PLEASE
DO NOT REMOVE

Link

The magazine for people with
Spina Bifida and/or Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

August/September 1994
Issue No 153 Price 80p

Make your Willpower work for ASBAH

If you and your family value our support now, a simple bequest will help to sustain it in the future. For details, please contact:

Paul Wootton
ASBAH, 42 Park Road
Peterborough PE1 2UQ
Telephone 0733-555988

LORD MAYOR TRELOAR COLLEGE
ALTON, HAMPSHIRE GU34 4EN
(Supported by the Treloar Trust.
Reg. Charity No. 307103)

Provides
Education, Independence and Care
for Young People aged 8-19+ with
Physical/Learning Disabilities.

National Curriculum offered to all up to 16.

'A' levels, GCSE, CGLI, RSA, AEB, Pitman, Diploma of Vocational Education, NVQs, GVNQs, Wordpower, Numberpower, Youth Award Scheme

A Large **Learning Difficulties Department** caters for those who cannot follow examination courses.

The therapy team helps the students to access all aspects of education and to increase independence in health care, self management and community skills.

A unique interdisciplinary programme (F.L.A.M.E.) is run by a team of staff for younger pupils with **motor disorders**

For Prospectus and informal visit,
Telephone Secretary on 0420 83508

GBL

WHEELCHAIR WAREHOUSE

MANUAL WHEELCHAIRS - ALL MODELS - ALL MAKES
ALL LIGHTWEIGHT - KIDS - ELDERLY - SPORTS

NEW, EX-DEMO, OR SECOND HAND CHAIRS (with a 3-month guarantee)
CUSTOMISATION TO SPECIFIC NEEDS - OUR SPECIALITY

OVER 100 CHAIRS IN STOCK
ALL THE MAJOR, MODERN AND BEST DESIGNS
YOU NAME IT - WE DO IT!
WE ALSO STOCK PARTS, DO REPAIRS, HIRE AND INSURE. HOME VISITS ARRANGED

WAITING FOR THE NEXT EXHIBITION? WE ARE AN ALL-YEAR ONE
THE PERMANENT EXHIBITION - OPEN WHEN YOU NEED IT
GBL IS A COMPANY OWNED AND RUN BY DISABLED PEOPLE

● PART EXCHANGE YOUR OLD CHAIR ●
● OPEN SATURDAYS - 10 - 2PM (or later by appointment) ●

GBL WHEELCHAIR SERVICES LTD
Units 1-3, Shield Drive, Brentford, Middx TW8 9EX Tel: 081-569 8955 Fax: 081-560 5380
Unit 3, Martello Enterprise Centre, Courtwick Lane, Litttlehampton, W Sussex BN17 7PA Tel: 0903-733528 Fax: 0903-733530

Comment

FROM news on the Civil Rights campaign to an in-depth look at an adult disability service are just some of the articles contained in your bumper 28-page August issue of *LINK*.

Also included is the launch of a new ASBAH initiative, aimed particularly at GPs who have patients with hydrocephalus shunts. Turn to pages 9 - 11 to find out what we have produced to help medical staff identify symptoms of shunt blockage early on, before they become life-threatening.

The shunt campaign is one of the most important ASBAH has conducted in recent years and we are keen that everyone with a shunt takes up the offer of a special alert card to be carried at all times, and four pages of invaluable notes for ASBAH to pass on to their GPs. Remember, please, when writing in, to let us have you and your GP's name and address.

The scheme is voluntary but is designed to prompt the treatment needed in case of emergency, as well as providing background information to your GP to help him or her understand a condition about which too little is known.

THERE is also a report on the annual meeting of the Society for Research into Hydrocephalus and Spina Bifida which attracted leading consultants in spina bifida and hydrocephalus from all over the world to Connecticutt, USA. *LINK* also runs a feature on John Holter, the American creator of the shunt.

All this is not to mention coverage in words and pictures of a farewell event at our Five Oaks centre in Yorkshire, which sadly closed earlier this month.

And, on pages 6 and 7, our vice-president Claire Rayner makes an appearance at the opening in Hemel Hempstead of our new Apple Mac trading subsidiary, Computer Sense Ltd, set up specially to boost ASBAH's income by giving us its pre-tax profits.

FINALLY: I want to say "hello" to all *LINK* readers as the newly appointed magazine editor. I hope you will help make *LINK* even better by sending in your news, views, photos and letters. If we're not covering an issue which affects you, it probably means *LINK* does not know about it!

Liz Cawthorne

Contents

ASBAH is a registered charity

Cover: ASBAH vice-president Claire Rayner at the opening of Computer Sense Ltd, with eight-year-old Elisabeth Hammond.

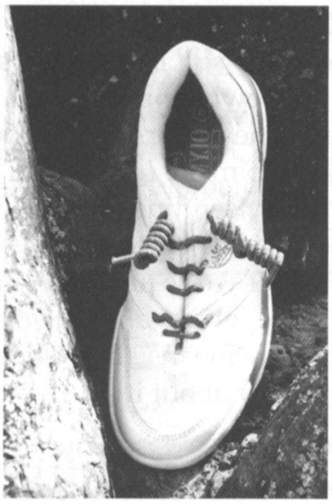
Racy Laces

A NEW type of shoelace which doesn't have to be tied will be a boon to all those who find the job fiddly or next to impossible.

Hot foot from the States, Coilers Shoelaces are simply twisted through each shoe eyelet and pulled as tight as you want.

Priced at £2.99 a pair or £4.99 for two pairs, they are available in black, fuchsia, royal blue or green rainbow.

