

Link

DECEMBER 1991 NO 137

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The magazine for people with
Spina Bifida and/or Hydrocephalus

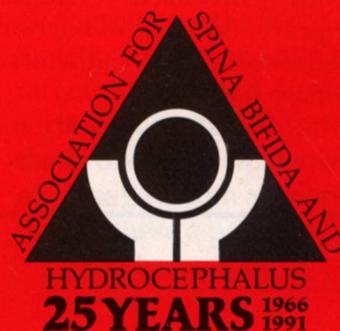


IN THIS ISSUE

STATEMENT SUCCESSES

Hydrocephalus in infancy - treatment advances

Incontinence conquered!



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HEALTH OF THE NATION

ASBAH has responded to "The Health of the Nation", the Government's consultative paper which seeks to promote discussion about objectives and targets for health care in England.

In a 30-paragraph submission, executive director Andrew Russell urges better co-ordination of health care and community care of people with spina bifida and/or hydrocephalus, whatever their age.

After consulting with members of our own executive and medical advisory committees, he presses among other targets for:

* Child Development Centres and Units for Young Disabled Adults to be set up in every health district;

* greater access to therapy at district level;

* a reduction in the incidence of pressure sores by greater staff and patient awareness of protective measures;

* a registration scheme for CSF shunts;

* a nationally-funded Serology Testing Service for bacterial colonisation of CSF shunts.

Mr Waldegrave, in a foreword to the consultative paper, wrote: "We must get the targets right. They must be sufficiently

challenging, yet not so daunting that they become a disincentive to achievement."



COVER - Peter Walker greets Study Day speakers - Leonie Holgate, Dr Geoff Lindsay and Dr Roger Bayston - outside ASBAH House. Peter's success - page 5.

ASBAH believes that the improvements and targets we propose are achievable. It is also wrong for the Secretary of State to claim that setting targets for physical disability services was 'inappropriate' as this will do nothing to encourage health authorities to give these a priority.

LINK No. 137 12/91



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Carolyn Smith Memorial Fund

*Carolyn, on her wedding day
earlier this year.*



A FUND in memory of former accommodation officer and fieldworker Carolyn Smith, who died in September at the age of 28, is to be set up by ASBAH.

At the request of her husband Richard Spencer, whom Carolyn married earlier this year, the fund will be used for developing and planning services for the training of young people in housing and independent living.

Instead of flowers at her funeral, Richard and Carolyn's mother requested that donations be made to ASBAH with the express purpose of setting up the Carolyn Smith Fund. Donations so far have reached £726.50.

"Our hope is that this fund could be left open for further donations in the future as with other ASBAH funds", Richard wrote from his home in Bradford.

"Carolyn was fully committed to ASBAH and thoroughly enjoyed the years that she worked with the Association, where she made so many friends."

Carolyn was a vivacious and popular members of staff who resigned in May when she moved to Bradford for her marriage. She first joined ASBAH as accommodation officer in June 1986, leaving in July 1989 to go back to college to further her housing qualifications.

Fieldwork manager Teresa Cole wrote: "Carolyn later decided that the course was not really what she wanted and we were very pleased when she accepted the post of North London fieldworker in October last year. She quickly became a valuable member of the team."

Her death shocked all who remembered her sheer love of life.

Anyone wishing to contribute to the fund should send their donation to the Finance Director at ASBAH House, clearly stating the purpose of the gift.

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ON THE WINNING SIDE

A family in Clywd have just won an appeal to get their child's statement of special needs re-written - thanks mainly to the intervention and support of ASBAH's education adviser, Peter Walker.

The local authority had sent Sally Mogridge's statement to her parents only two weeks before the end of the summer term, recommending that she attend a mainstream comprehensive school which is designated to integrate disabled pupils from that area. But Sally's parents were not happy with the 'choice' of school: "I just knew the school they'd chosen was wrong for Sally, at this time," said Mrs Mogridge. "In such a vast school she wouldn't be able to cope emotionally or educationally but we didn't have a clue about how to get the statement changed". Luckily an occupational therapist, at a unit attended by Sally, suggested the Mogridges contact ASBAH. The family had always managed on their own before but had now met a problem where they wanted outside help.

"Peter was very helpful, he went through he statement with us and

suggested what to say in letters to the authority, he visited the school chosen by the authorities and the one we wanted Sally to go to, and he visited us and spoke to Sally".

The Mogridges want their daughter to attend Hebden Green Special School for a year to give her time to "grow up emotionally and to gain more independence" so that she can hold her own in the comprehensive when she's ready.

At the tribunal, which Peter Walker attended, the authority were told to draw up a new statement for the child within two months. In the meantime, Sally is staying at her primary school until things are sorted out. The family will meet with the council again in January.

Mrs Mogridge is happy with this result and is full of praise for ASBAH's part in it: "We

wouldn't have won without Peter. We are too emotionally involved and didn't understand the procedures involved."

Our Education Adviser has had similar successes in helping families in Essex and Lincolnshire to get the schools they want for their children. Peter Walker feels strongly about parents rights: "If we had not challenged the LEAs in these cases children would have been misplaced in secondary school. It is important to challenge a statement that we do not regard as satisfactory".

If you need help, contact Peter Walker at National ASBAH.

Welcome Coventry

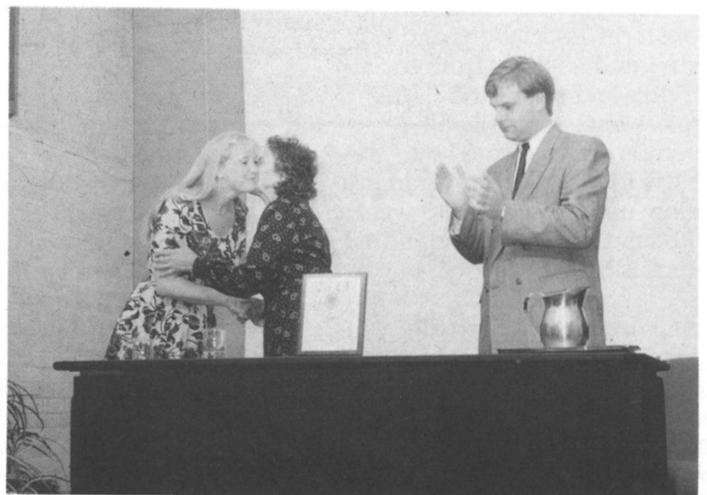
Coventry Association, which was formed a few years ago, has just affiliated to ASBAH.

CASBAH has about 40 members, produces its own newsletter and organises fundraising events, summer outings and a playgroup. They are now busy arranging their Christmas party. Their contact name and address is on the back page.

Lend me your ears

ASBAH accommodation officer Dominique Cull has won her way through to the national final of a public speaking competition by talking about her job. Dominique came first in the regional contest at the Institute of Housing's East Anglia Conference and won £150. The conference theme was Housing for a Changing World and Dominique's spoke on Housing Options for People with Disabilities.

As well as achieving personal success, Dominique took the opportunity to make ASBAH's voice heard: "There were no other representatives from similar organisations, but there were delegates from Housing Associations and local authorities and I was able to spread the message of what our clients need," said Dominique, who had entered the competition because it gave her free entry to the three-day conference.



Dominique receiving her award

POWER LIFTERS DO IT LYING DOWN



Strapped to a bench, disabled power lifters need great power in their upper body to lift up to twice their body weight in competitions.

Spina Bifida members of the British Power Lifting team who attended the International competition at Wolverhampton, in the autumn, included 21-year-old Nick Slater, who tied for fourth place. To make up for missing out on the medals on that occasion, he gained his third British record at the British Disabled Powerlifting Association Championships in November.

Members of the British team are still waiting to hear if any of them will go to Barcelona for the Paralympics in 1992

Nick Slater "on the bench" at Wolverhampton.

Caseload doubled

IN its first six months of operation our new regional office in Northern Ireland doubled its caseload from approximately 300 to over 600 clients. The improved service is obviously going a long way to meeting the needs of families in the Province as regional co-ordinator June Kerr explains: "Prior to regionalisation ASBAH was only able to scratch the surface in meeting the need for our services. Although the staff has increased from three to 13, most of them are part time and with 300 new referrals we are still busier than we expected to be."

