

Pastures new

HIGHLY regarded by the families he assisted as well as his ASBAH colleagues, our specialist education adviser, Bruce Graham, has left for pastures new.

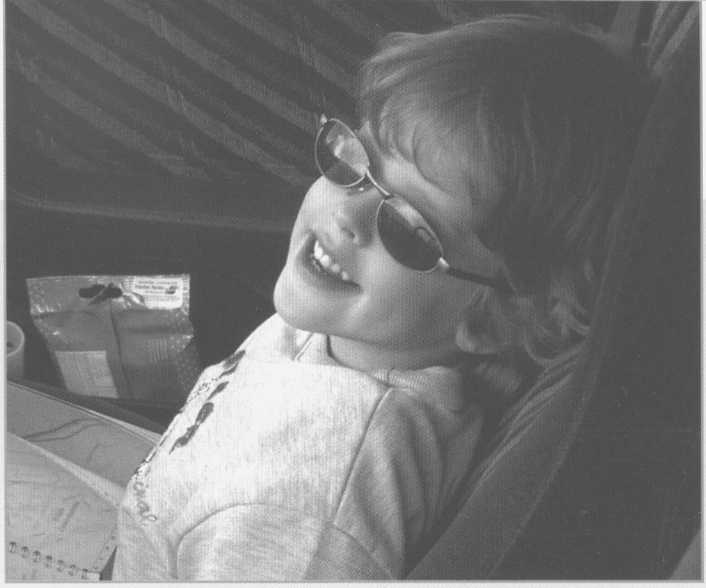
In his four years at ASBAH, Bruce *(pictured)* helped hundreds of families with problems over schools and LEAs.

After 25 years in education, he decided it was time for a change and has become a home-visiting advice worker for Age Concern Oxfordshire.

He told *Link*: “I will miss the support of my ASBAH colleagues and the families I’ve met and last, but not least, the children themselves.”

We’re very sorry to see him go and wish him well in his new role advising people over 50 on benefits, specialist aids, day centres, phone links, etc.

From East to West



2002 was a milestone in the life of Weronika as she made a journey halfway across the world from Warsaw for major spinal surgery and the elimination of a long-standing pressure sore.

Link readers first heard about Weronika soon after she was born, in 1997, when her mother, Rosita Turowicz-Wlazniak, requested information from other parents.

In Spring 2001, Rosita wrote to Chicago's Shriners Hospital for Children asking about the possibility of surgery to straighten Weronika's spine. That summer, the hospital assigned the date of Weronika's arrival to 23 January 2002.

The journey was made possible, Rosita says, by meeting good-hearted people on the way.

"Unfortunately, Weronika left for Chicago with a bedsore on her back. This had been treated in Poland for three years and the plastic surgery that followed was unsuccessful, whereas at Shriners Hospital it healed properly in six months. What followed was successful plastic surgery that led, in July, to seven-hour spinal surgery.

Weronika (*pictured*) stayed on to convalesce, arriving home in September with her mum.

Rosita said: "We cannot adequately express our thanks to Professor Lubicky for the milestone in Weronika's struggle for health and for making her parents' wishes come true. We are also extremely grateful to the Polish emigrants' Gift From the Heart Foundation in Chicago which organised different entertainment for us.

"The stay in Shriners Hospital was out of this world for us."

This year, Weronika starts mainstream school. We keep our fingers crossed for her.

Fisherman flies away with gold

IT WAS gold again for fly fisherman Martin Johns after the Welsh team hauled in the heaviest load of trout in a 'home international' competition against England, Scotland and Northern Ireland.

Thanks to sponsorship from ASBAH and South Wales ASBAH, Martin could more easily attend practice sessions and pay for accommodation during the contest in Corby, Northamptonshire.

Of the 110lb Welsh haul, Martin caught 20lbs of fish over the two days. It was the second time he won gold after qualifying for the Welsh disabled fly fisherman team.

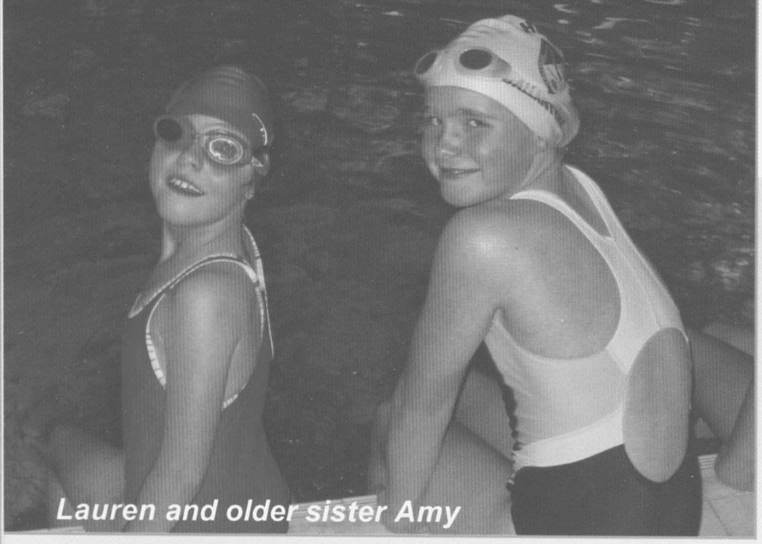
He started out in the sport young. He said: "I just felt that, being in a wheelchair, it was one of the few sporting things I could do, at the time. Now I have friends who I go fly fishing with. I love it."