Send cheques to NG Enterprises, 4 Swan Mead, Ringwood, Hants, BH24 3RD, stating which colour you want.



ALPHAMED LINK

THIS issue of LINK carries a Freepost envelope addressed to AlphaMed Limited which, if acted upon, will result in substantial extra income reaching ASBAH.

This idea has nothing to do with dubious chain letters, with their implicit threats of ill-fortune befalling the recipient who breaks the chain and fanciful claims of small fortunes awaiting those in the chain who get to the top of the list!

Instead, it has everything to do with making our clients aware of a new service which is offered to them which we are assured will source their continence supplies and equipment from a reputable supplier and get them dispatched in double-quick time.

Here's how it will work: when someone with spina bifida and/or hydrocephalus next visits the doctor and obtains a prescription for continence supplies or medical equipment, he or she can if they wish try the AlphaMed service.

Put the prescription in the Freepost envelope supplied with LINK. If the doctor's handwriting is so bad that the patient's name or address is difficult to read or is incomplete, please also include a separate sheet with these details shown clearly.

AlphaMed will then arrange supplies to be dispatched on the same day of receipt for delivery within 48 hours, and send further Freepost envelopes for you to use the service again.

Should an emergency arise, a next-day delivery service can be provided and a free 24-hour telephone line is available on 0800-515317 should any questions or concerns arise.

It's as simple as that.

Prescriptions for drugs should not be sent to AlphaMed as these must continue to be dispensed at one's normal pharmacy or a chemist.

While ASBAH cannot be held responsible for a service which it is unable to provide itself, we do think readers should know of this service and the following benefits to their national Association when the service is used.

For every prescription sent through AlphaMed using the Freepost envelope, AlphaMed will make a donation to ASBAH. If enough people use the service and send repeat prescriptions, the donations will add up so significantly that they will help ASBAH improve our services more quickly.

The arrangement has been ethically approved by ASBAH's Executive Committee; it does not infringe people's rights to obtain continence supplies and equipment from whatever source they choose and no ASBAH trustee, committee member, member of staff or volunteer will receive any payment, reward or commission from AlphaMed.

Spina Bifida Week

NATIONAL Spina Bifida Week takes places between August 15 and 21.

It is an initiative being led by Larkhall Natural Health, makers of Cantassium Folic Acid tablets, who give ASBAH 10p for each container of tablets sold.

The week will focus on the vital role of folic acid in helping to prevent prevent spina bifida, providing a daily 400mcg tablet is taken by the expectant mother before conception and until the 12th week of pregnancy.

Publicity has been targetted to national media and women's magazines, but with a wider scatter to see what happens in the regional media and local press.

ASBAH's folic acid link up with Larkhall Natural Health tablet was set up by our fundraisers in July last year and, since then, it has resulted in substantial extra income being donated to ASBAH.

The day I met the Duchess

by Claire Houseman age 12

My big day. I was having time off school to met the Duchess of Gloucester. I was to present her with a cup saucer and silver spoon. My Mum, Dad and I went to this very posh place called Mulberry Hall. Everybody made me feel very important. Everyone had their best clothes on and some were in uniform, like me, I had my Fulford School uniform on. We all lined up to meet the Duchess, me at the front.

When she arrived, I thought she was very nice and not in bright 'Duchess clothes' as I had expected. She said hello to me and thanked me when I gave her the presentation box. Cameras flashed everywhere. Lots of people thanked me and the Duchess spoke to me as she was leaving. I felt a bit shy, but really enjoyed myself. Everyone had champagne. I don't like champagne.

ASBAH patron, The Duchess of Gloucester, was presented with two commemorative items by 12-year-old Claire Houseman when she visited the Mulberry Hall fine china and glass store in York in June to open its new Royal Copenhagen showroom. Also pictured is Mr Michael Sinclair, chairman of the company. Claire, daughter of Mr and Mrs John Houseman, of Hornington Manor, Bolton Percy, near York, did the honours when Her Royal Highness visited Mulberry Hall to launch the commemorative items being sold in limited editions to benefit ASBAH (see Claire's comment,this page).

Officers & Staff

Patron:
HRH The Duchess of Gloucester, GCVO

President: Dr Jeffrey Tate, CBE

Chairman: Mr Patrick Daunt

Hon Treasurer: Mr Charles Ortner

Executive Director:
Andrew Russell, MA

Finance Director:
Derek Knightbridge, FCCA

Assistant Director (Personnel):
Paul Dobson, BA (Hons), FIPD

Fieldwork Manager:
Teresa Cole, MICA

Five Oaks Manager:
Joan Pheasant, NNC

Disabled Living Services Co-ordinator:
Rosemary Batchelor, SRN FETC

Publicity Manager:
Tony Britton

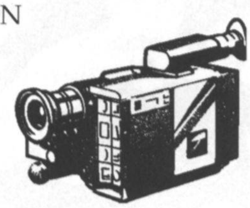
Appeals Manager:
Roy Johnston

Business Liaison Manager:
Paul Wootton, BSc

Research and Information Officer:
Gill Winfield

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

TV debut for Tracey Proudlock's video diary



A TELEVISION documentary called *Mother's Pride*, featuring the video diary made by Tracey Proudlock during her pregnancy and the subsequent arrival of baby Billy just before last Christmas, was shown on BBC2 on 26 July - in the third of six documentaries from the *Over the Edge* team .

Tracey, who lives in Muswell Hill, North London, edited down hours of footage to make the half-hour film and, although much good stuff ended up on the cutting-room floor, she says the end result is a pretty good programme.

