LINK

The magazine for people
with Spina Bifida and
Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS
ASBAH

Education special

Family Weekend

Continence news

Ray tribute

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MAY/JUNE 2002 ISSUE 199

ASBAH's LINK magazine

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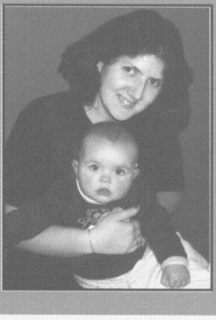

Cover: Tina Morgan, a volunteer at this year's ASBAH Family Weekend, is pictured with Emily. Tina, who has SB&H, particulary liked being with baby group, and soothed fractious infants.

Editorial

FROM this autumn, pupils with special educational needs will have a right to mainstream education. Many children with hydrocephalus or spina bifida are already educated in mainstream schools but their road to full inclusion is not always an easy one. On page 6 we have stories showing the experiences of families from around the country, from infant to secondary education. As in 'fairy tales' these real life stories all have a happy ending but they have had to fight battles against attitudes and ignorance along the way.

ASBAH will often only hear when things are not going smoothly and we are asked if we can help. There must be those of you who have found the mainstream experience a good one from the start, with plenty of understanding and co-operation from your child's school and we'd like to report these in *Link* too, so please get in touch and let us know if it's been easier for you.

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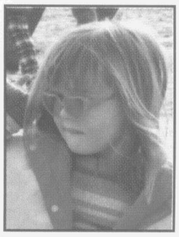

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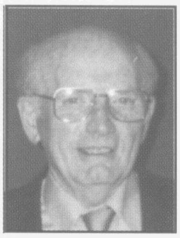

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ASBAH's vision is a future where everyone with spina bifida or hydrocephalus can get the most out of life.

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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www.asbah.org
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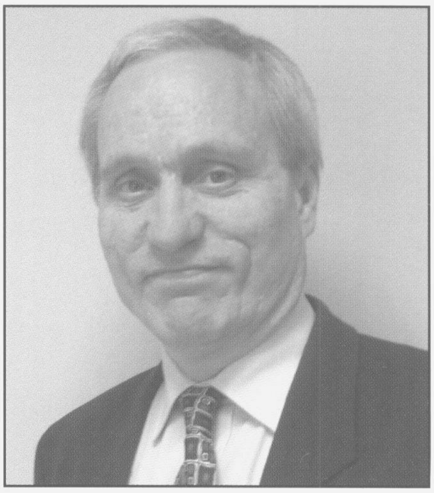
ASBAH staff redundancies

Andrew Russell, ASBAH Executive Director, writes:

I AM sad to announce that we have had to make several Area Advisers redundant for financial reasons, an action that I and the Trustees deeply regret. Times are very tough for medium-sized charities and, in the last resort, charities have to act in a businesslike way. The excellent work of our Advisers is highly valued throughout the Association, and the Area Adviser will remain a key part of our national services.

In all, three (full-time equivalent) Adviser posts are being lost. In the areas affected, we will do our best to continue to provide essential support for service-users. Information and advice is available from our National and Regional Offices, from Specialist Advisers on education and medical matters, and from our Information Department.



Why are these cuts necessary? The bulk of ASBAH's income is spent on staff costs, so the only way of making significant further savings is to reduce the staff establishment. Already last year, we had reduced our staff costs at National Office by more than £80,000 through redundancies, natural wastage and reductions in hours. However, because of income trends, the Trustees determined that costs must be further reduced by £100,000 in 2002, while we increase our fundraising efforts.

To help bridge the time gap, we appealed to Local Associations, many of whom have since given pledges of financial help. There is a real mutual interest here, and we are sincerely grateful for this generosity which has reduced the scale of redundancies.

These hard times are a sign that each and every opportunity and proper means of raising funds must be used, and that we must work together in our common purpose of improving life with and for everyone with spina bifida and hydrocephalus.

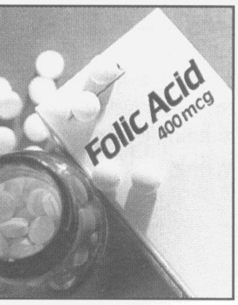
New hope for folic acid in flour

THE NEW Food Standards Agency will discuss fortifying flour with the vitamin folic acid at a meeting this month (May).

This follows ASBAH intensifying our efforts to focus Government attention on this important issue to prevent future babies developing spina bifida and anencephaly.

To raise Government awareness, we arranged Parliamentary Questions, a House of Commons Motion, and a Reception for MPs and Lords.

ASBAH has also been talking to the Food Standards Agency (FSA) which has been passed the issue by the Department of Health. Media publicity and a public debate is likely if the FSA recommends fortification.



For more than 10 years, folic acid has been known to have a powerful preventive effect for spina bifida and anencephaly.

ASBAH has been pressing the government, and the previous Conservative government, to make it compulsory for flour millers to add a small amount of folic acid to white flour. The government's expert committee, COMA, studied the subject for two years and recommended in 2000 that flour should be fortified with 240 micrograms of folic acid per 100 grams of flour.

No risks were found to be associated with increased folic acid. Most experts believe that the UK population is generally deficient in folic acid. It is now known that folic acid also helps to prevent heart disease and strokes and, possibly, bowel cancer.

Flour is already fortified compulsorily with calcium and iron, as a public health measure, so there are clear precedents.

Rebecca's a winner

DETERMINATION won the day for 11-year-old Rebecca Purseglove, earning her a place amongst 150 recipients of this year's Child of Achievement Awards.

Rebecca had a wonderful time with her family at London's Hilton Hotel – mingling with stars like J K Rowling, June Whitfield and Bob Holness.

It helped make up for last year when, four weeks before a Greek holiday, she fell seriously ill due to shunt failure. She was admitted to hospital where a ventriculostomy was planned. Being totally shunt dependent, her first operation had to be done as an emergency.

The ventriculostomy healed and Rebecca returned to theatre to have the old shunt removed and an external drain fitted. A week later, the ventriculostomy was repeated.

Rebecca, of Huthwaite, Nottinghamshire, left hospital four days before she was due to start secondary school.

Her mum, Wendy, said: "With her head totally shaved, clips and stitches still in, and wearing a baseball cap, Rebecca went in just for mornings."

But she was determined to go on a camp two weeks later and her parents agreed if big brother Richard could go too.

Mum said: "She returned, feet covered in blisters but she was so pleased because she had completed, amongst other things, a 21-mile walk."

Impressed staff nominated her for an achievement award.

Rebecca's ASBAH adviser, Janet Stewart, said: "It was wonderful to hear of her win particularly as it was touch and go for her last summer. Rebecca was the first baby referred to me when I started at ASBAH and we have kept in touch ever since."

The teachers understand Rebecca's balance, poor co-ordination and short-term memory problems. Mum said: "This seems worse since surgery and hampers homework as she often can't remember what they did in the lesson. So the teachers make notes for her.

"She has also had problems finding her way round such a big school. She is allowed to leave lessons early, with a friend, so she can get from A to B without worrying about crowds."

Otherwise, Rebecca is doing well, getting As and Bs in most subjects.

Worldwide survey on hydrocephalus

A GROUP in the USA is asking people with hydrocephalus everywhere (with or without spina bifida) to take part in a survey. Parents may also take part on their child's behalf.

The National Hydrocephalus Foundation (NHF) has produced an eight-page questionnaire to provide a 'knowledge base' of the 'hydrocephalus community' for researchers and others.

All collected data will be treated as confidential. Results will be compiled by a statistician.

Executive director, Debbi Fields, (*pictured*), who was 37 before she discovered she had hydrocephalus, said: "Our original survey of 10 years ago was quite small as the Internet was a baby then, and we were unable to connect with one another. "

Email: ***hydrobrat@Earthlink.Net*** *or write to: Mrs D Fields, 12413 Centralia Road, Lakewood, CA 90715-1623, USA.*

Or you can return questionnaires to Link *at ASBAH's Peterborough address for forwarding.*

Introduced by
Bruce Graham & Joanne Grenfell
ASBAH Education Advisers

Inclus

THANKS to Government policy, schools have a responsibility to provide a broad and balanced curriculum for all pupils and they should have a policy of inclusion. Pupils, too, now have a greater right to a place in a mainstream school. A welter of consultation, debate and legislation informs this policy direction. For example, from September 2002 schools must not treat disabled pupils less favourably, and must take reasonable steps to avoid putting disabled pupils at a substantial disadvantage. Also from September 2002, Local Education Authorities (LEAs) must plan to make their schools accessible for disabled pupils. They must improve the physical environment of the school, increase the extent to which disabled pupils can participate in school life and improve the way in which information is provided for disabled pupils.