All sorts of skills are learnt like how to cast a line, knowing about weather conditions, the habits of the fish you're after and entomology.

Martin (39) said: "All our flies are artificial. The closest you can make your fly look like a real insect, the better your chances of getting a good catch."

Usually he travels to the reservoirs of Mid and North Wales to fish, from his home in Pontypandy, Caerphilly.

"Trout are an aggressive species and the fastest you can pull your line in, and the brightest you can make the fly, the more they will snap at it. Or, if you can detect the insect they're after on a particular day, and try and copy that, you may be successful."



Lauren and older sister Amy

Lauren makes a splash

OUR cover girl, Lauren Ballantyne (8), and her sister Amy , made a splash with England swimming stars on the day she was presented with a special award.

Her mum, Lisa, told *Link* that Lauren (8) struggled for a long time to manage any form of swimming, but years of determination, effort and stubbornness paid off.

Last year, Lauren achieved her 100m swim badge, her Waterskills 2, and 25m butterfly. Her swimming teacher, Jane Hossack, was so impressed that she nominated Lauren for an Amateur Swimming Association (ASA) award.

Mrs Ballantyne, of Hereford, said: "The event was brilliant and Lauren was on a high for a long time afterwards."

Born 12 weeks premature with meningitis, Lauren had a brain haemorrhage which left her with cerebral palsy (a right-sided weakness), blindness in one eye and hydrocephalus. She also went on to suffer from septicaemia and pneumonia. Her parents were told on two separate occasions that she would not survive the night.

Mrs Ballantyne continued: "Lauren fought through all this and, in her short life, she has had 14 shunt revisions. She also had a third ventriculostomy which was unsuccessful."

Lauren started swimming at three-and-a-half – inspired by Amy, who swims for Hereford Swimming Club.

A Gala Dinner and awards ceremony, sponsored by Kellogg's, were held at Northampton's Hilton Hotel, where the sisters met swimmers who had represented England in the Olympics, European and Commonwealth Championships.

Well done Ben

AN UNFORGETTABLE two nights in London was spent by the Clinton family when six-year-old Ben won a national award.

HRH Prince of Wales presented Ben with his *Woman's Own* Child of Courage Award at a celebrity-packed service at Westminster Abbey, followed by lunch at the House of Lords.

Then it was off to 10 Downing Street to meet Prime Minister Tony Blair, wife Cherie and baby Leo. The day before, award families had ridden on the London Eye and been treated to an evening meal at the four-star hotel they were staying in.

Ben's mum, Anita, of Newcastle, said: "It was the best time we have ever had. Our other two children, Mark and Emma, were there too. We will never forget our two days in London. Maybe it was a little much for Ben, but he enjoys talking about it now."

Ben has hydrocephalus complicated by having tiny (slit) ventricles. He has spent one third of his life in hospital, which he has been terrified of in the past, though his nurse and nursery have helped him conquer some of those fears.

Despite three operations to remove bone from his skull (sub-temporal decompression), Ben still gets severe headaches with the part of his skull where the bone has been taken away bulging with the high pressure. He also has to contend with eczema which seems to become more itchy when his head bulges.

Mrs Clinton said: "When I found out Ben had won, I was so proud and so happy for him to have some pleasure for all his pain. When I told him, he was jumping all over the house, very excited."

Spotlight on ... Sussex ASBAH

SASBAH back on track

IN THE third of our series on the challenges facing local Associations today, we hear from one of the biggest local Associations, Sussex ASBAH.

IT was a baptism of fire for Beverley Rowe when she took over the chairmanship of Sussex ASBAH a couple of years ago. The group's experienced and committed county organiser of 26 years, Margaret White, had just retired. A difficult period followed when a new general manager started and left fairly quickly to be replaced by another who again only stayed a short while. During this period of change at the top, lots of other established members of staff became unsettled and left, so that at one point, there were six vacancies in the staff team and service provision became extremely patchy. Current general manager, Liz Owen, was appointed in August 2002, after already working for SASBAH for a couple of years as a buddy scheme co-ordinator.