"It opens with me saying we are very ordinary family, we go away on holiday, we have a nice flat, my husband Liam runs 60 miles a week but, some days, I can hardly walk out of the bathroom", said Tracey, who has spina bifida.

"And I don't dwell on the nature of my disability. I say I have spina bifida and then get on to other things."

One regret: Tracey tried to include a plug for the importance of folic acid before conception and during pregnancy into her film but, as the producer thought the explanation was taking up too much space, it was cut.

Tracey, who is a local government officer in London, is active in ASBAH's 'Your Voice in ASBAH' group. Her successful efforts to gain pilot's wings were featured recently in *LINK* and *LIFT* and her honeymoon trip to Jamaica was covered in *Disability Now*.

CLAIRE OPENS OUR

WELL-KNOWN agony aunt Claire Rayner pronounced ASBAH's own computer company alive, well and kicking when she formally opened the business at Hemel Hempstead in July.

Claire, a vice-president of ASBAH, said she had been a friend of the Association from its beginning - when, as a medical journalist, she realised that she at last had a point of referral for people with spina bifida and hydrocephalus.

Before unveiling a plaque to mark the openingof the new Apple Mac service company and dealership, she complimented ASBAH for making the transition from charity shops to fully commercial trading company.

"This will be the first of a huge chain, I am sure."

ASBAH chairman Patrick Daunt said that Computer Sense was an example of ASBAH self-reliance which he was sure would provide funds to assist the future development of the charity.

Not only would the company make a unique contribution to ASBAH, but the firm would in time become "a really ace" employer of people with disabilities in its own right.

Computer Sense,which has been operating since the turn of the year, has been set up to give all its pre-tax profits to ASBAH- not into somebody's personal bank account. ASBAH owns all the shares in the company.

Directors John D'Arcy and Gwyn Martyn, who have 18 years relevant experience between them, run a company which trades not only in its own hinterland of Herts, Beds, Bucks and Greater London but, by means of mail order, throughout the whole country.

Computer Sense specialises in selling and repairing 'Macs', together with printers, monitors, hard discs and all the other back-ups for the Mac system.

A high-tech treat for three ASBAH members as they have their photo taken by film-less technology at the opening of Computer Sense Limited

Pictures by Hemel Hempstead Gazette and Warren Gunn

NEW COMPUTER SUBSIDIARY

The firm's formal open day was attended by a large number of guests from commerce, industry, teaching and medical institutions, as well as civic dignitaries.

Hints of how far one can travel into the future with Apple Mac were given in several hi-tech displays. These included one system where a film-less camera took a photo which was then transmitted to a screen and outputted immediately as a high-resolution colour print.

Claire Rayner was treated to a picture of herself obtained by this process, as were a group of disabled members of ASAH. Two medical staff from a hospital spent a considerable amount of time examining the system, with a view to possible purchase.

ASBAH asks anyone with Apple Macs to consider using Computer Sense for their future needs, or to recommend leads if they deal with other firms using Mac technology. *Computer Sense Ltd, Grovelands Business Centre, Hemel Hempstead, Hets, tel 0442-252555.*

Pictured (above): Claire Rayner and director John D'Arcy outside Computer Sense. Right: Claire and John pose with John's fellow director Gwyn Martyn, co-ordinator Brenda Roshier and secretary Shirley Child.

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

London, Surrey, Kent, Sussex

123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (0181) 449 0475
Regional Co-ordinator: Gina Broughton, BA (Hons).

Northern Ireland

73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (01265) 51522
Regional Co-ordinator: Meta Harvey, BSc, Cert Ed.

Rest of England and Wales

National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (01733) 555988

A fond farewell

ALMOST 150 people - past and present staff, residents, families and friends - attended a farewell party at Five Oaks, ASBAH's independence training centre, which closes this month.

Guests arrived in the afternoon for wine and cheese and some had the chance to chat to people they had not seen for years.

Those attending included ex-Five Oaks manager Gill Harrison, Five Oaks Advisory Committee chairman Daphne Steele, former executive director Moyna Gilbertson, and her successor, Andrew Russell.

Centre manager Joan Pheasant, who is staying behind to set up ASBAH's new START training and assessment service, said the occasion brought with it feelings of sorrow and of joy. "Obviously we're sad that Five Oaks is closing down but the party was a chance to catch up with what people are doing now."

Joan, who joined Five Oaks in the year it opened in 1977, added: "It's going to be a very, very sad day when the last resident moves out. But we've got to look forward to the future.

"All five residents have somewhere to go but for some of the staff are still looking for alternative employment." *(We give the details below).*