To help LEAs and schools interpret this policy and turn it into practice, a forest of guidance documents has emerged. And in professional education journals, discussions abound on the meaning of 'inclusion' and the strategies required to ensure its success.

However, what of the views of those who find themselves faced with the local reality rather than the theory; those who have interpreted the policy in one way only to find an LEA or school which has interpreted it in another; those who have encountered openness and enthusiasm for the concept of inclusion but lack the resources of whatever kind to achieve success and, of course, those areas where the reality matches the theory and where success builds upon success? In other words you!

ASBAH supports the concept of inclusion and supports schools in its delivery through leaflets, study days and talks to staff. It also supports parents' and pupils' right to choose alternatives.

Inclusion is a concept that is admirable in theory but in your experience is it in reality?

From special school to comprehensive

EARLY on, Hameet Batebajwe's parents didn't know that mainstream was an option, so he attended a special school.

They think he would have achieved more in mainstream as he would have had regular one-to-one support and expectations would have been higher.

Now 12, Hameet, who has hydrocephalus, attends an SEN unit at a Leeds comprehensive where he mixes with mainstream pupils at break and in Art and PE.

Mum, Chernjit, said: "Hameet is very happy and staff are much better at picking things up."

"I understand they can't meet all his needs but if he gets to 19 and has not attained his basic reading and writing, he won't get a job. So I've advertised for private tuition to get what I want."

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IT WAS staff attitude, not lack of resources, that made secondary school life difficult for Rachel Linney (*pictured right).*

Rachel (16) is visually impaired, has mild cerebral palsy and hydrocephalus. Her school had a visual impairment resource base attached, with teachers giving support in mainstream classes.

Problems included:

- Some of the teachers in the visual impairment unit seemed to have little knowledge of other disabilities and a lack of willingness to learn.
- The school's ethos appeared to be that Rachel needed to fit in – not recognising that other pupils and teachers played a part in her behaviour. If she did not recognise pupils from a distance she could be seen as 'stand-offish and difficult' rather than just not able to recognise them.
- Teachers did not realise that she could perform tasks if they were modified to match her ability.

Mum, Cath, of Cheshire, said: "Inclusion is not just a matter of resources for the child, it must run through all aspects of school life. Rachel was under severe stress throughout school although there was some improvement in the last two years due to a change in personnel and her increased maturity."

sion or isolation?

JONATHAN Surrey (17) has been happy at a Warwickshire comprehensive, but it took his parents two years to get him a place there and it's been a fight all the way through.

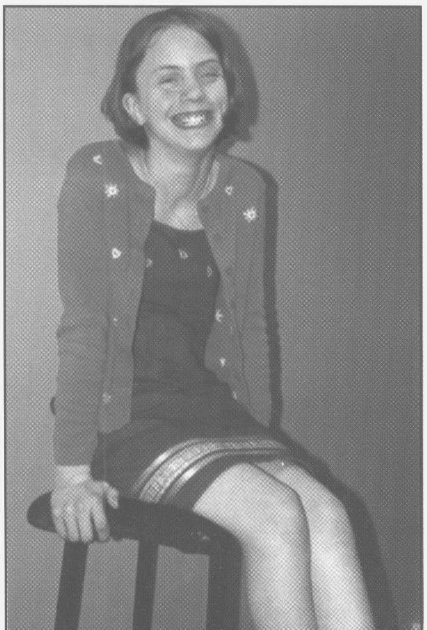
He was the first wheelchair-user at the school and older members of staff, including the SEN-Co, believed he should attend the 'designated' school.

His parents say his first review was 'awful' with teachers saying they were not prepared to teach children with disabilities. Parents' evenings have been a challenge.

With no lift installed until recently, Jonathan used a stair-climber which only his support worker could operate. If she was away, Jonathan missed lessons on the upper floors.

Before he learnt to self-catheterise, his mum was called in to deal with 'accidents' as his support worker was female.

Mum, Pauline, said: "Even in bad times, he had no regrets about the choice of school. He has gained a lot of respect from the other pupils and is looking forward to attending local college."



FIGHT for the placement you want, otherwise you won't get it. This is the advice to parents given by the mother of Nickie Kaye (*pictured right*).

The 10-year-old is happy in the class below her year-group in a mainstream primary school.

But mum, Julie, had to battle for the nursery and primary school of her choice. She is prepared to fight again to get Nickie into high school – she expects transport will be an issue.

Nickie, from Yorkshire, has 24 hours of learning support a week.

Mrs Kaye explained: "I wanted her to go to the same infants school as her friends, and her brother, so she didn't have to explain about herself again."

Her ASBAH adviser, Bernadette Baldwin, supported the family at tribunal over choice of school and they won the case.

ASBAH Family Weekend 2002
Sands Resort at Porth in Cornwall

Sands revisited

THE TRADITION of the ASBAH Family Weekend continues: this year we returned to Sands Resort at Porth in Cornwall, a truly child friendly hotel, where we also held our Millennium Weekend.

We took 17 families, each with a child aged six or under with spina bifida and/or hydrocephalus plus all their brothers and sisters.

The families travelled from all over England and Wales for the opportunities to meet others and learn more about the conditions.

There were 35 children: some had associated hemiplegia and epilepsy. One little boy had severe allergies which meant he carried an Epi-pen, two children had cerebral palsy and three were visually impaired. Two children had communication problems due to limited speech; there were two wheelchair-users. Two were profoundly disabled and needed one-to-one care. Several children had behavioural problems.

Two local families came in for the day: a five-year-old girl with spina bifida brought her classroom assistant and parents, and another family brought their three-year-old daughter with hydrocephalus.

We were overwhelmed with applicants and had to turn down12 families. Three families then cancelled due to illness but we easily filled their places (with days to go) and they will be offered places on future courses.

The children were divided into four groups by age and each group was identified by a seaside themed name. The nine babies became Octopus group; the 2–4-year-olds were the Flatfish; the five to seven-year-olds were the Turtles and the siblings (aged 8-13 years) were the Sharks.

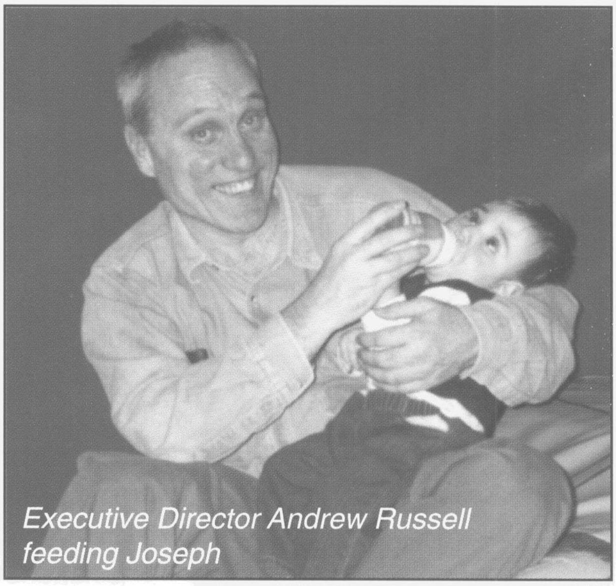
Each child had his or her own personal programme with age suitable activities and outings, and each group had a leader.