Added to this, in 2002, an administration office and an office base for Sussex advisers was set up. One of the consequences of all these changes, has been greater involvement from the committee and things are now beginning to run on an even keel once more. Margaret is still working as a volunteer, running the Christmas card operation and our two shops.

Fundraising

This has always been an important part of SASBAH's operations as it enables us to provide a wide range of services to our members. We have traditionally benefited from trusts, grants, two charity shops, Christmas card sales, a Christmas raffle, an annual golf day and street collections. Our new fundraising manager, Clive Rimell, is part-time (16 hours a week) and will be building on the tried and tested fundraising methods and also approaching local companies to get involved with the Give As You Earn scheme.

Services

We have a full-time adviser (Zoe Kane) and a part-time assistant adviser (Louise Fardell), partly funded by SASBAH. We have two social co-ordinators, Rom Sanglaji and Lisa Hosier, who each work 18 hours a week, running social events for service users' days out, drop-in mornings, themed events, weekends and organise a buddy scheme for adults with any physical disability.

We are involved with running the fortnightly, multi-disciplinary Chailey Clinic, a one-stop shop for over-18s with a consultant, a specialist nurse, a physiotherapist and one of our advisers present. We are hoping soon to restore the services of an occupational therapist at the clinic. We also run an annual study day, aimed at either service users or health professionals. And of course, there is the housing project.

We run Grand Avenue – an independent living project in Worthing – with a housing association. The rent from the tenants goes towards general costs of the house and support staff. The idea is that people go to Grand Avenue for a period to learn independent living skills and to find out where they would be happiest and most independent. We are aiming, at some point, to open a similar housing project in East Sussex. The SASBAH office is at Grand Avenue but is a completely separate entity from the house. If other Associations wanted to go down this road, they would first have to establish the need and then talk to housing associations locally to establish a partnership.

Beverley Rowe took over chairmanship at a difficult time

What makes SASBAH tick?

A committee of 12 committed volunteers

(including six service users) combined with a team of paid staff has been very important in making SASBAH a success. We have also been helped by having a large membership and a strong presence at Grand Avenue, which fulfils a definite and very real purpose.

In all, we have more than 400 service-users across East and West Sussex, with some 600 members and 18 paid staff, mostly part-time.

- ***SASBAH contact:* Liz Owen, 01903-507000;** sasbah.office@tiscali.co.uk


Photo: Jo Sangster

Staff and tenants at Grand Avenue, Sussex ASBAH's independent living project in Worthing. Back row (L-R): Claire Davidson, Victoria Gander, Harry Monaghan and Jane Hodgkins. Front row (L-R): Katie Baird and Hannah Sandford

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Book review

By Elizabeth Miers ASBAH Adviser

Sexuality & Disability

SEXUALITY and Disability – aimed at health professionals – is based on research which Maddie Blackburn carried out with Dr Martin Bax during the early 1990's into the sexual knowledge and experiences of young people with spina bifida and /or hydrocephalus. The result is an insight into an area of the lives of many disabled people which has been largely ignored in the past.

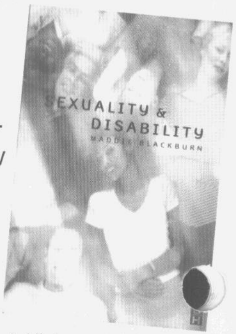
Maddie discusses the ethics of this kind of research, and the moral dilemmas it raises, at some length. It is interesting to note how protective parents/carers were in many cases of the young adults who were asked to take part.

The chapter *Understanding Spina Bifida and/or Hydrocephalus – the literature, the disability* will be helpful to professionals working with young people with the disabilities, as it highlights important topics such as social skills, self-esteem and body image, as well as sexual experience and activity.

The case studies that are included raise many issues about the sexuality of this group and society's attitudes towards them. They portray a depressing range of unsatisfactory or abusive relationships.

Nowhere in this book did I find any sense of young people with spina bifida and/or hydrocephalus having successful, rewarding relationships which we know many do.

I would like to think that in the decade since this research was carried out, young people with disabilities are being given better and more appropriate sex education and that attitudes to their sexuality have become more relaxed and accepting. In the new millennium, young people with spina bifida and/or hydrocephalus should have the same choices in relationships as their able-bodied peers. Maddie's book will give people working in this field a starting point from which to move on.



- **Sexuality & Disability,** ***by Maddie Blackburn, Butterworth Heinemann, ISBN 0-7506-2252-0.***

All profits from the sale of this book will be donated to ASBAH by the author.

Teach 'em young

Sitting comfortably: Holly (4) and Gareth (3)

GIVE children some basic wheelchair skills and wheelchair services will provide a chair that's better suited to their needs.