The referrals come from a variety of sources: regional hospitals, the adult spina bifida clinic, lists from local associations and individual referrals from social services and education professionals. Initially all referrals are confirmed by fieldworkers and they arrange a follow up visit within 2-3 weeks, with new babies and individual referrals taking priority.

Being in a relatively small geographical area ASBAH's Northern Ireland office has benefited from close links with local associations and the Northern Ireland Association. "We are all working together for the mutual benefit of families: some local associations have been able to help with small grants for family holidays and Northern Ireland Association

requested and organised a study day with ASBAH's counselling team," said Mrs Kerr.

The staff in Northern Ireland comprises two full-time and six part-time fieldworkers. Also on the staff at the new regional office are two disabled living advisers: Meta Harvey works part time as education adviser and Marie McConnell has a full-time post as continence adviser. Both DLAs cover the whole province though they work out of the office. Completing the advisory team is qualified counsellor Julia Greer, she again travels throughout the province and has built up a full caseload: "When Julia started we had a study day with counsellors from the mainland - the day was requested by the Northern Ireland Association, who organised the venue and catering.

At that time Julia's work consisted mainly of bereavement counselling," said Mrs Kerr. Since then it has developed to cover a wide spectrum including sexuality, family/personal relationships, behaviour problems, and coming to terms with disability".

Colin Robinson, who was disabled living adviser (mobility) has left ASBAH to go to university and will not be replaced due to financial restraints. But they are hoping to get some extra clerical help, in the form of a part-time secretary, through the Government ACE scheme (Action for Community Employment). This will be at no cost to ASBAH

At present ASBAH is financing the entire Regional initiative from charitable funds, but since the services fit the plans and priorities of the DHSS, ASBAH is hoping for significant financial support from the Northern Ireland Office and the Health Boards.

ASBAH's Northern Ireland Regional Headquarters are based at:

73 New Row, Coleraine,
Northern Ireland BT52 1EJ.
Contact them on 0265 51522.

Playing for ASBAH



A game of pictionary has resulted in over £1,000 being raised for our Fund-a-Fieldworker campaign. In an 11-hour pictionary marathon (in which teams raced against each other to guess a phrase as it is being sketched by one of the players) members of Havering 18 plus group notched up £1,248 in sponsorship.

Every year the social club for 18-29-year-olds chooses a charity to benefit from their fundraising activities and this year, after hearing about ASBAH at the National Conference of 18-Plus groups, they chose us. We're very pleased they did!



Above: Smiles all round at the start of their marathon board game.

Below: Sqn Ldr Richard Foers (from left), Deirdre Pawsey, WO Ken Woods (cake winner), Sgt Howard Whiting, WO Jim Seddon.



Cake brings in cash

A rich fruit cake, decorated with ASBAH's striking red and white logo, which was made as a centrepiece for our silver jubilee garden party, has been used to bring over £200 to our fund-a-fieldworker coffers. The cake was raffled at RAF Cottesmore - where it had been made by Mrs Marion Foers, wife of the officer commanding the catering squadron.

Want to be a journalist?

'Opportunities in Journalism' is a scheme operated by RADAR to enable disabled people to study journalism. They are currently funding three students and are now inviting applications for 1992/93.

All applicants must have at least two A-levels (or equivalent) and a pass in English O level, GCSE, or higher. They must also display commitment and an

understanding of the attitude barriers faced by disabled people. The RADAR bursaries cover all fees and living expenses plus equipment. The closing date is 31 January 1992. Contact Caroline Gooding, Employment Officer, RADAR, 25 Mortimer Street WIN 8AB.

Change of name

Bromley and District ASBAH have changed their name to South Thames ASBAH, to more accurately reflect the area covered by their Association.

Funds for the Kasbah

Kent ASBAH is £50 better off thanks to an overnight cycle ride by one of their supporters.

Mr Derek Boosey, brother-in-law of KASBAH's treasurer, took 14 hours to cycle 120 miles from Portsmouth to Milton and with the help of the scouts - who collected sponsors for the trip - he raised the money for this local association.

ON TOUR DOWN UNDER

Leonie Holgate, a disabled living adviser for ASBAH, reports on her recent trip to Australia to attend a conference on spina bifida.

August 1990 - a warm Australian voice on the phone asked to speak to Mrs Holgate.

"Speaking," I answered slightly tentatively. The next question made me rock on my feet.

"Would you consider speaking at the Australian Fifth National Spina Bifida Conference in September 1991?" Without hesitation I agreed. What an opportunity! My motto has always been 'Never miss an opportunity' and this was a very rare one. The conference was to be held at Maroochydore, 60 miles north of Brisbane, Queensland.

Subsequently I learned that I was to be the key-speaker and to deliver an address each morning of the three-day congress. This could then be discussed in more detail by small seminar groups. Quite daunting, as 300 delegates were expected from all over Australia - outback and city areas - as well as a few from New Zealand.

The months leading up to my departure were spent in preparation, whenever possible, and thoughts of the Congress were rarely out of my mind. I trawled for videos - Five Oaks, Head Office, UDET, Fords, Natural History Museum and ARROW and set off with eight in my hand luggage.

I left this country well prepared with slides, overheads, and handouts, not to mention the theme addresses on floppy discs - all of which had taken a great deal of thought and detailed organisation. It was a very good exercise and paid dividends as I was able to feel really confident and to enjoy all the appointments arranged for me. This was helped

by the amazing Australian warmth and hospitality.

The Congress was quite an incredible experience and almost overwhelming in the enthusiasm and interest generated. The opportunity for so many families, young adults and a sprinkling of professionals to be together was a wonderful stimulus for discussion and frankness. No-one was alone and almost no-one appeared to be silent: there were large groups, small groups, one to one - and frequent gales of laughter. One young lady who had spina bifida came from Darwin and she had never met anyone else with the same condition. To mix with other young adults who had similar problems was mind-blowing for her, she was on cloud nine and had no wish to return to Darwin. I believe there are only three or four cases of spina bifida in that region, so one can imagine the isolation.

Leonie with Scott McKenzie



Workshops on all manner of subjects were included in the Congress and the afternoons were given over to these sessions. I was responsible for a Mobility Workshop and had raided Banstead Mobility Centre for slides and leaflets before leaving and to ensure that I had the latest information on the subject.

Sport is given a good deal of attention in Australia and they have, as some of our members are only too aware, an excellent record in basket-ball. However, other less hectic sports are also encouraged and it was very exciting to actually hold a paralympic gold medal which Libby, from South Australia, had won for rifle shooting.

A very positive outcome of the congress was the formation of a National Youth Network which will have to be run by tele-conferencing as distances are so great. Their first secretary is

Helen Gwillam, now living in Hobart but with a two year lectureship. Helen took a law degree in Sheffield and Northern Ireland and her mother was one of our fieldworkers in the past. The group aim to be entirely self governing and will have no input from anyone who does not have spina bifida or hydrocephalus.

My husband arrived from England in time to join me at the Congress dinner and for the final day, which was a bonus. The friend who had accompanied me was also made very welcome and experienced Queensland hospitality.

As well as the Congress the Australian Spina Bifida Association (ASBA) had arranged a full programme of promotional press, radio and even TV interviews for me to undertake. The majority were linked with the Congress and took place in Queensland but Western Australia also jumped on the band wagon and organised some promotional air and press space while I was in Perth.

In Sydney I spoke at the AGM of the Spina Bifida Association of New South Wales and in Hobart and Perth I also addressed parent groups. The response was quite startling and the impression was that the parents had been starved of information. However, listening to the State associations and reading the summary of their activities, I realised that the emphasis had been almost totally on the spina bifida; hydrocephalus and its possible effects had not been given much consideration. They were aware of only a few children with purely hydrocephalus.

I ran two teachers' workshops, one in Brisbane for Advisory Teachers and one in Perth. Both were well attended and keen interest shown. All the teachers with whom I spoke were

generally well informed but they appeared to lack awareness of the extent of possible learning difficulties in conjunction with spina bifida and hydrocephalus.