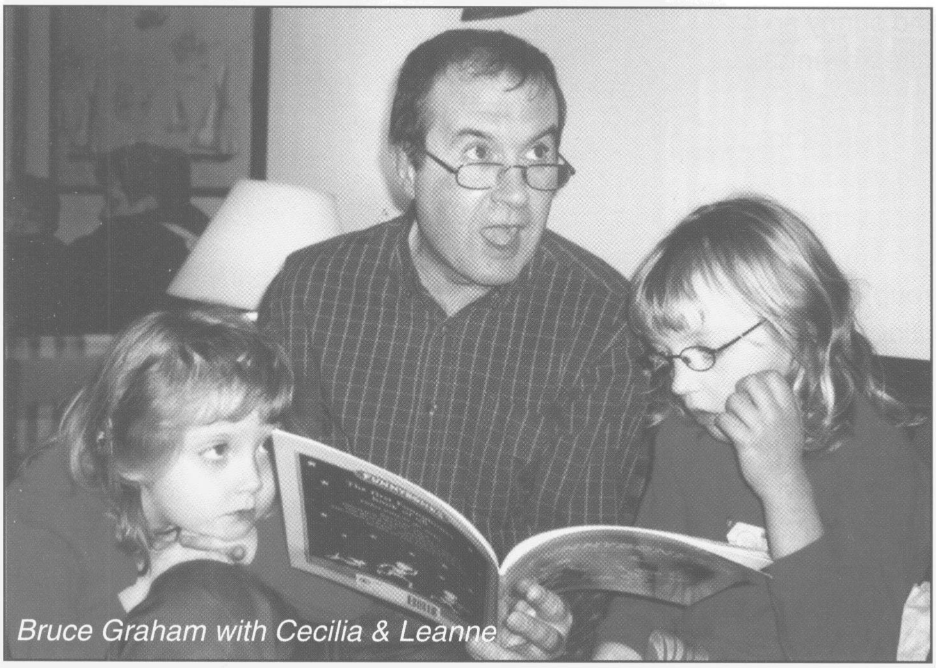
In all, we took 20 members of staff and four volunteers: one volunteer had spina bifida and hydrocephalus, another had hydrocephalus, one was a mother of a child with hydrocephalus and another (on her fifth weekend) was originally introduced to ASBAH when she was a PhD student researching infection in hydrocephalus shunts.

Two of our staff members had spina bifida and were able to provide good role models for both the disabled children and their parents.

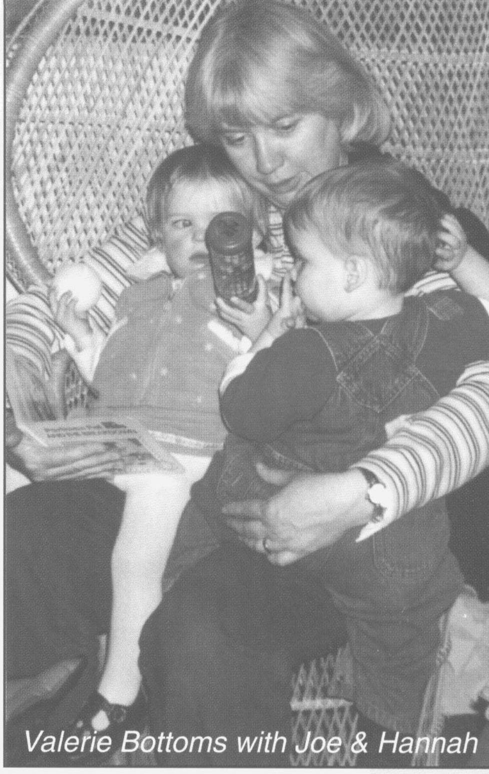
While the children enjoyed their programmes,


Ann Kane of Scottish Spina Bifida Association with Leanne & Amelia


Executive Director Andrew Russell feeding Joseph



Bruce Graham with Cecilia & Leanne



Valerie Bottoms with Joe & Hannah

parents had lectures and the opportunities to share experiences and ideas.

In the evenings we baby-sat and, as in past years, found that some families had never before left their children with babysitters.

On Friday night we started off with a quiz for those parents who were not too exhausted while the children played games with ASBAH staff.

The next morning was bright, cold and sunny and the children were excited and ready for entertaining.

We took the Turtles and the Sharks to the Blue Reef Aquarium in Newquay where the staff did everything to ensure that their visits were busy and enjoyable.

It was a very 'hands-on' experience and much appreciated by the two partially sighted children.

One little girl was anxious about the visit, but was soon persuaded that our Education Adviser (ex-headteacher) needed someone to look after him so went off quite happy to be 'in charge.'

For the Flatfish there was an opportunity to meet the animals from Newquay Zoo.

Ted the 'smelliest ferret in Cornwall' was a particular favourite! They also enjoyed meeting the albino hedgehog and, of course, the compulsory large snake.

Then it was back to the base room for face painting and playing in the ball pool and Wendy houses.

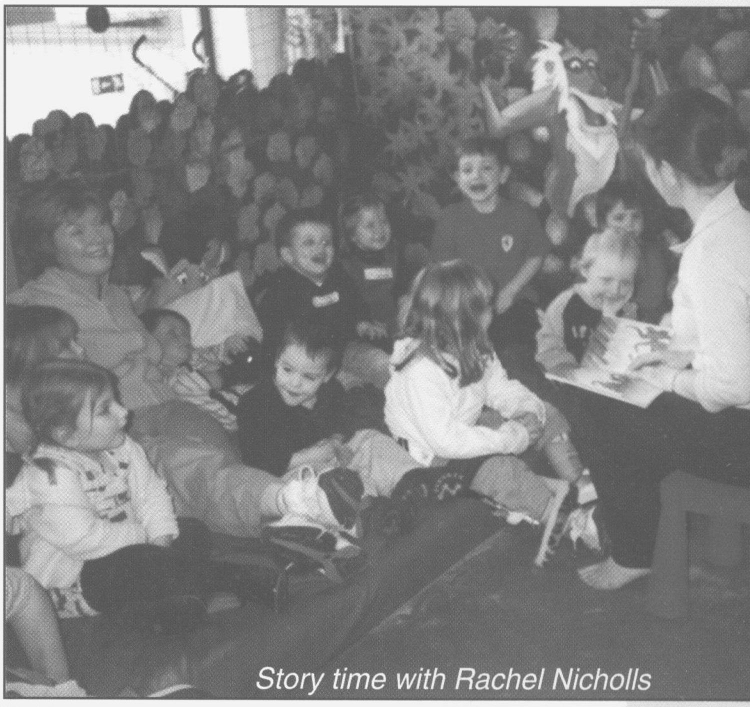
The Octopus group were happily (mostly!) occupied in their group with music and ride- on toys and plenty of people to play with them.

We found time for the families to divide into 'Porpoises' and 'Dolphins' to make use of the warm, indoor swimming pool. For one baby it was her first swimming lesson – as exciting for her parents as it was for her!

The hotel put on a candlelit dinner for the parents on Saturday evening, so the children had high tea with ASBAH staff while their parents got ready.

Feeding 36 children was chaotic! It was almost a relief to sit with them while the older ones were entertained by Chloe the Clown and the babies were in an impromptu creche.

By about 9pm, the parents started to appear and collected the babies who were not already in bed and by 10.30 all was quiet.



Story time with Rachel Nicholls

Sunday was again bright and sunny so it was trips to the beach and to the adventure playground.

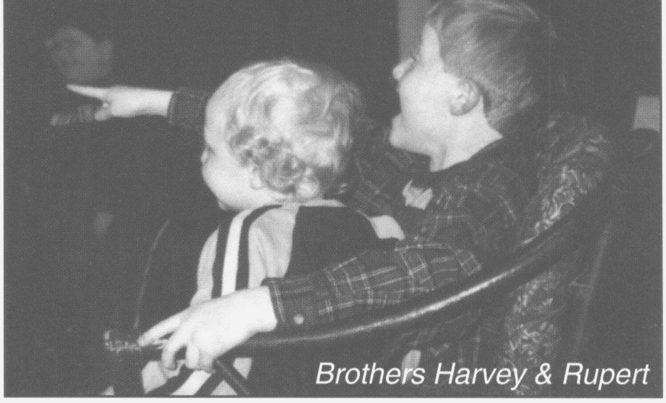
All the children decorated a box for their mothers for Mother's Day (the babies finger painted theirs!) and had a variety of other craft work to take home with them.