So says Owen McGhee, ex-wheelchair services manager and co-founder of the Association of Wheelchair Children (AWC).

The secret of gaining outdoor independence, he says, is to know how to back-wheel balance. Being able to tilt back on to the chair's rear wheels and balance there means you can manoeuvre the chair up a kerb, if you need to, and so cross a road.

Then, by the time the wheelchair-user is aged 12 s/he can be doing as his/her non-disabled peers – going to the local shops or school by themselves.

"If you're a wheelchair user and you can't back-wheel balance, you have a real problem going out on your own," says Mr McGhee.

Once a child can show that s/he knows how to back-wheel balance, parents/carers can ask the wheelchair service for something more.

Mr McGhee said: "Wheelchair services will respond to evidence. If none is available, they give you the basic chair. If you haven't got the skills, why should they give you anything more?

"But once you've attended our course, you can prove that a basic chair is inappropriate for you because you can't get up and down kerbs in it."

The AWC will set up a two-day course anywhere in the country.

Mr McGhee said: "Our aim is to see every child who will use a wheelchair in Great Britain and see they are trained, so the wheelchair service can give them a chair that will encourage them to develop skills that will be crucial for them as they grow up."

Courses are free to young wheelchair-users and professionals. A charge is made to adult wheelchair-users.

If a family has to travel far to attend a course, accommodation can be paid for.

● ***Association for Wheelchair Children, tel: 0870-121 0050;*** ***www.wheelchairchildren.org.uk***

Course leader, Owen McGhee, and Simeon (6)

Balancing act

A HANDFUL of under-fives took their places in a two-day course to master some basic wheelchair skills.

The day took off after Bristol mum, Ann Drain, approached ASBAH and the Association of Wheelchair Children over worries that her three-year-old was not sufficiently mobile in a chair issued by the local wheelchair service.

Owen McGhee, of the Association of Wheelchair Children, agreed to run a course to improve Holly's skills which would provide evidence to the wheelchair service that she would be capable of a lot more in a different chair.

ASBAH's Bristol Adviser, Julie Knight, who helped organise the day, said: "All the children arrived in chairs designed to be pushed – not the sorts of chair that the children would be able to go up kerbs and back-wheel balance in. So Mr McGhee got them out of their usual chairs into ones he'd brought.

"I was disappointed that all the children had wheelchairs which were unsuitable for the course. But now they've learnt how to go up kerbs and back-wheel balance, they can apply for different chairs."

The course – held at a local primary school with a large hall – was free to the participating families, though they had to bring their own packed lunches.

There was also a 'drop-in' for other parents

A game of British Bulldogs – or chase

who had problems with their children's chairs.

Julie said: "The course venue was an old building with some adaptations, so there were opportunities to practise skills. The children practised going up small ramps inside, and outside they practised going up a steep ramp and kerbs.

"There were a few tears but, on the whole, the children got a lot out of it and achieved the goals set to enable them to get more appropriate chairs."

Follow-up courses are planned so the children involved maintain their wheelchair skills.

Above: Ann Drain, a mum, and ASBAH's Bristol Adviser, Julie Knight, help two participants with back-wheel balancing

Mum, Ann Drain, with some of the youngsters

Safe wheeling

EVEN if your child goes away from a wheelchair skills course without a suitable chair in which to practise his/her new-found skills, crucial work can be done by parents to prepare him/her for future adventures in the outside world.

Every time you push your child outside, it is important to encourage him/her to help you make decisions about a safe place and time to cross and, when appropriate, discuss with them the significance of zebra crossings and the little green man. If you don't include the child in these decisions, they will pay no attention to what is going on.

Owen McGhee, founder of the Association of Wheelchair Children, said: "We'll sort out the back-wheel balancing because we'll probably see your child again on a follow-up course.

"Even if the child can do a back-wheel balance, it will take a lot longer to ensure they are crossing the road properly.