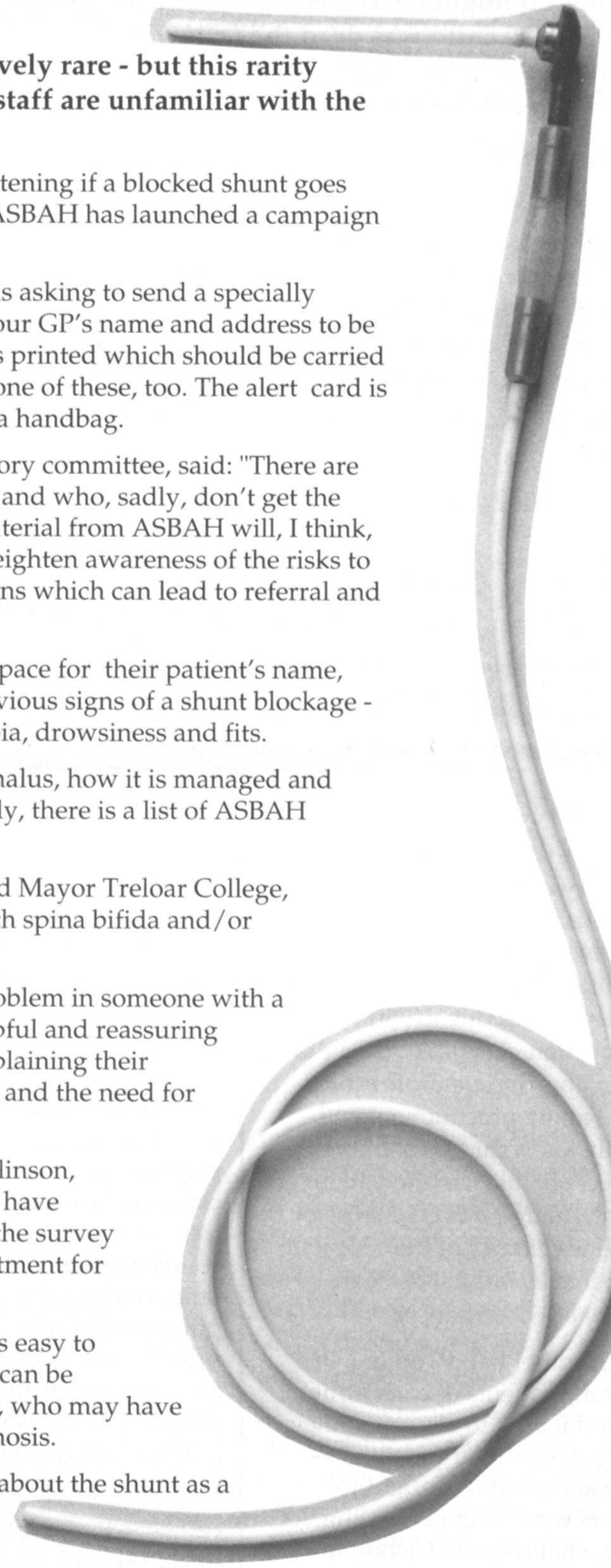
"One of the things that came out of the evening was that former staff regarded Five Oaks as one of the most enjoyable places they had worked. It always had a good feeling about it and staff have developed many skills from it."

From the left: trainees Lucy White, Helen Clay, Michelle Hawley, Jayne Verigotta

PLACES TO GO

- *Michelle Hawley, 22, and 23-year-old Kim Knowles have moved into Wharfedale independent living flats, which are adjacent to Five Oaks and run by Sanctuary Housing Association.*
- *Lucy White, 20, has been accepted at Papworth Village Community in Cambridgeshire to continue her training.*
- *Jayne Verigotta, 29, who has been living at Five Oaks for six months, will be returning to Manchester and will eventually move into sheltered accommodation.*
- *Helen Clay, 23, will be moving into a shared house, with some support, near her home in Essex.*

SHUNT CAMPAIGN



HYDROCEPHALUS is, thankfully, comparatively rare - but this rarity means that many family doctors and hospital staff are unfamiliar with the symptoms of a blocked shunt.

In response to this situation - which can be life-threatening if a blocked shunt goes undetected over even quite short periods of time - ASBAH has launched a campaign to inform GPs, hospital staff and the public.

People with hydrocephalus shunts should write to us asking to send a specially prepared information sheet to their GPs. We need your GP's name and address to be able to do so. We have also had 'medical alert' cards printed which should be carried at all times, in case of emergency - so please ask for one of these, too. The alert card is credit card size - small enough to fit into a wallet or a handbag.

Dr Martin Bax, chairman of ASBAH's medical advisory committee, said: "There are still people with hydrocephalus whose shunts block and who, sadly, don't get the immediate attention they need and deserve. This material from ASBAH will, I think, go a long way to overcoming this situation. It will heighten awareness of the risks to people with valves and advise on symptoms and signs which can lead to referral and prompt, safe treatment."

The free four-page information sheet for GPs gives space for their patient's name, with date of birth and address. It also details the obvious signs of a shunt blockage - including headache, vomiting, dizziness, photophobia, drowsiness and fits.

There are also sections explaining what is hydrocephalus, how it is managed and what happens when a shunt becomes blocked. Finally, there is a list of ASBAH services available to family doctors.

Dr Patricia Tomlinson, former medical officer at Lord Mayor Treloar College, Hampshire, which is attended by many students with spina bifida and/or hydrocephalus, welcomed the ASBAH initiative.

She said: "I have often been faced with a medical problem in someone with a very unusual diagnosis. It has always been very helpful and reassuring when the patient or their carer produced a paper explaining their medical condition, with an outline of the risk factors and the need for treatment or further action."

According to recent research carried out by Dr Tomlinson, involving 110 ex-students from Treloar College who have hydrocephalus shunts, some of those questioned in the survey had difficulty obtaining appropriate advice and treatment for shunt problems.

She said: "The symptoms can be very vague, and it is easy to blame a headache on a sinus problem or migraine.It can be extremely difficult for a GP or junior hospital doctor, who may have little experience of shunts, to make an accurate diagnosis.

"The most important thing for the doctor is tothink about the shunt as a possible cause of the symptoms and seek advice from a specialist hospital. It is essential for the patient or carer to remind the doctor of the presence of the shunt and, if appropriate, show the doctor the information sheet for GPs.

Continued on page 10

Case Study 1

A child was send home from school "poorly" - with a headache and sickness. His mother put him to bed until the following morning. She thought it might be 'flu as there was a lot going round. The child was dead the following morning, and the cause of death was later discovered to be a blocked shunt.