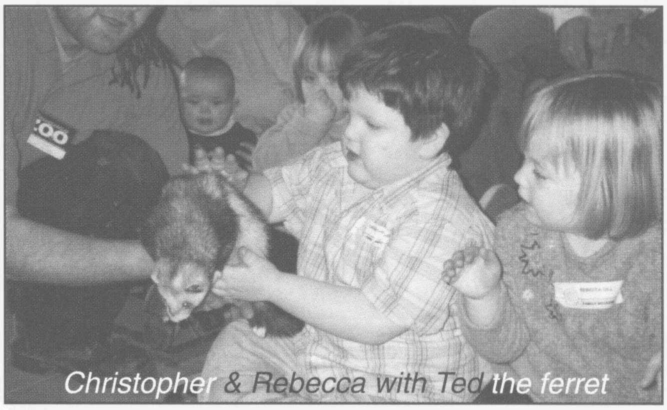
The Sharks (the siblings group) were deliberately given a busy, exciting programme which included a morning's adventure training as well as an opportunity to share feelings through playing games.

They bonded together well and, for one weekend, were able to do all those activities that they should be doing and which are not always possible when there is a disabled child in the family.

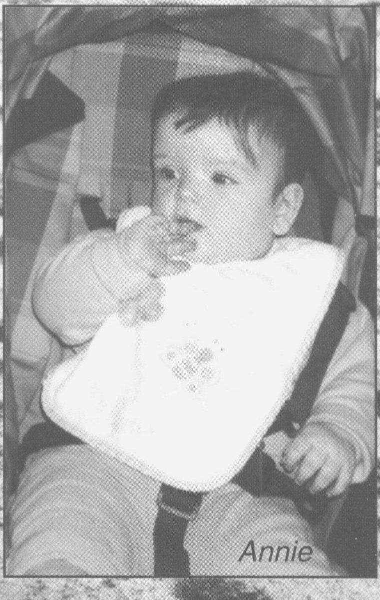
Our weekend finished – all too soon for the families – on Sunday after lunch. Time to pack up, exchange addresses and 'phone numbers and for the parents to cram in the questions that they had been saving up for the weekend.

The evaluation sheets reflect the enthusiasm for these courses. Our thanks to Sands Resort, Blue Reef Aquarium and Newquay Zoo for all their help, care and energy and to Children in Need for the financial support that made this Family Weekend possible.


Brothers Harvey & Rupert


Christopher & Rebecca with Ted the ferret


Abigail from Wales


Annie


Above: Cornwall Adviser Lynne Young & Rebecca


Main photo: Rosie enjoys the sand

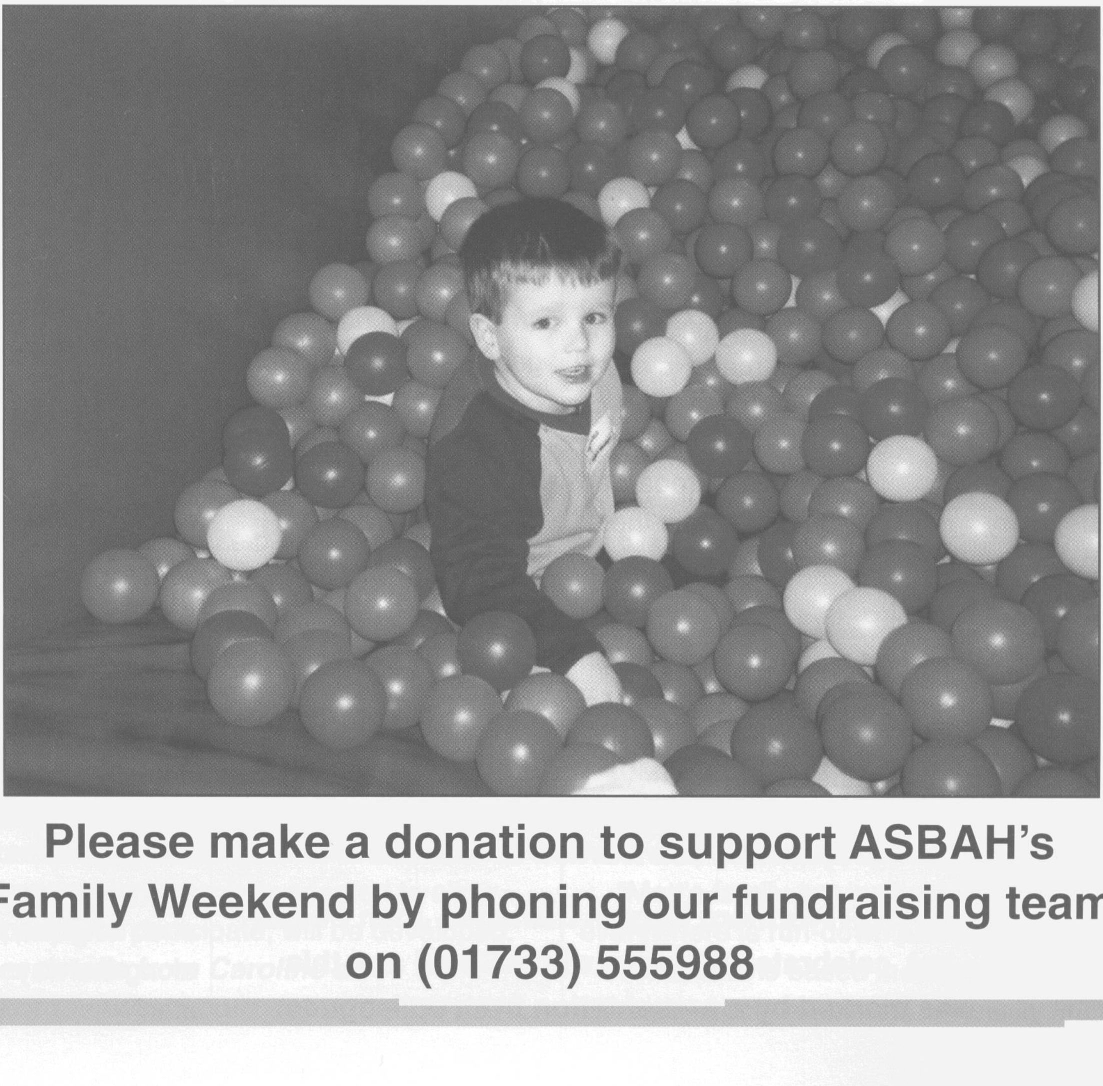
ASBAH FAMILY WEEKEND APPEAL

"It was a rewarding experience tto talk to other parents and have 'on tap' the knowledge and experience of all the ASBAH staff."

"I learnt that I have to look after my brother and that it takes a long time for him to learn stuff," Shane (9).

The funding of this annual event is provided by generous individuals and a grant from "Children In Need."

Please help to ensure that children continue to benefit from this valuable event.



Please make a donation to support ASBAH's Family Weekend by phoning our fundraising team on (01733) 555988

Farewell to Mary Castle

PARENTS and individuals in Cambridgeshire were sad when they heard Mary Castle was leaving ASBAH voluntarily – following the announcement that we were being forced to make some Adviser posts redundant.

For more than 14 years, Mary supported families and individuals in times of need and, therefore, understood what they had been through.

Mary believes the need for a knowledgeable advocate will continue amongst our service-users irrespective of the progress that has been made in areas such as mobility, benefits and education.

She said: "I regarded my job as filling in the gaps left by other professionals; being alongside people to make sure they get the best deal in life; giving friendly guidance; giving them emotional support and helping them to find out what the problem is and improve the situation.

"To some extent the world has changed. Children now have wheelchairs, and access and public transport have improved. However, people still do need support and not all parents are able to immediately rise to the occasion when they discover their child has a disability and so we're needed to give emotional support."

She has enjoyed her job with ASBAH, especially appreciating the strength that has been gained from talking to colleagues in different areas, and learning from young people with disabilities on ASBAH life skills courses."

In brief

- **HAMPSHIRE now has its own ASBAH Adviser thanks to a legacy which will fund the post for two years. Carol Cashman is a qualified physiotherapist and has worked as a social worker.**
- **OUR Northern Region manager, Joan Pheasant, celebrated 25 years with ASBAH and this was marked by a presentation from colleagues.**

Young achiever

ELEVEN-year-old Lewis Brown was among 150 winners of this year's Child of Achievement Awards.

Lewis, who has spina bifida, was nominated by his teacher at Chapel House Middle School, Newcastle-Upon-Tyne.

Lewis and his family, of North Walbottle, had a fantastic time at the glittering awards ceremony at London's Hilton Hotel. Lewis's award was presented by TV presenter Gaby Roslin.