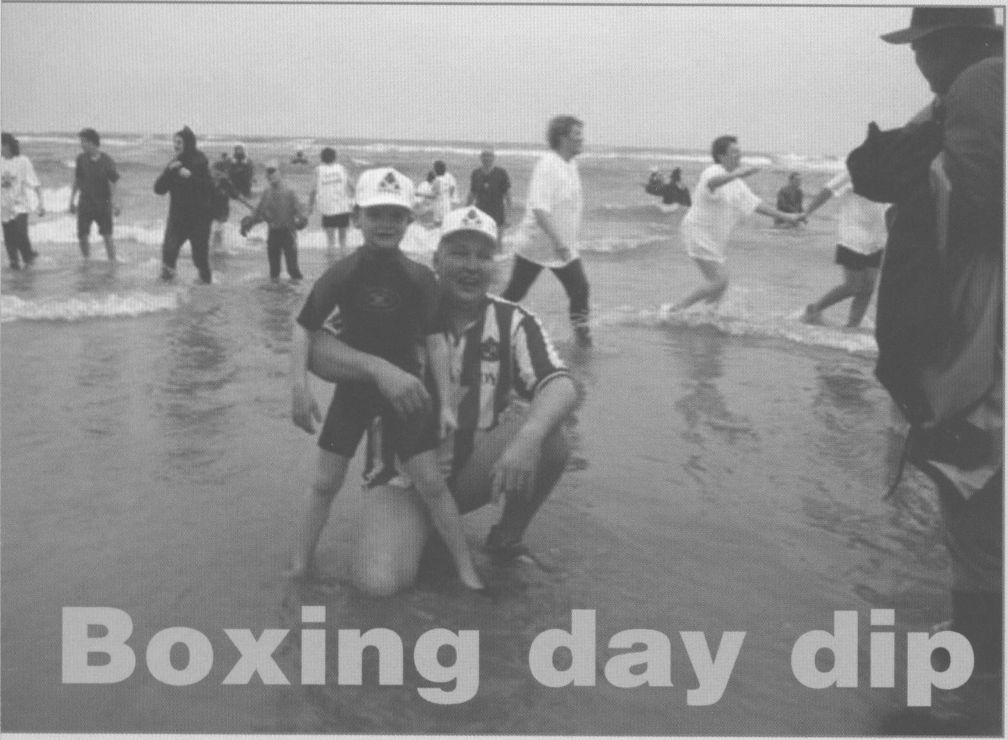
"And if they have never been on a British road as a pedestrian before, it's going to be far more difficult for them to learn to drive when they are 16."

By the time Mr McGhee sees Holly from Bristol again, he hopes her mum will have done kerb drill and pointed things out like zebra crossings.

"Then her daughter will be much better equipped to go out independently when she's older, than me simply teaching her to go up and down kerbs," said Mr McGhee.

Ready to practise back-wheel balancing indoors

fundraising



Boxing day dip

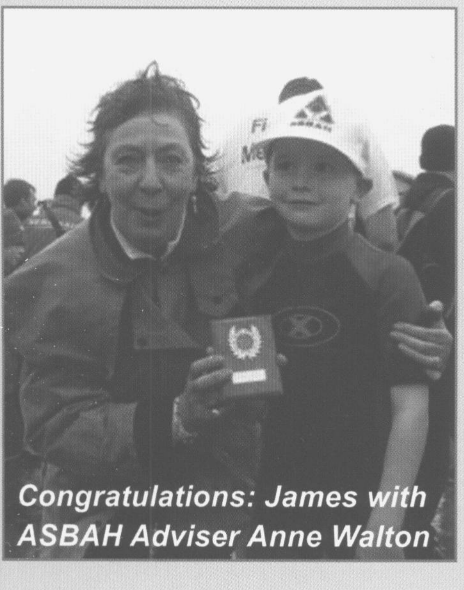
Ready or not: Ian and James Woods edge their way in to the North Sea

A FATHER and son braved the elements when they bathed in the icy waters of the North Sea to raise money for ASBAH.

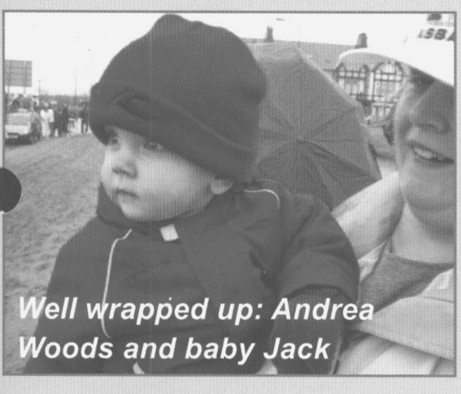
The 31-year-old Boxing Day Dip has become a regular fun day in the North-East and 5,000 spectators ignored pouring rain and strong winds to watch 290 bathers fully immerse themselves.

Although Ian Woods and seven-year-old James were dreading the prospect of entering the wintry sea, they got swept away by the enthusiasm of the crowd and other bathers.

James, whose baby brother Jack has spina bifida, told his mum Andrea: "It was absolutely brilliant."



Congratulations: James with ASBAH Adviser Anne Walton



Well wrapped up: Andrea Woods and baby Jack

They had seen the wacky event advertised in the paper and recognised an opportunity of raising money for ASBAH as they have been helped by ASBAH Adviser, Anne Walton.

A Highland piper had led them down, in a parade, to the beach at Seaton Carew, near Hartlepool. Many of the other bathers were in fancy dress and once the deed had been done, hot soup and a disco awaited them.

Anne, who joined the throng with her husband Reg, said: "It was bitterly cold and wet, but so exciting we did not notice."