In Melbourne I visited the Royal Melbourne Children's hospital and had a two hour 'round the table' discussion with some of their medical staff. I was also shown the most stupendous and superbly equipped special school, covering about four acres, with only 120 pupils. The government are running down special schools and the amazing resources and staff expertise will be lost for many children who sorely need it. It has to be said that the State of Victoria, of which Melbourne is the capital, has

organised a very good classroom support and advocacy system for children being integrated into mainstream school but it is costly and the parents see the axe about to fall on this. The reverse side of the coin was that they have some good housing; in the form of units or bed-sitting rooms, close to shops and amenities, with support-help available where necessary.

Whilst in Hobart I had the opportunity to speak to therapy staff at the Douglas Parker Rehabilitation Unit. They mainly cater for spinal injuries but they also have many spina bifida young adults and they showed particular interest in driving. Most people have to buy their

own car first, as few driving schools have specially adapted cars. There is no Mobility Allowance, so financial commitment is quite considerable. As an aside, unless someone is self employed they receive 17% extra pay for their holidays and every 10 years have 12 weeks fully paid leave plus the extra 17%. There were rumours that the Government was going to put a stop to this soon!

One morning was spent renewing memories at St Giles School and Home for Disabled Children in Launceston, Tasmania. There have been many constructional changes and philosophical changes since I worked there, 30 years ago, I am delighted to say. They also run a community programme which covers the whole of the State - quite an undertaking for a large island.

Last but not least, I was asked to give a lunchtime presentation the day before I returned to the UK, at Princess Margaret Children's Hospital in Perth. The audience consisted of medical and para-medical staff. Again enthusiastic interest was shown. I was impressed by the good rapport between hospital staff and the Secretary of the Western Australia Association. There is a very friendly relationship between the parents and the doctors and therapists - much less formal than is experienced here. This warm hospitality certainly extended to me and I felt as though everyone I met was a friend of long standing. I hope they will prove to be.



Thanks

I would like to thank Moyna Gilbertson, Teresa Cole, Phillip Watson, Mary Barton, Paul Dobson and Andrew Russell for their help and support in preparing for this trip. Also secretaries of local associations for information they supplied.

Bowel Function

The intestine is a tube down which the food you eat passes. The movement of this food from the top to the bottom of the gut is caused by the contraction of the wall of the intestine (peristalsis). Usually, when food is eaten peristalsis in the intestine generally increases. In the upper part, or small intestine, the complex chemical structure of the food is broken down into simpler units which can be more easily absorbed into the blood stream. This process is called digestion. The residue which remains after digestion passes into the lowest part, or large intestine. At this point the residue has the consistency of vegetable soup and contains valuable salts and water which must be reabsorbed. This is the the main function of the large intestine. The longer the residue (or faeces) remains in the

large intestine, the more fluid is reabsorbed and the harder the faeces will become.

Normally, the rectum (which is the lowest part of the intestine

above the anus) is empty. However, just prior to passing a bowel movement, the rectum begins to fill with faeces from above and the person senses the need to go to the toilet. Normally, the muscles around the anus (anal sphincters) will be in a state of contraction and because of this there will usually be no leakage of faecal material from the anus. Special nerves are stimulated in the wall of the rectum which causes anal sphincters to relax and peristalsis of the large intestine to increase. This chain of events will result in the passage of the faeces (defaecation).

Bowel Function in Spina Bifida

In spina bifida bowel function may be affected in different ways.

These usually result in constipation and incontinence unless correctly treated.

◆ There is usually a loss of rectal sensation and this results in the person being unable to know when a bowel action is about to occur. Many affected people, however, can appreciate cramps in the abdomen, which will often precede a bowel action. These can be used to anticipate defaecation and enable the person to get to a toilet in time.

◆ Usually the nerves which supply the large intestine from the spinal cord, and which are stimulated when the rectum fills, are not working properly. Peristalsis of the large intestine does not occur as normal and the faeces are retained in the large intestine for a longer than normal period. This allows more fluid to be reabsorbed from the faeces and results in hard bulky stools, which are more difficult to evacuate, and leads to constipation. If this stool is not evacuated completely, the intestine and rectum become chronically distended and because of this are less able to function normally.

◆ The anal sphincters and the muscles of the floor of the pelvis are usually paralysed and in most cases this results in relaxation with the risk of leakage of semi-liquid faecal material.

◆ Less frequently, the anal sphincters and the large intestine act automatically, and a normal bowel motion occurs often each day. This is because the important nerves going to the large intestine from the spine are not damaged. These people usually do not have normal rectal sensation and find it difficult to anticipate when a bowel motion is about to occur and as a consequence are often incontinent.

Not everyone will be affected in the same way by spina bifida. It depends on the level and extent of the lesion. Despite these differences, some basic principles can be applied to everyone.

Towards better management

Most people with spina bifida have an abnormal nerve supply to their bowel. To understand how this will affect bowel management, it is necessary to know how the bowel normally works.

Our Continence Advisory Service explains.

Adequate Fluid Intake

Approximately 6-8 cups minimum (or more accurately one ounce per pound of body weight) of drink per day are necessary - not only to prevent constipation but to stay healthy generally. More fluid may be needed if a person is very active or if fluid is lost through perspiration.

High Fibre Diet

A high fibre diet will help to keep the faeces soft and formed and, therefore, easier to pass. Introduce more fibre into the diet gradually; the recommended amount is 30g per day for adults. If it is impossible to modify the diet, then 'bulking agents' such as Fybogel can be used. Use foods which 'cause-effect' in an advantageous manner. For example, if beans induce a bowel movement they should only be eaten to induce a bowel movement, otherwise accidents may occur.

An information sheet on dietary fibre is available from ASBAH's head office.

Regular Emptying of Bowels

Regular emptying of the bowels should be started at the usual age (2-3 years) to prevent constipation (making stools easier to pass) and to reduce soiling and "accidents".

This is achieved by sitting on the toilet, perhaps two or three times a day initially, for periods of 10-15 minutes. This may be reduced later. The position on the toilet is important. Feet should be flat on the floor or stool and the body should be well supported so that it is comfortable and safe. The potty, or potty chair, is a good idea for even older children because it promotes the squatting position, which makes bowel evacuation easier. Young children should never balance precariously on an adult toilet, it does not help them to empty the bowels and may also make them frightened of using the toilet because they think they may disappear "down the hole".

Peristalsis and movement of faeces into the lower intestine will occur after eating or drinking. Therefore toileting should be after a meal to utilise this natural movement. Whilst sitting, exercises to aid evacuation should be performed. This is anything which increases the pressure in the abdomen eg laughing, coughing, holding breath and pushing, or blowing up a balloon. It may be very difficult to appreciate how the pressure can transfer from the upper trunk to the rectum if you have no feeling. A lot of patience and perseverance may be necessary.

It may also be helpful to chart bowel movements for a few weeks. This may show a particular time of day or activity when soiling is more likely to occur. Arrange the toileting time to be half an hour before these occasions.

Eventually, a "bowel habit" (a regular time to go) can develop and the number of sessions per day on the toilet may be reduced. It might be necessary to use medication initially to start the bowels moving, especially if constipation has been a problem in the past. Some people may need medication permanently. Ask your GP for advice.

Medications

Bulking agents such as Fybogel or Trifyba work by swelling in the stomach and holding a lot of water in the faeces. This helps to prevent constipation.

Laxatives: taken by mouth, they increase motility of the bowel and move the contents along quicker, preventing constipation. They range from the mild preparations such as Lactulose, to stronger ones such as Senokot which can cause colic pains.

Suppositories: inserted into the rectum, such as Dulcolax, causing the muscles of the rectum to contract. This may not work for everyone as the nervous supply to the rectum varies. Glycerin suppositories have no direct effect on the rectum.

Enemas: inserted into the rectum and causing contraction of the rectum. Mini enemas, eg Microlax, may be helpful and easy to use. It may be necessary to use a larger phosphate enema initially, in order to establish an empty bowel.