Northern Echo

His ASBAH adviser, Anne Walton, said: "Lewis was one of the first babies that I saw 11 years ago, so he has a special place in my heart."

Lewis's mum, Jennifer, added: "Lewis was so determined and such a fighter, he led us along the way. He's a star."

Marine challenge

SCUBA diver and marine conservationist Caroline Walsh is keen to get more disabled people under the water.

And she is making a splash by setting up Access to Marine Conservation for All (AMCA) which will soon offer diving courses to disabled people so that they can help monitor and conserve the world's northern-most coral reef.

Caroline's passion for diving was triggered in her teens on an activity camp, followed by a family holiday in Cyprus.

Early on, she knew she wanted to become an environmental lawyer. Now a first year law student at the University of Greenwich, and with an MSc in Environmental Conservation under her belt, her ambition is within reach.

Caroline (26) said: "My own experience has shown that physically challenged people can actively take part in marine conservation, in spite of their difficulties. Tourism is one of Jordan's most important industries and by raising awareness of the marine environment in Aqaba, we can encourage people to appreciate it and contribute to conserving it in a sustainable way."

AMCA focuses on the Aqaba Coral Reef in Jordan. Prince Ra'ad bin Zeid, Lord Chamberlain to the King of Jordan and patron of the country's disabled organisations, is also involved. He met Caroline, who has spina bifida, last year on her 10th trip to the country.

The Jordan Projects for Tourism Development and The Jordan Royal Ecological Diving Society are also participating.

Volunteer programmes and two courses in marine conservation, specially adapted to allow disabled people to participate, will be developed.

Further details from Caroline at a.m.c.a@btopenworld.com ***tel: 020-8294 1515.***

Jimmy changes gear

A FOUNDER member of Northern Ireland ASBAH and the Mid Ulster Branch has retired after more than 30 years.

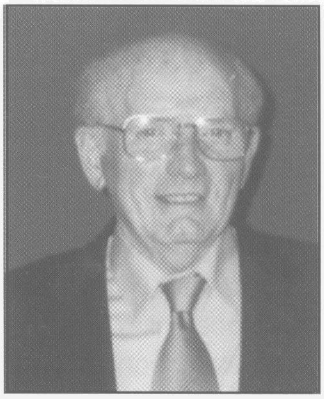
Jimmy Rippey was secretary of NI ASBAH for 15 years and in Mid Ulster he held most offices. He continues to maintain his strong links with the Mid Ulster Branch as a committee member.

Most of all, Jimmy (*pictured*) enjoyed making a contribution to the welfare of children with spina bifida. He will be remembered for his experience, wise guidance, dedication, and his sense of humour.

His own daughter, Siobhan, has spina bifida and is a teacher.

Elizabeth Graham, who takes over as NI ASBAH's honorary secretary, in addition to her role as honorary secretary of the Mid Ulster Branch, said: "Jimmy's biggest contribution was when NI ASBAH organised weekends/respite care for children with spina bifida, many of whom had not been away from home before."

At the Mid Ulster Branch's annual dinner/disco, a presentation was made to Jimmy to mark his retirement as branch representative on NI ASBAH.



Another thank-you and presentation evening was organised by NI ASBAH.

John's Eastern promise

ASBAH adviser John Richards and his wife, Sue, have set up a trust to bring relief to two towns in Eastern Europe, following a visit late last year.

The purpose of the visit was to introduce their 12-year-old son Matthew to his Romanian birth-mother, and to stay with a visually impaired Albanian, with whom John corresponds.

"Matt's family are in dire straits and, in Albania, everywhere is run-down and uncared for," he said.

John, who is based in Milton Keynes, has spina bifida, hydrocephalus and is visually impaired.

LIKE hydrocephalus, benign intracranial hypertension is caused by raised intracranial pressure and many people with BIH have been taken under ASBAH's wing. At 15, RACHEL HICKEY, from Huddersfield, is one of our youngest service-users with BIH. This is her story of a long and incredibly painful road to diagnosis.

True Story

Headaches became part of my daily life

THREE years ago, when I was 12, I was constantly getting headaches which, each day, were becoming more frequent and more painful. When I took part in exercise classes, I'd have a thumping headache afterwards but was told I'd overworked myself.

Eventually, I became sick of these headaches. I'd wake up in the morning and they could last from a few minutes to all day.

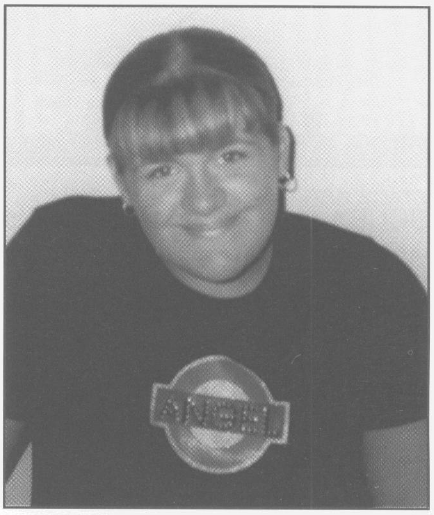
My GP's first diagnosis was sinus problems. But the tablets didn't seem to work so a few days later I went back and was given tablets for migraines.

When these didn't work, I paid another visit to the doctor's. I was becoming very annoyed with getting constant headaches.

The doctor now had two choices – tension or stress. When the medication for tension headaches didn't work, I was given pills for stress.

After a few weeks of continual visits to the doctor's and not knowing what was wrong, I was told to see the doctor daily. I gradually got worse until I was in bed all the time – unable to sleep nor eat or drink much.

On 20 August, I was vomiting and my mum noticed a squint in my left eye. I had whooshing noises in my ears and the headache was unbearable. I'd been taking painkillers 24/7 to no avail. I went to the doctor who sent me to casualty where I underwent MRI scans. Shortly afterwards BIH was diagnosed.



I also had my first lumbar puncture which I found very distressing. The reading was over 30. The doctors were astonished and couldn't explain how I'd been able to go through so much pain.

My eyes were checked and a patch was placed over one to help my sight return to normal.

On 23 August, I had another lumbar puncture as the headaches were getting bad again and I had started to feel sick again. The reading was 17. I was then put on acetazolamide.

I came out of hospital a few days before school started. I was eager to see my friends so I went back, though the teachers were aware of what had happened and that I couldn't do PE.

Over the next few months, when the headaches became severe, my dose of acetazolamide was increased. When at their worst, I had swooshing noises in my ears and a pain behind my eyes.

I still get headaches most days and can't participate in sports without a thumper. My vision sometimes feels like it could go blurred but, luckily, is still OK.

I now take acetazolamide, frusemide and potassium chloride – the frusemide was affecting the salts in my blood. I take 10 tablets a day as well as inhalers for my asthma.

My family and friends are supportive but it's often hard to explain how bad the headache is and I don't want to complain a lot, so normally keep it to myself. often go to the hospital for check-ups and try not to let the BIH interfere with my life although, sometimes, this is impossible.

Note: When BIH is difficult to control with drugs, shunting is the next treatment of choice and Rachel is having to consider this. Her email is Rachel_hickey69@hotmail.com

'Ray gave it all he'd got'


Lancashire Newspapers

RAY Gainer, who led an action-packed life in which he was awarded an MBE for his charity work and was the subject of a *This Is Your Life* programme, died in April.

The 41-year-old stayed an active member of Wigan, Leigh & Districts ASBAH, despite living in Liverpool and then Bickerstaffe, Lancashire.

His wife, Gillian, described his fighting spirit which never left him even after a stroke and total kidney failure forced him to cut back on his activities two years ago.

His first love was flying. In 1986 he got his training licence for small planes and took part in the successful world record bid for the most take-offs and landings in 24 hours, raising £2,000 for charity.

The Red Arrows then sponsored Ray to take the Douglas Bader Flying Scholarship so that he could get his commercial licence.

In 1992 he had health problems and he had trouble walking which meant he could not spend as much time flying. This led to him becoming more interested in both playing and coaching sport. He went on to be one of the country's best disabled basketball and tennis players, winning the French Open in the latter just a year after first playing the sport.

He also did charity work and raised thousands of pounds for spina bifida research and other causes.