The whole event is organised every year by the local Lions Club, whose headquarters are just a stone's throw away from the beach.

It was the first time in the event's history that bathers had been drenched from the sky as well as the sea.

Ian and James are on course to raising at least £200 for ASBAH.

Life begins at 40

LIFE certainly seemed to begin at 40 for Mark Chenoweth (*pictured*). Not only did he become the first Round Table area leader who uses a wheelchair, he came up with a daring idea to raise money for us – abseiling in his chair from the top of a 60 foot building.

As a keen scuba diver, he is used to plunging to great depths at sea, which he has found has a positive effect on his mobility.

Organising the abseil has been more difficult, for safety reasons, but raising money for ASBAH hasn't been a problem! Many of the 22 Round Tables in Cheshire and North-West Midlands that he oversees have given donations totalling £1,000, and smaller amounts have come in from the public following local radio interviews. Even elderly patients cared for by his wife, Denise, who's a nurse, have contributed.

Mark joined the Round Table 13 years ago when he was an accountant – a career he had to abandon for health reasons.

He is particularly interested in the international element of Round Table and, as area chairman, has travelled 15,000 miles from his home in Leek, North Staffs, to attend meetings and social functions in his patch and in other countries, including Kenya.

In March, he plans to visit Round Tables in countries on the eastern side of France.

Mark said: "A good Round Tabler doesn't have any particular job. The main requirement is commitment. About half a dozen meetings a year are business; the rest is fun."

He says people have different reasons for joining, though most have a desire to put something back into the community – and have some fun along the way!

Fingers crossed that all goes well for the wheelchair abseil.

dates for your diary

Upcoming events

Northern Region drop-in
Wed 5 February
Regular drop-in from 10–12 at ASBAH's Northern Regional Office, ***tel: 0113-255 6767.***

Support group, Dunstable
Monday 10 February
Regular meeting for parents/carers of children/young people with SB/H organised by the South Bedfordshire Support Group. 1–3.30pm, Disability Resource Centre, Poynters Road, Dunstable. ***Details: Valerie Bottoms, tel: 01582–757745,*** *valerie.bottoms@ntlworld.com*

ASBAH Family Weekend, Cornwall
Fri 7 – Sun 9 March
This event is now full.

Support group, Dunstable
Monday 10 March
For details, see above.

Wheelie Club, Belfast
Saturday 15 March
Opportunity for young people to improve their wheelchair skills at McKinney Hall, Musgrave Park Hospital, Belfast. Three groups: Wheelie Kids (10–11.30am); Speedy Wheelers (11.30–1pm) and Wheelie Power (2–3.30pm). Free maintenance by Gerald Simonds Healthcare Ltd. ***Details: ASBAH Northern Ireland, tel: 028-9079 8878; email:*** *niro@asbah.org*

Support group, Dunstable
Monday 14 April
For details, see above.

Wheelchair skills, Ealing, London
26 April – 31 May
Free Whizz-Kidz course over six Saturdays for manual/powered wheelchair-users aged up to 18 at Elthorne Park High School, Hanwell. Each Saturday split into three sessions so children/young people can learn skills in their own peer group. Emphasis on developing independence, making new friends and having fun! ***Sarah Jefkins, tel: 0207-233 6600;*** *s.jefkins@whizz-kidz.org.uk* for registration pack. Places limited.

Support group, Dunstable
Monday 12 May
For details, see above.

Naidex, Birmingham
13–15 May
The UK's largest exhibition for disability and rehabilitation products at Birmingham's NEC. ***Details: 020-8332 0044 or check their website*** *www.naidex.co.uk*

Wheelie Club, Belfast
Saturday 17 May
Opportunity for young people to improve their wheelchair skills at McKinney Hall, Musgrave Park Hospital, Belfast. Three groups: Wheelie Kids (10–11.30am); Speedy Wheelers (11.30–1pm) and Wheelie Power (2–3.30pm). Free maintenance by Gerald Simonds Healthcare Ltd. ***Details: ASBAH Northern Ireland, tel: 028-9079 8878; email:*** *niro@asbah.org*

Mobility Roadshow, Leics
12–14 June
2003 Mobility Roadshow, Castle Donnington Race Circuit, Leicestershire. 10–5pm daily. ***For details tel: 0870-770 3222.***

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Generations - Working with kids who can't ride bikes.

DAVE'S DIARY

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LOOKING out my window all I see is torrents of rain. I cannot believe that only a few weeks ago I was in France lying on a warm beach sipping cold beers. Now I'm back at home, back at my jobs.

I tried to recreate that holiday feeling by buying the foods I ate on holiday from the supermarket. I always try this but it never really works. There's just something not right about eating croissants and French jam when there's a black sky and howling gale outside. This time though, shopping at the supermarket raised my spirits higher than any breakfast could do.