Case Study 2

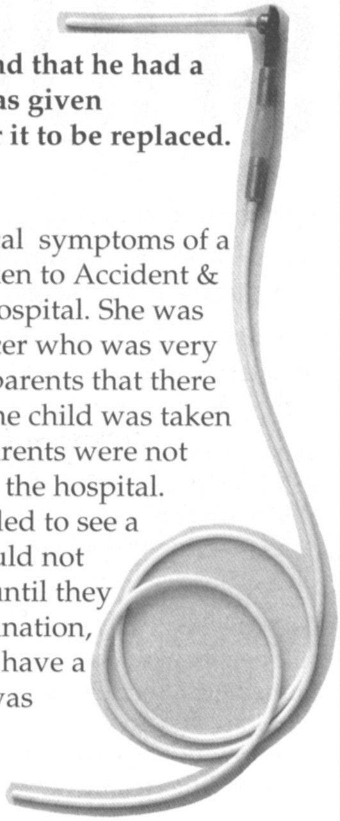
A parent phoned up ASBAH worried about her daughter's condition. Her daughter had a rash and headaches but mum suspected the problem was chicken pox. The family was advised to go to the child's neurosurgeon, and the shunt was found to be blocked due to infection. The condition was treated successfully and the girl survived.

Case Study 3

A client was seen by his GP and given Paracetamol for a headache. His condition worsened and he was finally rushed to hospital where he became extremely poorly.
Eventually it was found that he had a blocked shunt, and was given immediate surgery for it to be replaced.

Case Study 4

A child, who had typical symptoms of a blocked shunt, was taken to Accident & Emergency at a local hospital. She was seen by a casualty officer who was very busy and assured the parents that there was nothing wrong. The child was taken home again, but the parents were not happy and returned to the hospital. This time they demanded to see a neurosurgeon and would not leave the department until they had done so. On examination, the child was found to have a blocked shunt which was subsequently revised.



GETTING THE SHUNT SEEN TO - QUICKLY

From page 9

Dr Roger Bayston, ASBAH's honorary consultant in hydrocephalus who works as a microbiologist at Nottingham City Hospital, commented: "When a problem arises due to shunt malfunction, it is often difficult to obtain appropriate professional help. Family practitioners will usually know far less about hydrocephalus than the patient or parent, though this is because of the relative rarity of the condition compared to influenza, heart disease or bowel cancer.

"On the other hand", added Dr Bayston,"patients or carers might not find it easy to convey to their family doctor their own knowledge and experience, and to suggest what might be wrong, let alone what course of action to take. It is not surprising, therefore, that there are often delays in diagnosis and in obtaining specialist treatment and assessment for shunt problems."

"Infections in ventriculoperitoneal (VP) shunts usually appear as shunt blockage, though there may be fever or abdominal pain. How ever, it is the blockages, whether due to infection or to other causes, which generally require prompt attention. The chronic blockages often give rise to subtle changes in behaviour, with problems at school or work connected to inability to concentrate or increased clumsiness. Of course these aspects might have other causes such as onset of puberty or another illness, but the problem needs to be recognised and assessed professionally as soon as possible so that a shunt malfunction can be dealt with - if this is indeed the cause.

"It has to be noted that, in some cases, there is rapid deterioration due to shunt blockage with increasing headaches and drowsiness, leading to loss of consciousness. This requires very urgent specialist attention, though here again there have been a few instances of delay due to lack of appreciation of the seriousness of the condition, with grave consequences"

"The medical advisory committee of ASBAH has recommended that guidelines are sent to family practitioners responsible for people with hydrocephalus to assist them to adopt the most appropriate course of action should a problem arise.

“The present document owes a great deal to Dr Pat Tomlinson, until recently a family practitioner, who was unusual in that she had many people with hydrocephalus on her list, In addition, ASBAH have designed an "Alert Card" to be carried by people with hydrocephalus so that, should an acute problem develop in a public place, again appropriate action will be forthcoming."

Points from our shunt leaflet

ASBAH has been listening to people with hydrocephalus or their parents for over 25 years, and we are frequently approached by medical practitioners for information about the management of this condition. It is the combination of these two factors which has led to our Medical Advisory Committee producing this leaflet.

Only GPs who are responsible for someone with hydrocephalus will receive this information, and it is sent only with the permission of the patient, or his or her parents.

Problems encountered in a general practice may include subtle symptoms of a shunt blockage.

WHAT THE PARENTS SAY:

"I think his head is larger" (of a six-week-old baby)

"He seems so tired all the time"

"She has a headache, has vomited twice, and seems drowsy"

"He's been so irritable and bad-tempered lately"

"I don't know why but her teachers say she won't pay attention, and she's falling behind"

"She's getting so clumsy"

Other symptoms can be more obvious indications of a possible acute infection, causing a shunt blockage. They may include:

Vomiting, headache, dizziness, photophobia and other visual disturbances, drowsiness and fits.

Or there may be symptoms of a possible chronic shunt blockage. These include:

Fatigue, general malaise, visuo-perceptual problems, behavioural changes, decline in academic performance, being 'not right' from the carer's point of view.

Many parents find it difficult or painful to absorb medical information at the emotionally traumatic time of their child's diagnosis of hydrocephalus and looking to the future can seem frightening when a shunt is inserted.

For these reasons, many parents choose to discuss their situation with a more familiar general practitioner once their child is discharged from hospital.

Research finds show that parents never forget how news is broken and explanations are given, and that a successful relationship between a family and general practitioner can develop the confidence to face the future and the security to live comfortably in the present.

A good understanding of their own or their child's condition enables a family or individual to live life with the minimum of distress caused by uncertainty.