In 1994, he raised £11,000 for Mere Oaks School, with the late Mike Pyke, by pushing their wheelchairs 516 miles from the Eiffel Tower to Blackpool. He was also a volunteer at the school where he was a former pupil – helping to inspire the next generation.

Gillian told the *Wigan Observer*: "Ray was very determined – nothing got in his way. He is never going to be forgotten. Whoever he has come in contact with he has left his mark on."

Pat Stridgeon, secretary of Wigan, Leigh and Districts ASBAH, said: "Ray was always there for us at Wigan & Leigh. If we wanted something, he would do it straight away, without thinking of himself."

Angela Lansley, Ray's ASBAH adviser, added: "At the funeral, there was very little mention of disability – Ray just got on and did all sorts of things.

"Ray gave it everything he'd got even though, in later years, he had lots of medical problems. We weren't talking about spina bifida but getting the most out of life and I ended up thinking 'gosh, what a man.'"

A great friend for 35 years

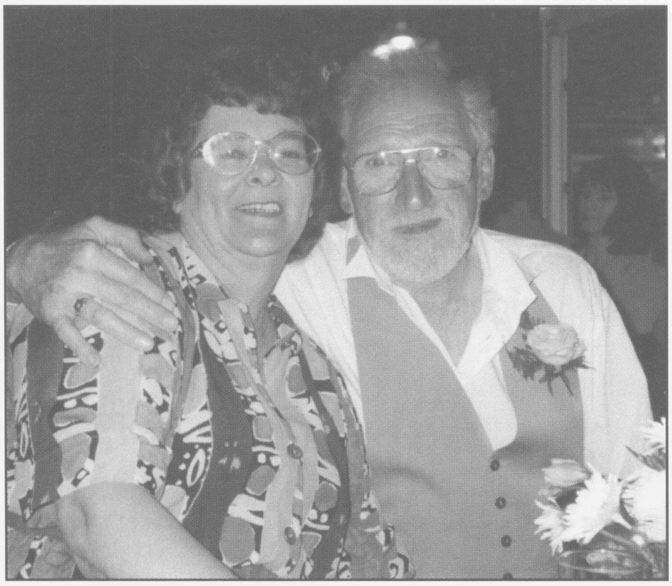
A FRIEND having a baby with spina bifida set Mary Roberts on course for giving 35 years of voluntary service to ASBAH.

Chairman for the last 13 years of Wigan, Leigh & Districts ASBAH, Mary was a founder member of its forerunner, Leigh ASBAH. She was also a representative on national ASBAH Council.

Pat Stridgeon, secretary of Wigan, Leigh & Districts ASBAH, said: "Mary was a good friend and support to everyone in the group."

In 1998, her voluntary work was recognised by Wigan Council with the presentation of a community award.

Mary (58) leaves a husband Bob and son Barry.



If it's help with continence you need, PromoCon's got it

WHEREVER you live in the UK, a Department of Health-backed exhibition and helpline, based in Manchester, can help with information on thousands of continence products.

PromoCon aims to give independent, impartial, confidential and up-to-date information on continence products and services. However, PromoCon doesn't give medical advice; this is provided by ASBAH, ERIC or the Continence Foundation *(see panel below).*

PromoCon can help with:

- Continence products that help with staying clean and dry.
- Continence treatment products such as bedwetting alarms etc.
- Incontinence management products such as catheters, bedding protection pads, urinary sheath drainage systems etc.

Choosing continence products can be difficult as there are many on the market, and your local NHS specialist nurse can help with product selection. Some products are available on prescription and some via the local health service. To see the full range of what's available in the UK, you could visit the PromoCon national exhibition at Manchester's Disabled Living Centre. It is best to book an appointment first (see final paragraph).

National continence products helpline

An independent and confidential helpline service **0161-834 2001** is open Monday to Friday 10–3pm. Commonly-asked questions cover: bedding protection, swimwear, pads, clothing, and specialist products to help with independent toileting.

Free information guides

PromoCon has two free guides to the full range of continence products available – *The Guide to Children's Continence Products* and *The Guide to Continence Products for Adults*. Please send an SAE with a 33p stamp, stating which book.

Product design and innovation

PromoCon also works to bring manufacturers and users of products together to influence the design and development of new products.

To encourage manufacturers to focus on user-friendly products, PromoCon has introduced an annual 'Look Good, Feel Good' award. A recent winner was the Undercover Belly Bag from Ward International, a urine drainage bag worn on the abdomen.

Occupational Therapist

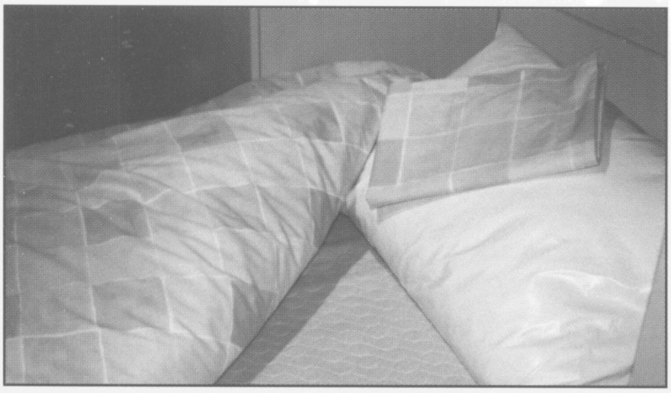
An Occupational Therapist, specialising in the field of functional incontinence or problems reaching the toilet due to mobility or dexterity difficulties, is also based at PromoCon. This post is mostly educational and for research.

Awareness campaign

PromoCon's continence awareness worker works with schools, libraries and healthcare trusts to publicise continence awareness. Public toilet provision or lack of it can mean the difference between isolation and having a normal life.

Other useful organisations

- The Continence Foundation, helpline 0845-3450165, Mon–Fri 9.30–12.30, www.continence-foundation.org.uk
- ERIC (The Enuresis Resource and Information Centre), helpline 0117-960 3060, Mon-Fri 10–4pm).
- ASBAH, 01733 555988
  email: postmaster@asbah.org


Protective pillow, mattress and duvet covers

Interactive story packs

With the charity 'Bag Books', PromoCon has developed three interactive packs to enable school teachers and nursery nurses etc to tell fun stories about continence to get key health messages over. The packs include stories on bedwetting, preventing constipation, and help with toilet training for children with a learning difficulty. For further information ring Bag Books on 020-7385 4021.

How to contact PromoCon

PromoCon is located at Manchester's Disabled Living Centre, Redbank House, 4 St Chads Street, M8 8QA. You are welcome to visit the centre or phone the helpline (*see previous page*). For an appointment ring: 0161-214 5959; email: promocon 2001@disabledliving.co.uk website: www.promocon 2001.org.uk

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ASBAH's perspective on continence

ASBAH knows what its service-users require in terms of continence services and works hard to help them achieve a good service. However, ASBAH no longer offers a 'hands on' service.

These days, our specialist medical advisers are more likely to be giving continence advisers information about spina bifida so they can manage their caseload effectively. We have produced a set of 10 continence topic sheets (*see box*) to help focus attention on issues associated with spina bifida. Occasionally, when there is no obvious NHS advice in a particular locality, we will track down a reliable source of information and support.

Improvement in the level of specialist NHS information and advice has resulted in a reduction in demand on ASBAH from service-users so we are taking fewer calls on the subject. The number of children with spina bifida who need help with continence issues is falling, but pressure to help with problems associated with hydrocephalus is growing. ASBAH medical advisers, who are nurses, are thus having to change their priorities.

Nowadays, continence is just one of the topics on ASBAH study days, rather than having a whole day devoted to it.

ASBAH *does* campaign for improved continence services, however, and we have had some success – by ourselves and in coalition with other groups – in raising public and political awareness of the issues. The NHS review of continence services identified a desperate need for improvement and we totally agree. We frequently join forces with organisations like the Continence Campaign, InContact and PromoCon to try and achieve change for the better.

ASBAH continence information pack

Each pack contains sheets on these topics:

- Toilet training and spina bifida
- Toilet training and hydrocephalus
- Adaptations for toileting
- Antegrade Continence Enema
- Bladder augmentation
- Colostomy, ileostomy and urostomy
- Clean intermittent self-catheterisation
- Artificial sphincter
- Dietary advice
- Tests and procedures used to check function of the urinary system.
- Mitrofanoff procedure (available soon).