Anti-diarrhoeal drugs: eg Lomotil, slow down the passage of the faeces to allow more liquid to be absorbed and therefore produce a more solid stool. These have to be used very carefully. It is possible to be constipated and have overflow diarrhoea. If such medications are then taken, it aggravates the situation.

All these medications affect people differently, and it is a matter of trial and error until the most suitable preparation is found. Once a regular toileting pattern is established, medications can often be reduced and then withdrawn altogether. Remember, that other drugs such as antibiotics can have an effect on the bowels and disturb the pattern.

If at first you don't succeed...

Bowel habit may change due to emotions, general activity or inactivity, types of food, change of routine or environment and medications. It is necessary for us to understand how our own body works so that we can be prepared for any change. Planning ahead will avoid embarrassing situations. Constipation can cause nausea, lethargy and headaches.

Bowel management in spina bifida is never easy and requires patience and perseverance. The results are not immediate, often taking months to achieve the ideal situation.

Sometimes more complex management or even surgery may be necessary when all else fails.

ASBAH's continence advisory service understands the special needs of our client group and is ready to give advice and support.

"I WILL NEVER TAKE CONTINENCE FOR GRANTED"

Brian, a college lecturer, is 31 years old and all his life has had to cope with the "debilitating effects of incontinence" - until he met an ASBAH continence adviser. Together they found a solution and a new independence for Brian.

This is his story.

"From my earliest memories, I was never able to control my bladder and this was greeted by my parents and primary school teachers as being something which I would 'have to live with'. My mobility at that time was poor and I was mobilising with callipers and occasionally using a wheelchair. Between the age of five and 11 years I had 15 operations which involved long absences from school and from home and family. I actually remember taking my 11 plus exam whilst in hospital and being told that I would never pass it because I had missed too much school.

I proved them all wrong, however, and did pass. I started at the local grammar school where the teachers were completely ignorant about both my spina bifida as it was then and about the developmental changes which would inevitably take place. Continence control at this stage was becoming more problematic. At no time did I or my parents receive any advice or support whatsoever even though I was still having regular medical and surgical attention.

My method of bladder management was very ineffective as I would try bladder evacuation by manual expression (pressing directly on my bladder). This meant that my bladder was not being completely emptied. I was still wet and urinary infections became a frequent and distressing occurrence.

I was very isolated at school and felt as though I was the odd one out because everyone else was 'able bodied'.

I finished school at 18 and started to study at Bristol University,

majoring in modern languages. I cannot stress too strongly the determination, or indeed the effort, involved in gaining sufficient qualifications to be eligible for a course of this standard - given the amount of school time lost over the years.

Having successfully completed the degree course, I started social work training with a view to working with physically and sexually abused children. By now I was 24-years-old and still manually expressing my bladder. I started buying my own incontinence pads, at great expense. I had become acutely aware of the social implications of 'being wet' and was feeling increasingly desperate to find a more appropriate form of continence management.

I was very anxious to retain the level of independence I had achieved and was afraid to take any risks. I did try CISC (clean intermittent self catheterisation) without success - through lack of perseverance, professional guidance and, therefore, any real commitment.

It was by chance that I came in contact with Mary White (then ASBAH fieldworker, now continence adviser) who has proven to be an invaluable source of reference to me, in terms of informing me that I could be continent and that a range of options were open to me. Mary's special interest in the field of continence management, and the networks which she had established on a local and national level, meant that she was able to guide and support me at a time when I had to make decisions which would give me a level of

independence and personal confidence consistent with my increased professional status and standing.

After a lifetime of poor bowel management, I decided to examine more closely the bowel washout system Mary had described to me. This involved referral to a suitable centre, admission to hospital for bowel preparation and a course of instruction on the ward. I have now achieved full bowel control by the use of a rectal washout system and I am considering the possibility of a new surgical procedure which enables bowel evacuation by washing through a small catheter site on the abdominal wall.

I took the decision to accept the opportunity of implantation of an artificial urinary sphincter for bladder management. Although this involved further extended hospitalisation and major surgery, I now feel that the effort and discomfort involved is far outweighed by the benefits of complete independence, greater self esteem and full control over my bodily functions. This is something I have never experienced in my life before.

My life to date means that I am acutely aware of young people who are still experiencing the debilitating effects of incontinence, which could be relieved by access to specialist professional advice. This could and should eradicate much of the distress and unhappiness caused by incontinence.

To be 'continent' is an experience which I will constantly cherish and never take for granted."

HYDROCEPHALUS IN INFANCY

Recent advances in treatment

THE pattern of infantile hydrocephalus is changing. For a variety of reasons, fewer babies are being born with hydrocephalus associated with spina bifida, whilst the proportion with hydrocephalus due to congenital or postnatal reasons, such as meningitis, remains fairly constant. However, growing numbers of premature infants are developing post-haemorrhagic hydrocephalus (PHH) as a result of bleeds into the immature brain during the first few days of life.

Population based studies from Sweden have shown a marked increase in this type of hydrocephalus in the past 10 years. Neonatal care has improved and more premature infants survive. Statistics suggest that highest incidence of post-haemorrhagic hydrocephalus is found in the most premature infants. (REF 1).

Statistics for infantile hydrocephalus in Wessex reflect this trend. (Fig 1). In 1981, six out of 13 infants requiring shunts in the first year of life had hydrocephalus associated with spina bifida. By 1988, six out of 12 infants shunted had post-haemorrhagic hydrocephalus.

Cerebrospinal fluid (CSF) is manufactured in the lateral ventricles and circulates through the third and fourth ventricles before flowing over the base of the brain and into the spinal canal. It circulates around the surface of the brain and is reabsorbed into the blood through minute drainage channels in the walls of large veins inside the skull. (FIG 2).

Small bleeds from fragile vessels near the wall of the lateral ventricles are relatively common in infants born more than two

months premature. Studies have shown that the majority of such babies will settle without treatment. (REF 2). Severe bleeds block the drainage channels, resulting in dilation of the ventricles, raised pressure inside the head and rapid head growth.

Treatment is much more difficult than in infants born at the correct time with otherwise normal brains. Small sick babies often have a variety of ongoing medical problems which mean that they are too ill for surgery when the ventricles first start to enlarge. They have decreased immunity and high levels of protein in the CSF, leading to increased rates of shunt infections and blockages. (REF 3).

Removal of CSF, via lumbar punctures, direct ventricular taps, or surgically implanted reservoirs, is a common treatment for post-haemorrhagic hydrocephalus in the UK. It may be the only treatment required or

may serve to 'buy time' until the baby is fit for surgery. However, a large study published in 1990 casts doubts on its efficacy. Early CSF removal did not improve the neurological disabilities in survivors and actually increased the short-term mortality rate due to infections in the CSF. (REF 4).

Drugs have been used to treat hydrocephalus in the past, with varying degrees of success. They fell out of favour with the advent of effective surgical techniques in the 1960s. Interest has been rekindled in the past few years due to their possible role in the non-invasive treatment of post-haemorrhagic hydrocephalus.

In 1985, workers in the USA reported a large series of hydrocephalic infants who had been treated with drugs. The hydrocephalus was of varying types but all had reached the stage at which shunt insertion would be considered. A combination of two diuretic drugs, acetazolamide and

Infantile Hydrocephalus in Wessex De Novo shunt insertion

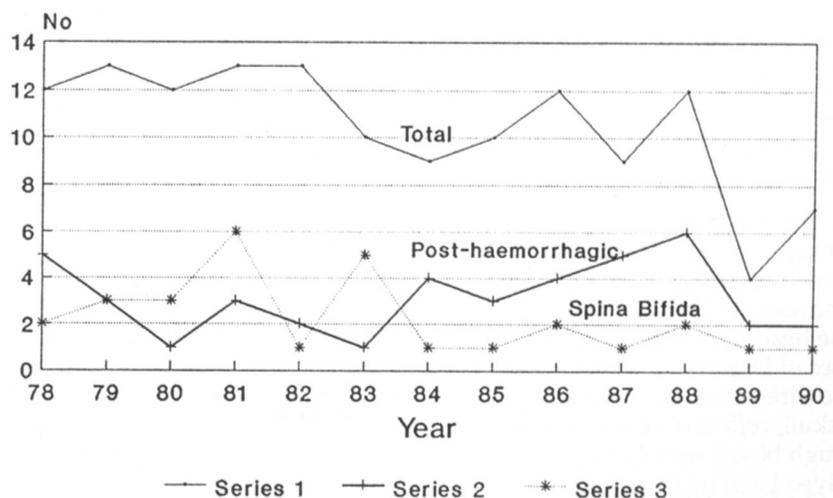


Figure 1

frusemide, was administered for an average of six months. CSF formation is reduced by 50-60%, thereby reducing pressure inside the skull and controlling excessive head growth over a period of weeks.