WHAT HAS ASBAH TO OFFER?

▲ Family support through local fieldwork services, including up-to-date advice on disability benefits.

▲ Advisory medical committee and a point of reference to consultants specialising in this field.

▲ Access to advice on the management of continence problems, and advice on childhood vaccinations.

▲ Support for children with hydrocephalus in school and guidance for teachers.

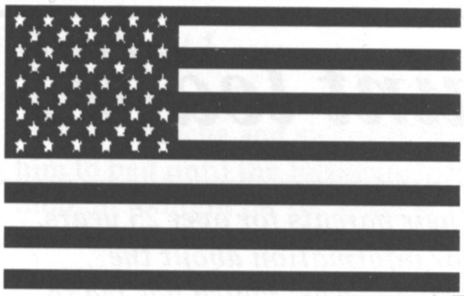
▲ An active support group called *The Hydrocephalus Network* and quarterly newsletter.

▲ Study days for professionals, parents and people with hydrocephalus.

▲ A wide range of Information Sheets

Information Sheets include: ▲ What is spina bifida? ▲ What is hydrocephalus? ▲ Ante-natal screening ▲ Genetic counselling ▲ Vitamin supplementation in the prevention of neural tube defects ▲ Vaccinations and spina bifida and/or hydrocephalus ▲ A guide to the Statementing Process ▲ Notes for Employers ▲ Access to Work for an Employee with Hydrocephalus. ▲ These and a list of other ASBAH publications are available free of charge from the Information Officer at ASBAH, 42 Park Road, Peterborough PE1 2UQ *(please enclose large SAE).*

Copies of the Information Sheet (for us to send directly to your GP) and of the Alert card (for us to send to you) may be obtained by writing to: Disabled Living Services Co-ordinator, ASBAH, 42 Park Road, Peterborough PE1 2UQ. Please enclose two 19p stamps and remember to let us have your doctor's name and address.



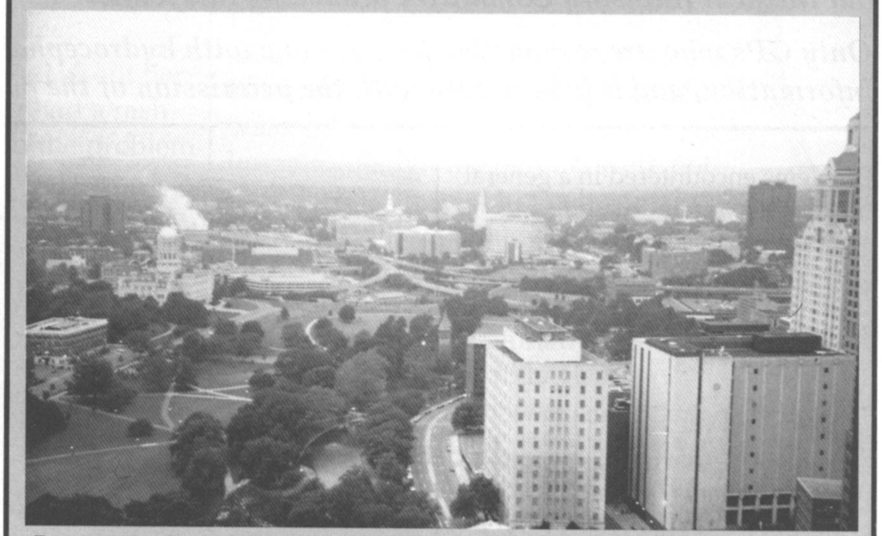
No jokes please

WHILE England basked in hot sunshine at the end of June, several privileged members of ASBAH staff were winging their way across the Atlantic to the annual meeting of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB) in Hartford, Connecticutt, USA.

This annual international meeting is always a high spot in the year as the papers and the discussions that follow keep us very much in touch with new trends and developments in the management of spina bifida and hydrocephalus, and provide us with a valuable source of contact within the medical and research fields.

Papers were presented from representatives from Holland, Italy, USA, Ireland and Scotland, and covered subjects ranging from shunts to urological management.

This year there were also several papers with a sociological base including one from Brian Walsh of Nottingham Trent University, who is well known as a lecturer and colleague to ASBAH staff.



Panoramic view of Hartford, Connecticutt, USA venue for the 1994 conference.

It was the first SRHSB meeting that Brian had attended and his paper was received with great enthusiasm, and he says he will be back again!

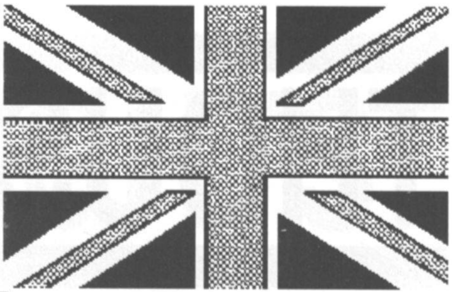
Maddie Blackburn (whose research grant from ASBAH finished on 30 June) gave her final paper on the health and social needs of young adults with spina bifida and/or hydrocephalus. It is sad that this is the end of an era for us, but Maddie is not going to lose touch with ASBAH and is in the throes of writing a book on her research.

There was a lot of interest in neuropathic bladder both from the research angle and from updates on various treatments. In conclusion, it appears obvious that correct continence management

Afternoon drinks at the home of one of our hosts.

Another view of Hartford and River Mystic.

... we're British!



remains of paramount importance both medically and socially.

There are always subjects new to us that come out of any research meeting. This year the Americans again raised the problem of latex allergy which appears almost commonplace in the USA but is virtually unknown here.