Price: £3 (inc p&p) from ASBAH Information, 42 Park Road, Peterborough PE1 2UQ.

Ideas for independence

PRACTICAL ways of encouraging children aged between five and 12 years to be more independent were shared at a study day in Northern Ireland.

Eighteen parents, representing 15 children, attended *Taking A Back Seat*, at Musgrave Park Hospital's Disabled Living Centre.

A talk on 'Growing up' by Marie McGonnell, ASBAH's specialist adviser (medical), covered managing toileting, puberty, diet and exercise.

'Back Care' by Angela Lalor of Green Park Hospitals Trust gave practical tips and exercises for reducing spine damage and discussed products to help manage lifting and handling in the home.

'A Brighter Future' by ASBAH adviser, Veronica Buckland, looked at difficulties faced by older service-users and ways of preventing these occurring in those growing up now. Examples included: encouraging children to make friends in their home area to help them get used to socialising; treating the disabled child the same as their brothers and sisters, and encouraging independence.

Parents were also shown around the Disabled Living Centre to look at products and furniture which could be helpful.

Evaluation sheets showed that parents found the day very useful and appreciated meeting others with similar problems to themselves.

ASBAH's London Forum

ASBAH'S Housing/Independent Living Consultation Forum had a successful first meeting in February at which some provisional aims were agreed by those attending. A plan was made to continue with a series of meetings, and set up some working groups.

The next meeting took place on 27 April in Croydon. The main subject of that meeting was independent living and included discussion of support systems, skills training and ways to help people avoid social isolation.

● *For more information, please call Lucy Hughes, 0118-9343452, or Judy Hunt, 0208-363 4110, or write to them via our SE Region Office, 209 Crescent Road, New Barnet, Herts, EN4 8SB.*

'No limits' on your ideas

CASH awards are again up for grabs for young wheelchair-users who have a brilliant idea for a project.

The Whizz-Kidz 'No Limits' Millennium Awards is now in its second round and the closing date is **2 July 2002.**

First time around, Eleni Burgess (*pictured above and featured in the last issue of* Link) won £5,500 to do a nationwide survey on access in schools.

Other successful projects have included: a multi-media variety show; website design; improving personal horse-riding skills to give inspirational talks; dance projects; art exhibitions and TV footage on access in holiday resorts.

Applicants should be aged 12–18 with a permanent disability affecting their mobility and use a wheelchair (or other mobility equipment). They must be able to commit 3–4 hours a week to their project over a 32-week period.

● ***To discuss your idea and receive an application pack, phone 0207-233 6600 or email:*** *nolimitsawards@whizz-kidz.org.uk* ***website:*** *www.whizz-kidz.org.uk*

Whizz-kidz
THE MOVEMENT FOR NON-MOBILE CHILDREN

Congratulations and thanks

THOUGH it was the first time 46-year-old Steve Hunter had run a marathon, he is keen to do the London all over again for ASBAH next year.

Happy with his time of just over three and a half hours, he had lots of support from his wife, Denise, and daughter, Emma, plus members of his running club, the Egdon Heath Harriers.

The aircraft engineer, from Weymouth, Dorset, has received sponsorship pledges of more than £1,300 and is hopeful that most will come in. His brother-in-law, Alan Stevens, of Uttoxeter, Staffordshire, has hydrocephalus and curvature of the spine and has been helped by ASBAH.

Steve said: "This was my first marathon but I'd like to do it again. Although I've been running since I was at school, I've only taken it up seriously in the last 18 months."

- More marathon congratulations to Paralympic gold medallist Tanni Grey-Thompson who notched up her sixth London victory on 14 April – just two months after having a baby.

Hills beckon for East Anglian trio

HUNDREDS of pounds are set to be raised for ASBAH by some staff of a Peterborough outdoor shop and a friend in the forthcoming Great North Run.

Assistant manager Anthony Ng will be joined by colleague Ross West and old friend Brian Baker in the October half marathon.

Outdoor Travel, where two of them work, is a stone's throw from ASBAH's national centre in Peterborough and Anthony noticed us when he was passing.

He said: "I try to do a run for charity every two or three years as I feel I may be an innocent bystander as far as conditions such as epilepsy, asthma, spina bifida and hydrocephalus are concerned. One day, I might find I am affected by them or a friend or relative is affected."

The trio are asking for sponsorship from customers of Outdoor Travel, relatives, friends, and at the local hospital, the RAF (where Brian works), and a school.

Anthony is an experienced marathon runner, with the London, Dublin and Nottingham under his belt. With Brian, he has done three Great Eastern Runs and, this year, he has completed the Fleet Half Marathon.

Anthony (32) said: "It was Brian who introduced me to road running 12 years ago.

"The Great North Run is something I've been trying to do for three years and if I'm running it for ASBAH, I'll have even more motivation to do it."

Training for the Great North Run will also stand them in good stead for a Tour de Mont Blanc planned for August.

dates for your diary

NEC's double showcase

FIND out what's new in equipment at Naidex 2002, the UK's only international disability event.

Running alongside at the Birmingham National Exhibition Centre will be the successful KideQuip show which attracts thousands of visitors interested in the needs of children with disabilities and those who care for them.

Also new for this year, the Disabled Living Foundation will be running a helpdesk giving advice and information on equipment available to aid independent living.

There will be free seminars, including moving and handling, off-road driving for disabled drivers and addressing the problems that face disabled people before they venture out into the world of work.

One of the exhibiting companies, Day's Medical Aids, will run a prize draw for a scooter.

- *Free ticket hotline on 0870-429 4428. Website: www.naidex.co.uk*

Make life easier

USERS and carers have the opportunity of seeing a range of equipment that could maintain and enhance their daily lives.

Expo 2002, a free event, is held on 19 June at Keele Conference Park, Staffs. It will be of particular interest to users of community equipment and their carers. *Details: 01208-25 1426; Pam.Abraham@cht.swest.nhs.uk*

Upcoming events

Naidex, Birmingham
14 – 16 May
Naidex/KideQuip show at Birmingham's National Exhibition Centre. Huge range of equipment to help you at home or outside. ***Free tickets on 0870-429 4428 or go to** www.naidex.co.uk **for more information.***

Dunstable meeting
Tuesday 14 May
Monthly meeting for parents/carers of children/young people with SB/H, organised by the South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. ***Valerie Bottoms, tel: 01582-757745.***

ASBAH Summer Experience
4 – 7 June
Four-day activity holiday for teenagers with SB/H at the Kepplewray Centre, Cumbria. ***Details: Joan Pheasant 0113-255 6767,** joanp@asbah.org*

Children's Fun Day, Belfast
Saturday 8 June
M'Kinney Hall, Musgrave Park Hospital. ***Inquiries to ASBAH's Northern Ireland Office, 028-9079 8878.***

Dunstable meeting
Tuesday 11 June
See entry above. ***Valerie Bottoms, tel: 01582-757745.***

Expo 2002, Staffs
Wednesday 19 June
Free exhibition and seminars on equipment that can maintain and enhance daily life. Keele Conference Park, Staffordshire. Organised by National Association of Equipment Providers. ***Details: 01208-25 1426;** Pam.Abraham@cht.swest.nhs.uk*

Mobility Roadshow, Derbyshire
Thur 20 - Sat 22 June
Donington Park, Castle Donington, Derby. Comprehensive range of cars and specialised mobility vehicles. ***To pre-register for a test drive, tel: 0870 770 3222;** choice@gtnet.gov.uk, website: www.justmobility.co.uk/roadshow*

International conference
6–8 September
YOU are my world – inclusion of children and adults with SB/H. Organised by International Federation for Hydrocephalus & Spina Bifida (if). Mercure Fryderyk Chopin Hotel, Warsaw. ***For registration, email:** if@wanadoo.be **More information on:** www.ifglobal.org*

Exhibition, Bolton
Wednesday 6 November
KIDZUPNORTH, free, annual exhibition of children's disability equipment suppliers along with fun things to do. 10am–6.30pm, Reebok Stadium, Bolton. ***To register, call 0161-214 5959 and ask for Dympna Harrison.***

link.forum

Last issue's problem:

We are finding it hard dealing with our five-year-old's VP shunt. We know the signs of shunt failure, but the signs can mean so many other illnesses and he is a child who always has a cold, a UTI or something. How do we know when to use his open access to his neurological centre and bypass our local hospital? What should I do?