Quite randomly I went over to a checkout. The assistant there was a very nice lady in a wheelchair. As she scanned my shopping she started telling me her life story.... Why so many people I've never met suddenly feel the need to tell me their life story I don't know, but they do. Anyway, she told me that she was married, enjoyed the job and liked the money even more! And why not?

The woman at the checkout *also* told me she was not the only person with a disability working for that supermarket. I cannot express how good it felt to hear that. Down through the years I have worked for many different companies. But wherever I went I was certain to be the only disabled person in the company. That can be a pain and a bit lonely sometimes, trying to communicate with people who have never experienced what you have, wondering *why* I'm alone. Even today, I work in two different jobs and I'm *still* the only disabled person there. So to hear of a company employing *several* disabled people is wonderful news. Finally, companies are realising that people with all sorts of disabilities make good (or in my case wonderful) employees.

But I shouldn't be too harsh on employers. If all they get from newspapers, magazines and the telly is that doing sports and being heroic are all we are about, how can they see us working in their industries? Or indeed running them. *And how can we?*

The truth, that there are thousands of people with disabilities doing all sorts of responsible, rewarding jobs, may soon be told.

"There are now a lot more disabled people in the media. They are coming out of all the recesses and corners to have their say," says Margi Woodward of Scope.

If I have a hope for the New Year it is that these people will take their place in the media and use it to shout out that, with a little understanding and co-operation, we can and will be part of the workforce and of society. So that one day seeing people like us at work won't be reason to stop and stare. Or write columns about it.

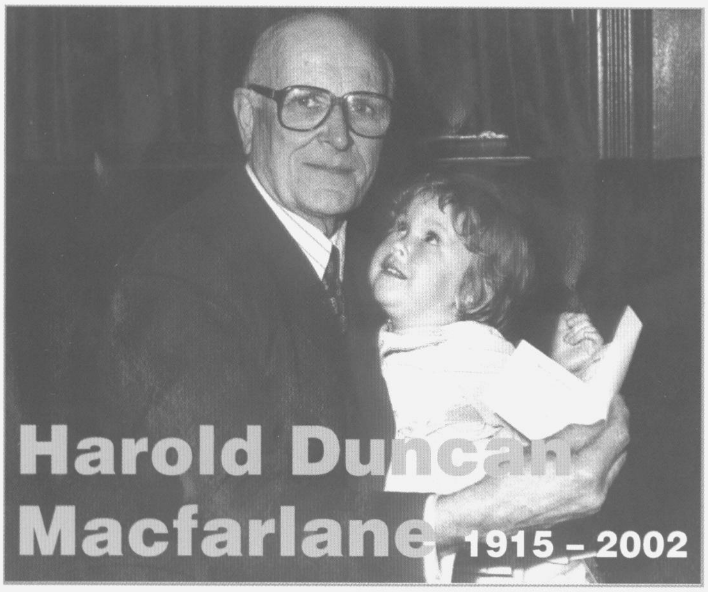
Next issue

March / April 2003

- **YOUNG** readers **listen up**. We're starting a new series in *Link* just for *you* – including brothers and sisters. To make it really wicked, tell us **what grabs *you* in a *big* way**. Could be fashion (looking cool), text messaging, net surfing, Play Station, Harry Potter, S-Club, Gareth Gates, karaoke. Send your message to: ***link@asbah.org***

- **Why not share your TRAVEL experiences with other readers?** Maybe you've made a stunning holiday find or you're planning something really 'big' this year? Let us know your experiences – good or bad – ***asap***, by writing to: ***Link*, ASBAH, 42 Park Road, Peterborough, PE1 2UQ; or email *link@asbah.org***

tribute



Harold Duncan Macfarlane 1915 – 2002

A FATHER figure, a friend, and the one ‘constant’ in a changing world is the way a former ASBAH employee has been described. Harold Macfarlane – better known as ‘Mac’ – passed away in December, aged 87.

Mac served in the forces in the Second World War, after which he became a civil servant before joining the (then) Westminster Bank.

In 1972, Mac was appointed as ASBAH’s national liaison officer. He travelled extensively, assisting local Associations and helping families and individuals with their personal problems.

Teresa Cole, who joined ASBAH in the early 80’s, later becoming our former assistant director (services), said: “Mac was a source of support and encouragement during the lifetime of hundreds of people who have grown up in the years since national ASBAH was formed.

“I gained much from his wide experience and, when he retired, he continued to be a mine of information and great help to new fieldworkers in the London area for some years, and was always happy to advise on tricky problems in their early days.”