Nearly half the patients in this study did not require subsequent shunt insertion. The drugs were well tolerated and had few side-effects if monitored carefully. (REF 5).

NON-INVASIVE METHODS OF MONITORING HYDROCEPHALUS

Until recently, CAT scans were the only means of visualising the brain. They had the disadvantage of x-ray exposure, were expensive and not portable. Pressure inside the brain could only be measured directly at lumbar puncture or shunt insertion. However, modern monitoring techniques are able to provide similar information in non-invasive ways. They are cheap, safe and can be used at the cotside.

• *Transfontanelle ultrasound*

Ultrasound scans are used for routine monitoring in Special Care Baby Units. Probes placed over the anterior fontanelle (soft spot) transmit ultrasound waves which are reflected from structures inside the brain. The technique is used to detect bleeds into the ventricles and to monitor ventricular size.

• *Transcranial Doppler Sonography*

This is a recently described technique used to measure blood flow velocity inside the brain. A transducer is placed on the side of the head of a sleeping infant. Pulses of Doppler ultrasound waves are transmitted through the skull, reflect off blood flowing through blood vessels and are received back by the transducer.

Mathematical analysis of the waveforms gives a numerical

value which is thought to indicate resistance to bloodflow, downstream from the site of measurement. A full description of this technique was given in the article by Ian Pople in the June edition of LINK. (REF 6).

• *Fontanometry*

Over the years, numerous devices have been described to measure pressure inside the skull via monitors attached to the anterior fontanelle. Workers in

also to examine the role of non-invasive monitoring techniques.

METHODS

Infants throughout Wessex were referred via their local paediatricians. Once parents had received explanation of the trial and given consent, baseline investigations were performed. The drugs were started whilst the child was an in-patient, in order to monitor the response to treatment and any possible side-effects. Once stabilised, the babies were sent back to their local Special Care Baby Unit or directly home if they were otherwise well.

Repeat measurements of head size, ventricular size, anterior fontanelle pressure (AFP) and transcranial Doppler bloodflow were repeated on an

outpatient basis every few weeks. Close liaison was maintained with the families, local hospitals and GPs. This was a particularly important and successful aspect of the project. Drug therapy was stopped after six months and the babies monitored carefully until all parameters had stabilised.

Repeat measurements of head size, ventricular size, anterior fontanelle pressure (AFP) and transcranial Doppler bloodflow were repeated on an

RESULTS

Eight infants received drug therapy, four (50%) of whom did not require shunt insertion. Four out of five (80%) of the premature infants were treated successfully (see table over).

All infants had raised anterior fontanelle pressure, increased ventricular size and high resistance to blood flow when originally seen. Those who responded to drug therapy showed a gradual fall in all three parameters over the first few months of treatment, whereas those who required shunting did not. In patient 2, who had rapid

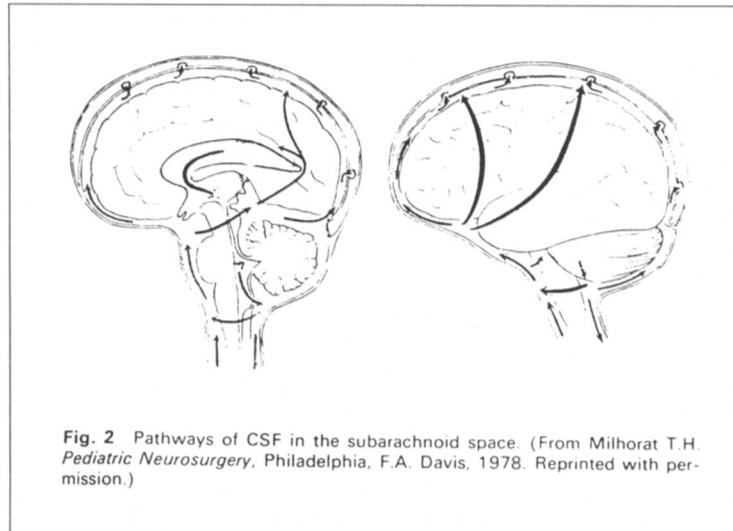


Fig. 2 Pathways of CSF in the subarachnoid space. (From Milhorat T.H. *Pediatric Neurosurgery*, Philadelphia, F.A. Davis, 1978. Reprinted with permission.)

Figure 2

Southampton have produced a fontanometer that is relatively free of technical drawbacks and which has been shown to correlate well against direct measurement of intra-cranial pressure. A strain gauge sensor, the size of a 10p is attached to the fontanelle, using an adhesive disc. Doppler studies are often performed simultaneously whilst the baby is asleep.

SOUTHAMPTON PILOT STUDY

A pilot study based at Southampton General Hospital was set up in 1989 to evaluate the efficacy and safety of acetazolamide and frusemide in the treatment of post-haemorrhagic hydrocephalus and

increase in head size in the two months prior to referral, the head growth stabilised during the six months treatment and he remains well, more than one year later.

CONCLUSIONS

It appears from this study that drug therapy is most effective in premature infants with moderately severe post-haemorrhagic hydrocephalus. Drug treatment is well tolerated if monitored closely and should be started as early as possible. It must be stressed that shunt insertion will remain the definitive treatment for rapidly progressive hydrocephalus.

Further studies are needed to investigate the complex relationship between pressure, blood flow and ventricular size. It is hoped that this knowledge may help to select the optimum type and timing of treatment for all infants with this condition.

Figure 1 shows the dramatic fall in PHH in Wessex since the start of this pilot study in 1989. Whilst it is tempting to assume that drug therapy is responsible for this, other important factors such as improvements in neonatal care and the short time scale must be considered. Large scale studies are, therefore, needed before objective scientific conclusions can be reached.

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Patient	Gestation (weeks)	Diagnosis	Age at referral	Shunt
1	30	PHH	5 weeks	No
2	30	PHH	4 months	No
3	26	PHH	4 weeks	Yes
4	Term 40	Post meningitic	5 months	Yes
5	32	PHH	6 weeks	No
6	Term 40	PHH	1 week	Yes
7	Term 40	Spina Bifida	2 weeks	Yes
8	26	PHH	7 months	No

Figure 3

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5 Shinnar S, Gammon K et al. *Management of hydrocephalus in infancy: use of acetazolamide and frusemide to avoid cerebrospinal fluid shunts. Journal of Paeds 1985; 107: (1) 31-37.*

6 Pople I. *The Doppler Effect. LINK June 1991; 8-10.*

ACKNOWLEDGEMENTS

Special thanks to the Wessex Regional Research Trust for financial assistance, Dr Colin

Kennedy and staff, Southampton General Hospital and to the children and families.

FUTURE PLANS

An international collaborative trial is being planned currently, in order to establish the role of acetazolamide and frusemide in the treatment of post-haemorrhagic hydrocephalus. It is important to establish:

- a) whether drug therapy can reduce the numbers of infants requiring shunts.
- b) whether it can be used to delay shunt insertion in small sick babies who are unfit for surgery.

Two hundred infants are required for the study. Centres throughout Europe and as far away as New Zealand wish to participate. It is hoped to start recruitment into the trial in early 1992: results will be available in three-four years time.



• HSG STUDY DAY •

The first Hydrocephalus Support Group study day in 1992 will be on 29 February at ASBAH's National Office, Peterborough.

For more details and to book your place, contact Trish Jones at ASBAH, 42 Park Road, Peterborough PE1 2UQ.