Joy Golland, parent: I HAVE a six year old who had a VP shunt fitted at six weeks old. He has a cold every year from 'October to March', and picks up every bout of sickness or bug that is going around, consequently having lots of time off school.

He also loses weight in winter and I find myself longing for the spring when things always improve.

His first year in school was particularly bad as I was tempted to allow him to stay at home if there was a 'bug going around' just in case. Our paediatrician has assured us by the time he is seven his immune system will be better and he will not catch so many things.

He is one of three boys and it is heartbreaking when he spends so much time ill. As to how to deal with it is very difficult. We spent many weeks in Nottingham when he was younger with viral infections and such like. Now I am much more cautious about contacting the hospital and try to deal with things myself at home, mainly to keep him as normal as possible. I monitor his temperature and keep a chart, I watch his fluids intake and basically use my common sense, watching for the slightest signs of deterioration.

My son found his stays in hospital very traumatic as did all the family. There is no easy answer. You have to cope as well as you can and do what you feel is right, dealing with each spell of illness as positively as possible, trying not to associate every symptom with hydrocephalus and to feel extremely lucky each time they pull through the many childhood illnesses that they encounter.

Here's another problem:

MY 16-year-old son, who has hydrocephalus and is partially sighted, is having a problem using the debit card issued by his bank as there are variations in his signature. His bank has offered to supply an explanatory letter for him to show retailers, but can anyone suggest a safer way in which he can pay by plastic?

- To suggest a solution – or submit your own problem – please email link@asbah.org or write to: ***Link.forum, ASBAH, 42 Park Road, Peterborough PE1 2UQ.***

Devon ASBAH goes global

DEVON ASBAH is spreading its wings locally and globally by setting up a message board on its website and gaining another permanent sign at its local zoo.

Its website – www.dasbah.be – invites the participation of people anywhere in the world.

Chairman Charles Harper explained: "The message board gives people the chance to pose questions, find answers and chat with others about spina bifida and/or hydrocephalus. It's new and needs your help to get started. So why not check it out and leave a message now!"

Closer to home, DASBAH, which was formed last year, has adopted another animal at Paignton Zoo.

Its first animal – a prairie dog – earned DASBAH a plaque and local publicity. Now a second plaque, for a golden lion tamarine (*pictured*), has gone up. Mr Harper said: "The zoo is a good place to gain long-term publicity."

DAVE'S DIARY

david.fulford-brown@ntlworld.com

IT'S less than a month till my brother's wedding and I will soon be reaching for a gun. But don't worry. This isn't about cutting down the guest list! It's for Nick's stag night.

The stag night is a traditional part of any wedding – a male activity shrouded in secrecy. However, having been asked (with elder brother Anthony) to plan Nick's stag night, I can now reveal that the rumours are true. The stag night involves a bunch of otherwise sane and sensible guys making complete prats of themselves by playing silly games and drinking lager until they all collapse in a drunken heap and have to be dragged off to bed!

Unfortunately, as the family (except me) and guests are lightweights when it comes to drinking, this collapsed state may be reached sooner rather than later. We need to do something to delay the start of drinking time.

You have to be sober to go clay pigeon shooting, which is where the gun comes in. Like most of the people on the stag I've never done any kind of shooting before. Shooting is a sport and consequently a form of exercise, something I usually avoid like the plague. But I have to say shooting looks like fun. It's got noise, explosions and it can be done sitting down. Apparently it's a popular sport for disabled people. As I only want to fire guns off, not train for the Paralympics I'm just borrowing the guns and gear. That makes it a fairly cheap day out.

We found a shooting club that will lend us the guns, show us which end the bang come out of and give us targets to shoot at. Clay pigeon shooting means we shoot at clay disks rather than real birds. If you just want to fire off some guns (which we do), why kill dumb animals? It's not as if I'd want to eat them anyway. I mean, if it was OK to shoot cows with shotguns not only would I stand a chance of hitting something, but could have a steak or beef burger afterwards. But people usually shoot at birds, most of which I don't fancy and are usually so small you'd need a dozen to make a hamburger!

The best reason for going clay pigeon shooting on the stag night is it seems safer than some of the other activities people end up doing. I think safe is good where Nick and co. are concerned. I have spent far too much time in spinal injuries units next to people who went racing and lost it, or decided they absolutely needed to dive head first into six inches of water when they're smashed. They end up spending the rest of their lives breathing through a machine.

Besides loving my brother I fear that if anything bad were to happen to Nick, (waking up naked in Scotland, having his hair shaved off, or finding the names of previous girlfriends tattooed on his rear etc), the bride would ensure the gentlemen responsible all end up singing the high notes in the church choir! (Enough said).

City of London eases parking

CONGRATULATIONS to the City of London for introducing a one-day parking certificate that can be used with Orange/Blue badges.

This means that, for one day, disabled car users can park within easy reach of some of the City's many attractions.

The one-day parking certificates can be obtained by phoning 020-7332 3553/4.

We await with interest to see if Kensington & Chelsea, and Westminster, make a similar dispensation.

Access guide to historic Britain

A GUIDE to access at National Trust properties is out now.

Information for Visitors With Disabilities 2002 is available free from*:* Access for All Office, 36 Queen Anne's Gate, London SW1H 9AS.

Got a strong opinion on any of the stories in *Link?* Email link@asbah.org now

holiday lets

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

SELSEY, WEST SUSSEX (SASBAH)

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

ISLE OF WIGHT ASBAH HOLIDAY BUNGALOW

Fully-furnished and equipped two-bedroomed bungalow. Beautiful area. Wheelchair-accessible. Site clubhouse, shop. Local indoor heated pool. Transport advisable. Excellent rates. Offers early/late season. ***Details: Mrs S Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF. Tel: 01983-863658*** *www.iwasbah.co.uk*

ORLANDO, FLORIDA

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

ORLANDO, FLORIDA

Purpose-built vacation homes for the disabled of all ages. 3, 4 & 5 bedroom luxury villas. All villas are wheelchair accessible, with roll-in showers and hydraulic lifts for access to the private pool. Situated 20 minutes from Disney and close to all amenities. Wheelchair accessible transport available. ***For further information, contact David & Elaine Foley, tel: 0191-488 6845, email:*** *david_foley@lineone.net* *www.floridadream.sagenet.co.uk*

TORREVIEJA, SPAIN

Fully furnished wheelchair accessible 3-bed 2-bathroom apartment. Will sleep up to 8 people. Shops, town centre, medical unit, beach etc all within 10-minute walk. Quiet family location. Ideal for group holidays. Available all year. Rates are £250–£400 per week. ***For further details/bookings, contact Julie on 0775-3684708 or Pete on 0780-3614770.***

NAISH HOLIDAY VILLAGE, NEW MILTON – Cliftop park with "excellent" status at New Milton, Hampshire. Excellent site facilities within 100 yards, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible log cabin accommodation. Sleeps six, well-furnished. Free club membership.

GRANGE COURT HOLIDAY VILLAGE – Park with "good" status at Goodrington Sands, Devon. Excellent site facilities within short walk, with indoor/outdoor pools, restaurant, bar, take-away. Fully-equipped, two-bedroom, fully wheelchair accessible, mobile home. Sleeps 4–6, well-appointed. Free club membership. (Purchased with funds from National Lottery).

MILLENDREATH HOLIDAY VILLAGE – Excellent seaside site with good facilities, just outside Looe in Cornwall. Restaurant, clubhouse, indoor pool. Fully-equipped, and fully wheelchair accessible, two bedroom chalet accommodation. Sleeps six – well-furnished and comfortable.

Details: Mr P Cash, tel: 01425-672055, *petercash1@compuserve.com* ***Bournemouth Spina Bifida Association, registered charity number 261914.***

Advert rates

- Classified Rates:

  £3.75 for 30 words max.
  £5.50 for 30-45 words
  £6.75 for 45-60 words
- Cheques and postal orders should be made payable to 'ASBAH'
- Classified adverts for the next issue of *Link* (July) should be submitted by Wednesday, 22 May.

  Please send to:
  Editor, ASBAH
  42 Park Road
  Peterborough PE1 2UQ
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  lizc@asbah.org

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