After retiring from ASBAH, Mac became welfare officer for Staines, Hounslow and Districts ASBAH. Until two years ago, he was still offering advice and assistance. Tony Bassett, chairman of trustees, said: “Mac was a wonderful ambassador for the Association and a great friend and comfort to many families and individuals who knew him. He will be greatly missed.”

letters

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

For victims of bullies, there is always hope

AFTER reading your article, *Buddies not bullies*, in *Link* No 202, I felt I should write in. By the age of seven, I was being bullied at school. Not knowing what to do, where to go, or who to talk to, I resorted to sitting in the corner of the playground alone. It was not just my peers who bullied me but also one particular primary school teacher, who pulled my hair quite frequently.

When I started senior school, I thought things would be different, but it didn’t last so I resorted to skipping lessons to avoid the bullies. I left school in 1980 with no qualifications but at least I was free from the bullies.

On the subject of class work, I struggled in infant school (age 5-7) and was left to play with toys. By the time I went to junior school (age 7-11), I could not even hold a pen properly. But within a year I had caught up thanks to my class teacher who realised that, with a little dedication, she could unlock my full potential.

As I got older, because I was having a hard time with school work, I was put into remedial classes. This only made matters worse as my peers thought I was ‘thick’ which, of course, I am not.

To anyone out there who is a victim of bullies, be assured that it is not our condition that is a problem but others’ ignorance of it and their lack of ability to understand it. I am now happily married with three children. Although I do not work now, I have done in the past.

So the bullies did not win as I am leading a normal life. Hopefully, there will be light at the end of the tunnel to whoever is suffering because, one day, the bullying will stop. Then you will be able to lead a normal life. So long as you believe that, you will have hope, as I did.

Jacqui Powell

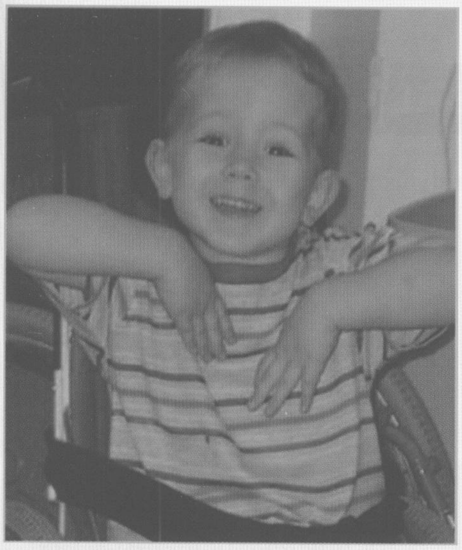
Editor’s note: *If you are the victim of bullies, tell a grown-up or a friend – it will help. Most schools now have an anti-bullying policy and actively work to prevent bullying. Don’t suffer in silence for longer than you have to.*

More please – we can't thank you enough

WHEN walking long distances is not an option then a wheelchair is a necessary tool to enable you to be mobile. Yet like all tools it is of limited use without a manual or some training.

Gareth was given his first wheelchair a year ago when he was two and a half. It was handed to us with a smile! So for a whole year Gareth developed his skills in moving forwards, backwards and turning at speed. He even managed to negotiate tight places with great skill. However, we were desperate for more advice and some training to enable Gareth to achieve greater independence.

When ASBAH told us of the course in Bristol *(featured on pages 23–24)* we were very excited. It was everything we had hoped for and more. Owen (course leader) was the first professional to say "Why not?" as opposed to "Mmm I don't think so." Owen's expectations were very high. We were challenged to attempt the previously impossible – using an escalator on the London Underground, coming down a flight of steps or a very steep ramp. It felt so positive and empowering knowing that our children weren't just being 'patched up' but given inclusive life skills.



Gareth Picken learning new skills at an ASBAH wheelchair course

The objective of the weekend was to learn to cross the road safely, learning to tip up the wheelchair in order to get up and down kerbs, and to fall out of and get back into the chair. It was amazing how quickly these skills were learnt.

Each child and adult was given the use of a 'Roller' chair as it was felt to be much lighter than the 'Blades' most of us had been issued with. It was the first time that I had spent any significant time in a wheelchair and did my arms ache at the end of the day?

Julie Knight (ASBAH adviser) joined in the experience giving encouragement, friendship and continuing support. In two days the children became good friends and responded so much to being part of a group of wheelchair-users.

With the continuing inclusion of children with SEN into mainstream schools, it is becoming a matter of urgency that wheelchair-users of all ages are given the opportunity to meet regularly and develop their skills further. Splendid isolation does not necessarily equal a happy, fully integrated member of society.

Nici Picken
Cheltenham

holiday lets

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- Cheques and postal orders should be made payable to 'ASBAH'
- Classified adverts for the next issue of *Link* (March) should be submitted by Friday, 7 February.

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*Used equipment advertised in **Link** must be brought as seen – ASBAH cannot be held responsible for any fault or injury caused after purchase.*

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