We also had a very interesting session on orthopaedics this year and possibly prompted by the fact that John Banta, our host, is an orthopaedic surgeon.

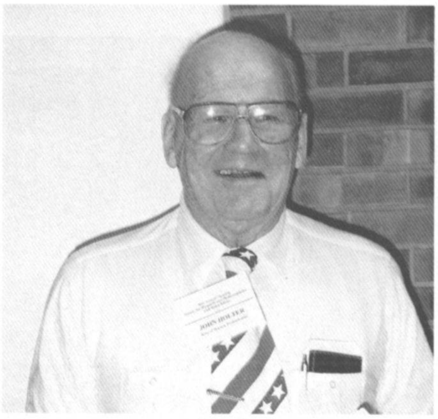
Roger Bayston, ASBAH's honorary consultant in hydrocephalus, chaired one of the final sessions which, as was to be expected, was particularly shunt-orientated. His chairmanship was also memorable for the feeble joke he cracked which had the British contingency groaning and which totally nonplussed the rest of the world!

The social side of the programme was, as usual with this society, highly enjoyable. We were wined and dined (while the discussions often still continued) and shown as much of New England as our hosts could fit in with such a busy schedule of lectures.

Among the distinguished delegates, it was particularly good to see John Holter again looking fit and well, and sporting a patriotic tie. Also present was Duncan Forrest who has long associations with ASBAH and, of course, Moyna Gilbertson, ASBAH's former executive director.

We are all looking forward to renewing acquaintance next year in Bristol, UK.

Rosemary Batchelor
Disabled Living
Services Co-ordinator



John Holter, American inventor of the world's first hydrocephalus shunt and honorary member of the Research Society, sporting a patriotic tie. Picture: Lynette Hare.

The John Holter story

JOHN HOLTER (pictured above) never misses an annual meeting of the Society for Research into Hydrocephalus and Spina Bifida.

He is an honorary member of the society and has taken an active interest in its work and donates money to scientific research through the Casey Holter Memorial Lecture, which was set up in memory of his son.

Mr Holter's son, Casey, was discovered to have hydrocephalus within three months of his birth in November 1955.

The American engineer gave up his job to save his young son's life by inventing the world's first hydrocephalus shunt.

He worked in his garage seven days a week on a clog-free tube which would stay in the body indefinitely and which would control the pressure in the brain with mechanical precision.

While his father worked, Casey made his fourth trip to hospital to have excess fluid removed. During the operation his heart stopped beating. The surgeon cut open his chest and began massaging the tiny heart. Casey survived but with the terrible price of brain damage.

Mr Holter produced the miracle tube in about three weeks. It worked for Casey and for other children. Mr Holter never went back to his job but continued making the valves for tens thousands of children who had hydrocephalus in 50 countries.

Unfortunately, his own story ended in tragedy. Casey lived for only five years. He survived 13 major operations and his father's valve kept the pressure in his brain well under control. Casey was, however, subject to occasional convulsions and during one of these attacks he vomited. As he was unconscious, he inhaled some of the vomit and had no strength to clear his throat. Attempts by his mother to help him and nurses in the ambulance on the way to hospital failed, and he died leaving a large gap and nostalgic memory in his devoted family. His life was short but not in vain.

(Taken from *The John Holter Story*, an article by Professor Lorber, published in Issue 3 of *LINK*, Winter 1966/67).

THOUSANDS SHOUT

AROUND 5,000 people, including *Your Voice in ASBAH* members, joined a national rally in protest over the government's handling of the Civil Rights (Disabled Persons) Bill.

They gathered in London's Trafalgar Square to hear more than 20 speakers, including MPs and representatives from disabled groups, interspersed with entertainment by singers, comedians and poets.

Speakers included the Bill's sponsor, Dr Roger Berry MP, Jane Campbell, chair of the British Council of Disabled People, Rt Hon Lord Ashley, co-chair of All Party Disabled Group, and Rt Hon Alf Morris MP, first Minister for Disabled People.

Your Voice In ASBAH members Zem Rodaway, Kevin Towner, and Alan and Margaret Twyford thought the event was well organised and were inspired by the speeches.

Allan Hollingsworth, of Direct Action Network, leading the way to hand in a petition at 10 Downing Street.

Alan Twyford said: "We would be happy to take part again. Events like this help move things along.

"Those who attended would have taken back to their homes and groups thoughts to continue campaigning on this issue, which people are getting more and more anxious to win."

Organisers of the rally - the second of its kind in two months - were Rights for disabled people Now! formerly known as the Voluntary Organisations for Anti-Discrimination Legislation (VOADL).

Labour MP Dennis Skinner addressing the crowd at the Rights Now! rally.

RIGHTS
FOR
DISABLED
PEOPLE
NOW!

FOR THEIR RIGHTS!

Rights Now! chair Stephen Bradshaw, one of the rally speakers, said the event had been a great success.

"There was a tremendous programme of speeches and letters read out from America supporting us in our campaign for rights for disabled people and anti-discrimination legislation."

Mr Bradshaw said for disabled people to join the rally in London was itself an empowering experience.

"Most disabled people are stuck in homes all the time and the rally gave them a great sense of liberation. This is curtailed by the fact they don't have the rights of black people or women."

He mentioned an incident of wheelchair users being excluded from a Camden pub.

Mr Bradshaw, who is also executive director of the North London-based Spinal Injuries Association, congratulated the crowd for getting there and the many organisations which had signed up in support of Rights Now!

These include RADAR (The Royal Association for Disability and Rehabilitation), Mencap, Mind, the British Council of Disabled People, Disability Alliance, the Spinal Injuries Association and Arthritis Care.