Tel: 0733 555988

...BE THERE

Research update

Maddie Blackburn (right), ASBAH Research Fellow, gives us the latest news on her research into Sexuality and Disability.

Recently 100 young adults (aged 16-25 years) with spina bifida and/or hydrocephalus, living in the North West Thames region and Kent, were interviewed about their sexual knowledge and experiences. Ten young adults with cerebral palsy and 100 able bodied people of the same age were also interviewed to give a comparison. The results of this study appear to indicate the need for more specific sex education for the disabled person both in special schools, colleges and on an individual basis, as well as heightening awareness of the problems associated with sexuality and disability in mainstream education and among health professionals.

All the young adults interviewed felt that doctors, nurses, teachers etc, require greater assistance in preparing sex education programmes. Health professionals, teachers, parents/carers also need to explore their own feelings and



attitudes towards sexuality. Parents/carers should have greater involvement in their son/daughter's sex education teaching.

Over half of the adults with spina bifida felt they needed more sex education teaching and requested this be carried out in schools, colleges and other institutions by teachers with appropriate training. The following audio visual aids were recommended; videos, leaflets and simple charts. Individual tutorial work as well as counselling were also given high priority.

Specific information requested included; attitudes towards sexuality, defining the meaning of friendship, relationship and love according to individual circumstances, religious and cultural beliefs, sexuality and disability, genetic counselling, explanation of incontinence to a partner, comfortable positions in a physical relationship, as well as more specific teaching on pregnancy, labour and child care.

An introductory training package is currently being produced for ASBAH, by the Community Paediatric Research Unit (Westminster Children's Hospital) in conjunction with the medical illustration department of Charing Cross and Westminster hospitals. It is hoped that a more comprehensive package may be produced on receipt of funding. The materials are being designed specifically for young adults with spina bifida, their parents/carers and teachers, but may also be of interest to teachers, as well as health professionals.

A detailed report of this study will be available in 1992. If you would like further information about this, or other projects being carried out by the Community Paediatric Research Unit for ASBAH, please contact:

Maddie Blackburn, Research Fellow, ASBAH, Westminster Children's Hospital, 144 Vauxhall Bridge Road, London SW1. Telephone 081 746 8631.

References: 1 Blackburn M, Bax M, Strehlow C, (1991) 'Sexuality and Disability'. *European Journal of Paediatric Surgery, Conference proceedings.*

2 Dorner S, (1977) 'Sexual Interest and Activity in Adolescents with Spina Bifida'. *Child Psychology, Psychiatry, 18, 229/237.*

Maddie Blackburn was awarded a research fellowship by ASBAH to carry out this and other studies related to spina bifida, in 1991.

Medical Matters

Drug Advice

In the last issue of LINK we informed readers that the anticholinergic drug Terodiline (Micturin) had been withdrawn from sale by the manufacturer. The decision to withdraw the drug had been made because cardiac complications had been noted in the over-75 age group. Other people at risk are those with heart problems and those on certain other drugs, ie diuretics, tricyclic anti-depressants and anti-psychotics.

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If readers require any advice or further information regarding Terodiline please contact the Continence Advisory Service at ASBAH.

Florence Nightingale Scholarship

Mary White, one of ASBAH's continence advisers was shortlisted for interview for this year's Smith and Nephew Foundation/Florence Nightingale Scholarship. This prestigious scholarship gives the

opportunity to carry out research, in a relevant area, anywhere in the world and finance is provided up to a maximum of £4,000.

Mrs White helped set up ASBAH's continence advisory service a year ago, after three years as a fieldworker in Derbyshire and Nottinghamshire. She was a Registered General Nurse for 20 years. She started taking an interest in disability when her eldest son was born partially-sighted and she has since gained school nursing and special needs qualifications.

The interviews take place as LINK goes to press - we'll let you know how she gets on.

Publications & Services

Special Mail Order

The autumn/winter catalogue for 'The Special Collection' is now available. This is a mail order fashion catalogue for men and women with special needs, from the JD Williams Group. It includes daywear, nightwear and shoes etc which have easy fit features such as front or no fastenings, stretch fabrics and elasticated waists - designed to help those with dressing difficulties. To obtain a copy of the catalogue write to: The Special Collection, Mason Williams, Freepost (MR8421), Manchester M126GL (no stamp required) or phone free on: 0800 262 717.

Contact Register

The National Childbirth Trust operates a national Contact Register, for mothers with a disability, called Parentability. The co-ordinator can be contacted on 05086 4086 or you can get more details about Parentability from Jo O'Farrell on 0344 773366.

Publications

Places that Care is an access guide to places of interest suitable for disabled people. It includes properties of the National Trust, English Heritage, RSPB reserves, zoos, gardens and Stately homes. Price £4.00 per copy + £1 p&p, from Michael Yarrow, Mediair Marketing Services, 72 High Street, Poole, Dorset BH15 1DA. Donations from the sale of this book will go to six charities, including RADAR.

Riding for the Disabled is a practical guide to teaching and helping disabled people to ride. It gives details of existing groups and how to set up a new one. Written by Vanessa Britton, it costs £14.99 and is published by Batsford.

ASBAH AWARDS

In response to demand, we have been asked to remind readers about the existence of ASBAH's award-making funds and how they operate. Below we reprint details from an information sheet which is available on request from the national office at Peterborough.

ASBAH is also in the process of deciding the criteria which will apply when making awards under the new Carolyn Smith Fund, see opposite.

Specific ASBAH Funds

We have three distinctly separate and named funds which provide money for different purposes.

1. The Professor Zachary Fund - This was set up when Professor Zachary retired as ASBAH's first Chairman. The purpose of the fund is to encourage young people to use their own initiative and undertake some activity. This is very often related to a hobby or recreation but not necessarily so. Applications to the fund should be made by the young person. Only in very rare instances will an application be accepted on behalf of a young person. Awards granted from the Professor Zachary Fund are usually less than £100.

Donations to the Fund are welcomed and from time to time the fund is topped up on the authority of the Finance and General Purposes Committee.

2. The Professor Lorber Bursary Fund - Professor Lorber was the first Chairman of ASBAH's Medical Committee. The Bursary Fund was set up when he retired. Money from this fund is used to support students who are attending an ASBAH course. These are usually courses held at Five Oaks but not always. The level of support is about £100 and applications can be made on behalf of individuals. Donations to the Professor Lorber Bursary Fund

are welcomed and, again, this fund is topped up on occasion on the authority of the Finance and General Purposes Committee.

3. The ASBAH Bursary Fund - This is our newest and largest fund. It was set up following a generous anonymous donation. The money was invested and only the interest received is used. This fund is to help with expenses to attend a course which is approved by ASBAH but not organised by ASBAH. The limit of support for each individual is likely to be £1000.

Administration of the Special Funds

Applications for assistance from the Professor Zachary and the Professor Lorber funds should be made by letter addressed to the Executive Director.

Applications to the ASBAH Bursary fund should be made on the appropriate application form, which is available from the Peterborough office, and sent to the Executive Director.

Decisions are generally made by the Executive and Finance Directors together, the Chairman and Treasurer are kept informed and consulted as appropriate. Additional information is sometimes required following receipt of the first application. Application to these funds should be made as far ahead as possible, bearing in mind that only in very exceptional circumstances can applications be processed in less than two months.

Please state clearly the fund to which you are making an application.

Converted Caravans

Holiday caravans can be accessible for wheelchair users and United British Caravans of Middlesex have been exhibiting their caravan conversions this year at the Mobility Road Show and, more recently, at the Earl's Court Caravan Exhibition. Adaptations allow for easy wheelchair access and suitable interior facilities.

The company will be displaying five specially converted models throughout 1992 at the Heathrow Touring Caravan Centre so that potential customers can inspect the vans and discuss the options available.



Inside a converted caravan

For further information on conversions contact UBC at Colnbrook-by-Pass, West Drayton, Middx or telephone 0753 682606.

Pennies from Heaven

Peterborough Parachute Centre offers a discount on training and a first jump to people being sponsored to parachute for ASBAH.

Since the scheme started this summer, ASBAH has benefited by over £400. If you would like more details contact our own 'free faller' Trish Jones at National Office on 0733 555988. (The centre is not able to train people with disabilities.)



Diary Dates



Until 20 December: Exhibition of Louis Hellman Cartoons from the Centre for Accessible Environments at the Royal Institute of British Architects, 66 Portland Place, London W1. The exhibition is open Mon-Fri, 10-5 and Sat 10-1, admission free.

16 January: Keep Able Foundation: one day course on

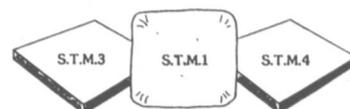
Advanced Assistive Devices for Severe Disability - introducing a range of modern equipment aimed at assisting those wishing to increase their independence. Fee £35 in advance, including lunch and refreshments. More details from Course Secretary, Keep Able Foundation, 2 Interchange Way, Brentford, Middx. Telephone 081 994 6614.

22 January: Keeping up Appearances: a one-day conference at the Disabled Living Services Style Centre which looks at personal image and clothes for disabled people. Fee £35 including lunch. The conference will be held at the Style Centre, Redbank House, Redbank, Cheetham, Manchester, from 9.30-4. More information from Mrs J Whitworth, telephone 061 832 3678.

Sitting Comfortably?

STM (Services to Medicine) have developed a range of economy, standard and pressure-relieving cushions to fit any seating need. Fibre and foam cushions are available in many sizes for most chairs, wheelchairs and care chairs.

More information from; STM, Azalea Close, Clover Nook Industrial Park, Alfreton, Derbyshire, telephone 0773 830426.



Affordable Pressure Sore Prevention

Disabled visitors welcome

Unlike some historic houses which have hit the headlines recently, the National Trust "welcomes disabled visitors to its properties". Severely disabled visitors who require a companion can bring one for free.



Most of their historic houses and gardens have wheelchairs available and they have also introduced golf buggies, which carry up to three passengers, at some of the steeper gardens.

A free annual information booklet is available from the National Trust by sending a large stamped, self-addressed envelope to them at 36 Queen Anne's Gate, London SW1H 9AS. The Trust's Adviser, at the same address, is happy to answer enquiries by letter or phone - 071 222 9251.

Christmas Walks with the Trust

Walks designed for disabled walkers and wheelchair users, across National Trust land, have been organised for the week following Christmas. Details from Valerie Wenham at the same address above.



Holiday Winners

Winners of the first **Holiday Care Awards** have just been announced and should be appearing on our screens in ITV's *Wish You Were Here*, this month.

The awards were launched in April, by Judith Chalmers, to recognise the positive attitude of those in the travel industry who offer excellent service to all - irrespective of disability. There were six categories. Category 1 - Accommodation, 20 bedrooms and over - has been won by **Westwood Country Hotel**, Oxford. The Category 2 winner for Accommodation, under 20 bedrooms, is **Northill House**, Wimborne, Dorset. The 3rd category was for Self Catering Accommodation and this was won by **Eildon Holiday Cottages**, Melrose, Roxburghshire, Scotland. Category 4 - Attractions - which included museums, was won by **Marwell Zoological Park**, Winchester, Hants. The Most Helpful Individual member of staff in tourism was the 5th

award and this went to *Isold Rothery*, Rooms Division Manager, at Copthorne Effingham Park, West Sussex. The final category was for Best Journey Experience of someone with a disability and the winning author was *Jane Murray*.

If you've still to plan a holiday in this country for 1992 you may like to bear the winning locations in mind and you can obtain more details, including those establishments which were highly commended in the awards, by contacting The Holiday Care Service. HCS is a national charity which provides free information and support on holidays for disabled people. Contact them at: 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW or phone 0293 774535.

New premises for GBL

Set up three years ago, to offer quality lightweight wheelchairs at affordable prices, GBL were unique in selling only secondhand chairs. The company was also unusual in that they offered hire purchase on the secondhand models.

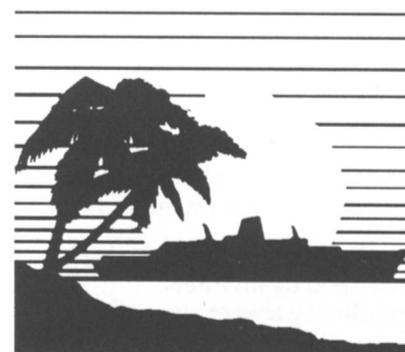
Despite the recession, GBL has expanded and has added new wheelchairs to its stock. They now sell most makes and models, in a bid to suit all customers' requirements. But this expansion posed a problem, as Jamie Hamilton (a former DLA for ASBAH), a partner in the firm, explained: "There wasn't enough space in the garage from where we operated to hold the stock we required, so we took a big step and are now renting two industrial units as a showroom and workshop."

GBL now has four partners and two part-time employees - all of them disabled. You can contact GBL on 081 569 8955, or visit their showroom at Units E4 & E5 Shield Drive, Brentford, Middx.

Cruising

If you've saved enough to take that cruise you've always dreamed of in 1992, then Page & Moy claim they can accommodate you in "ships built and refurbished with the disabled person in mind", to give you a real holiday in a relaxed environment with entertainment and activities.

Though we can't verify these claims we can tell you that the company has produced a leaflet (after consultation with RADAR)



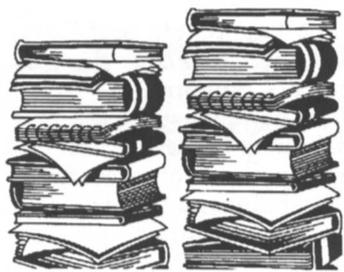
entitled 'Cruising and the Disabled Traveller' outlining facilities on their ships and giving holiday tips. To obtain a copy of the leaflet and cruise brochures contact them on 0533 513377.

Irish Weekend

BBC's Children in Need appeal will raise millions of pounds to sponsor all kinds of events next year. One of the beneficiaries of their 1990 appeal was Northern Ireland ASBAH who recently received a grant to hold a residential weekend for 30 youngsters. The course included wheelchair mobility as well as recreation and proved highly successful.

TAXI

ASBAH has been receiving reports of minicab firms refusing to pick up passengers "because they are disabled". If readers have had a similar experience which they believe warrants further investigation, please contact publicity manager, Tony Britton, at National Office.



BOOK SHELF

What a good idea!

A series of four spiral-bound books has appeared for students with physical disabilities and staff working alongside them - complete with an instant publisher's permission recorded on every page to photocopy any of the pages for classroom use only.

These Folens' copymasters, published in association with RADAR, cover 'Sport and Mobility', 'Living Skills' and 'Pre-Vocational Skills'. There is also a volume specially for staff called 'Inservice: practical approaches, attitudes and equipment.'

They have been based on work developed by an inter-disciplinary team at Impington Village College, Cambridge - one of the schools which gave ASBAH almost limitless help in the making of our latest video, 'Hydrocephalus: a guide to Education.'

The work was led by the college's co-ordinator of special needs, Aileen Webber. So this is what she was doing when she was not around during all of our several visits!

The series recognises that photocopying materials has already turned school resources centres into a growth industry, and gives them legal immunity. There are even sticky strips of paper at the back of each book, so the contents can be changed to suit particular students or staff. Could save schools a fortune!

Tony Britton

The copymasters are published by Folens, priced £14.95 each.

LINK No. 137 12/91

ASBAH's latest successes in challenging slipshod statementing for special educational needs are reported elsewhere in this issue of 'Link'. A book which puts the whole complicated process within its legislative and historical context has just been published by Longman.

'Special Education in the 1990s' - written

by members of the Society of Education Officers and edited by South Glamorgan's former education director, Fred Adams - deals with the strains in the system and offers pointers for the future, not all of them optimistic.

The upsurge of interest in the education of children with special needs, since the publication of the Warnock Report and the 1981 Education Act, has continued to engage the minds of parents, teachers, education officers and other professionals.

Ten years after the Act, substantial progress has been made but the 1988 Education Reform Act presents additional changes - for instance, local management of schools and the introduction of the National Curriculum - which if not managed well could swing the balance away from integration.

The book provides an overview of the tasks facing the education service. It describes the principles and practice at issue in regard to, among others, assessments and appeals, integration, post-16, teacher-training and the role of parents.

Tony Britton

'Special Education in the 1990s', published by Longman, price £14.95.

Despite this flesh

Reviewed by Zem Rodaway who has spina bifida and hydrocephalus.

Despite this flesh is an anthology of poems and prose which explores various aspects of disability - how it affects the people with disabilities themselves and those around them.

The anthology was the idea of, and is edited by, Vassar Miller, who has cerebral palsy and is a poet herself. Through it, she is hoping to inform the general public "because if the general public is uninformed it needs to be exposed, and what better means of exposure than good literature". The editor also intends to help schoolteachers in "mainstreaming handicapped children".

Some writers appear to have written about themselves, or members of their family. For example, there is a chapter from a book by Christy Brown (subject of the film 'My Left Foot').

I have to admit that I did not understand most of the poems. I also found terms such as "cripple" and "retarded", used throughout the book, offensive. However, it may be that, as the book is published in the USA, these are accepted terms in America. I did enjoy some of the prose but was sometimes frustrated that only an excerpt from a book was included, as I wanted to read on!

Some of the pieces are very disturbing. For example, 'The Sacrifice' describes a Basque tradition in which, at harvest time, each year, a village 'idiot' (ie person with learning difficulties) is sacrificed. Although several members of the family made efforts to save that year's 'sacrifice', in the end, several people died. In The Glen, a step-mother hopes her "retarded" step-daughter will eat a poisonous mushroom.

I can perhaps see how the editor is seeking to expose the various different attitudes to disability

which exist. However, I cannot see how she hopes to educate the general public by doing so. Nor can I see how the book will benefit teachers trying to integrate disabled children into the classroom.

Children with Special Needs

*A guide for parents and carers
by Richard Woolfson*

This book discusses children with special needs frankly, realistically and with practical suggestions and is a welcome addition to family and professional bookshelves alike.

The author's style is not patronising or sentimental and is easy to read. The similarities between children with special needs and children whose development is normal are emphasised and the emotional needs of all family members are consistently addressed. The focus is on children as individuals and parents as human beings!

Woolfson begins with the moment special needs are identified: "Few parents forget the intense emotions of that episode." He sympathetically discusses possible reactions to the news. He continues by discussing the effect of this news on the family unit; and the influence of parental expectations in the formation of a positive self image. There is also a useful section on family discipline.

The final chapter outlines the legislation governing the education of children with special needs and the book finishes with contact addresses and suggestions for further reading.

Children with Special Needs gives a valuable overview and lives up to its subtitle. Woolfson makes one or two contentious comments regarding mobility and continence training in the child with spina bifida and I would recommend readers to disregard these. However, this book does not set out to be a specialist text and within its own terms of reference is highly successful.

Rachel Stanworth

Published by Faber and Faber, price £4.99.

BENEFITS NEWS

DFG - your flexible friend?

At a meeting with the Department of the Environment, attended by Parliamentary Undersecretary Tim Yeo, (reported on in the August 1991 LINK) ASBAH representatives advocated greater flexibility in administering the Disabled Facilities Grant. A letter received recently by one of our clients may indicate that the voice of ASBAH, and other interested organisations, has been heeded on this issue.

An ASBAH client who had been denied the DFG wrote to the Housing Minister, Sir George Younger, and in his reply Sir George said that Local Authorities should look at each case individually and not just adhere rigidly to the guidelines for approving the grant. As a result the grant was awarded to this applicant.

We hope this means a brighter outlook for those applying in future. If you have any problems with the Disabled Facilities Grant contact our housing officer Dominique Cull, or your fieldworker, for advice.

Claiming benefit arrears

This autumn an amendment was made to the regulations on claiming arrears of benefits to which you were entitled. The current position is that unlimited arrears of benefit can be claimed in cases where there has been an official error. Arrears may therefore still be payable when:

*specific evidence relating to a claim was ignored OR

*a member of staff did not pass on documentary evidence to the decision making authority OR

*a provision in case law or legislation was misconstrued or overlooked.

If you need further advice on claiming benefits contact your local Citizens Advice Bureau or your fieldworker.

Care cannot be denied on cost grounds

A disabled man may have sent an important precedent in obtaining care after taking his case to court. The man took legal action against his county council (Hereford and Worcester) after the social services assessed that he needed a carer but cost constraints meant they were unable to provide one.

Solicitors for the claimant argued that the council had a duty to provide adequate services under the Chronically Sick and Disabled Persons Act 1970 and could not escape this obligation by pleading lack of finances. The matter was settled out of court when the council provided a carer and paid costs and compensation.

Letters

Tribute to Carolyn

As a family we would like to say how very sad we are to hear about the death of Carolyn Smith. Carolyn came to us as a fieldworker for ASBAH but soon became a very good friend.

Our son Reggie's greatest pleasure was going around different places in the old Volkswagen van, which we have had for many years. As his legs will not bend he has a very large, long wheelchair and as we are not getting any younger we cannot push him very far. As the old van was rapidly deteriorating we looked at the possibility of giving up Reggie's mobility allowance to get a new van from Motability but then found we had to pay many thousands of pounds deposit which no way could we afford. But Carolyn was not deterred by this, she said: "Let's ask for a grant towards it," and patiently helped us fill in the forms.

No-one can describe the joy we all got from Reggie's face when we got a letter from Motability to

tell him to go ahead and order his new van. It is fitted with ramps, lift, and clamps, to hold his wheelchair safely.

I hope that knowing about this one instance, of many, where Carolyn helped to make life easier and brought so much pleasure will bring some comfort to Carolyn's husband and family. Carolyn was a lovely girl, with a lovely nature. We will never forget her. Reggie loves cars and always gives them a name, needless to say, Reggie's new van is called Carolyn.

Mrs P Nobbs
London

A memorial fund has been set up in Carolyn's name, more details on page 4.



Reggie and his new van in Porthleven, Cornwall

CONTACTS

Unshunted experience

I desperately want to find out if there are any other people with similar problems to my son Steven. He is 33 years old and was born with hydrocephalus alone. Steve did not have a shunt inserted and it is from others with hydrocephalus, who have not been shunted, that I would like to hear.

We would like to know how they have coped throughout their lives, the problems they have encountered, and how life is for them now.

Steven has particularly severe fits, requiring hospital care, and although he understands all that is said to him and probably everything he hears, he does have considerable difficulty in explaining what he means. Steve now needs extra help and possibly other people's experiences may give us some guidance in how to help him further.

If you would like to contact Steve's mother, Helen, send your letters to LINK and we will pass them on to her.

German penfriend

I would like to find a penfriend (boy friend) for my son Niko. Niko is 12-years-old and has spina bifida. He attends a German high school where he has been learning English for over a year. Niko likes reading, swimming and playing wheelchair basketball. He can walk short distances with aids.

Write to Niko Rodel, Waldstr 4, 5108 Monschau-Hofen, Germany.

German exchange

I am a 16-year-old girl with spina bifida, from Germany. I am a wheelchair user and am looking for a group of people of my age with whom I can spend my summer holidays in Great Britain. I would like to come to Britain between 20 June and 5 July 1992. Any offers please to: Nina Mitra, Frahmstr. 1a, 2 Hamburg 55, Germany.

ADVERTISING

FOR THE USE OF LOCAL ASSOCIATIONS
AND OTHER READERS

Rates: £3 for 30 words max; £4.25 for 30-45 words;
£5.50 for 45-60 words.

Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of Link (February) should be submitted by Friday, 10 January. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

HOLIDAY ACCOMMODATION

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

ISLE OF WIGHT ASBAH

Completely refurbished, fully equipped, wheelchair accessible, 2 bedroom holiday chalet, sleeps 6 plus cot. Clubhouse, indoor heated pool, shop, etc. Site overlooks sea. Own transport advisable. Details from Mrs P Burden, 36 Sherbourne Avenue, Brimstead, Ryde PO33 3PX



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Happy New Year
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readers and their
families

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