Mr Bradshaw said: "The one organisation we don't thank is the government which has blocked our Bill, which doesn't provide us with any extras but a level playing field."

Photos by Michael Stavri/ Disability Alliance

Hundreds of people fill Whitehall, with London traffic following slowly behind.

Some of the demonstrators "sit in" near the Prime Minister's Downing Street home while the petition is being handed over.

"PRICE TAG DOES NOT STAND UP TO SCRUTINY"

A close up view of some of the thousands of people who gathered at the Trafalgar Square rally.

GOVERNMENT claims that Civil Rights legislation for disabled people is too expensive to bring in have been discounted by Rights Now!

A critique of the government's *Cost Compliance Assessment* by the All Party Disablement Group and Rights Now! campaign, reveals that the real cost of implementing the Bill could be reduced by a staggering £12 billion to just £5 billion.

Civil rights campaigners have now challenged the Government to look again at the real cost of the Civil Rights (Disabled Persons) Bill - and have offered to work with civil servants to produce a genuine assessment of the cost of ending discrimination against Britain's most disempowered minority.

The critique, *What Price Civil Rights?* written by Caroline Gooding of RADAR, details huge errors in the calculation of the government's £17 billion total, including:

* Duplication of figures (included in estimates from more than one government department).

* Failure to calculate economic advantages and potential increased tax revenue.

* Speculative "guesstimates" creating inflated figures.

* Assuming draconian across-the-board action would be needed in a short time frame (misunderstanding the Bill's terms).

* Failure to acknowledge access work already complete, or buildings already designed to be fully accessible.

* No recognition of savings in welfare benefits paid and services provided to keep disabled people unemployed and immobile.

* Ill-informed estimates of the amount which could be spent on enforcing the Bill through a commission.

Caroline Gooding, a specialist employment lawyer, said: "If the government genuinely believes that their figures represent the real cost of the Bill, they need our help. Whilst our research cannot be complete without full access to government figures, our costings are demonstrably more accurate than the grossly exaggerated £17 billion 'guesstimate' that helped kill the Bill."

Protestors venting their anger and frustration over the treatment of disabled people by the government.

RIGHTS
FOR
DISABLED
PEOPLE
NOW!

Rights Now! is a coalition of major charities and civil rights groups working together to support the campaign for anti-discrimination legislation.

Letter from 10 Downing Street to ASBAH's executive director Andrew Russell in response to ASBAH's complaint about the Government's handling of the Civil Rights (Disabled Persons) Bill.

Dear Mr Russell

The Prime Minister has asked me to thank you for your letter of 12 May in which you express concern about the handling of the Civil Rights (Disabled Persons) Bill. You will know that the Bill did not complete its Report stage on 20 May. I am sorry for the delay in replying.

The Government has said on a number of occasions, both within and outside Parliament, that they share with the sponsors of the Bill the overall aim of eliminating unjustified discrimination against disabled people. There is no place for such discrimination in today's society and the Government is committed to seeing it removed. However, views diverge on the best means of achieving this. The Government believes the most effective approach is through a rigorous and practical programme of education, increasing awareness and persuasion, backed up, where appropriate, by legislation.

The Government has never tried to hide the very real concerns that they, in common with business, industry and commerce, have about comprehensive anti-discrimination legislation. The Bill introduced by Dr Roger Berry was virtually the same as the Private Member's Bill introduced in the House of Lords over a year earlier which failed to secure a second Reading in the House of Commons last year. Both at second Reading of the Berry Bill and in Committee, the Minister for Disabled People Nicholas Scott expressed his disappointment that the Bill had returned to the House in precisely the same form that it had appeared previously. He was particularly concerned that it had been reintroduced without any consultation with those who would most be affected by its requirements.

Nonetheless, the Government listened carefully to supporters of the Bill in Second Reading. It went into Committee where they sought to explore and clarify its scope, implications and costs and to identify aspects of it that might be appropriate for action. At the same time, the Government continued to carry forward work on alternative proposals. It was this which led to the announcement during the Report stage on 6 May that they intend to consult widely on five key areas: preventing unjustifiable discrimination in employment; in access to goods and services; in the provision of financial services; extending access provisions under the building regulations; and creating a new independent body to advise Government and report on progress towards eliminating discrimination. These five areas are all component parts of Dr Berry's Bill.

The Prime Minister has given his personal commitment to pressing ahead with these consultations which will take place within six months and will take account of all sectors with an interest. The Government believes they now have a real opportunity to work with business and the voluntary sector to achieve this end.

Mark Adams
Private Secretary

Scott out in Major's reshuffle

A NEW Minister for Disabled People was been appointed by the Prime Minister in his reshuffle .

Nicholas Scott (60) told Radio 4's *Does He Take Sugar* that his departure was due to his age and not his falling foul of the disability movement.

He is replaced by 33-year-old William Hague, who was previously principal private secretary to Chancellor of Exchequer, Norman Lamont. Mr Hague's main political interests are listed as agriculture, defence and economic affairs.

Mr Scott was Minister for Disabled People for seven years and before that he was a Minister at the Northern Ireland Office.

Meanwhile, a report on a consultation on Government measures to tackle discrimination against disabled people has just been published.

Disability on the Agenda outlines what the Government says it has done to improve living standards, employment opportunities and services for disabled people.

It also gives details of a new independent advisory body, the National Disability Council, which will report regularly on progress towards reducing and removing discrimination, as well as making recommendations for further improvement to Ministers.

Members of the public are invited to give their comments on the Government's proposals in writing by 7 October 1994.

Copies of Disability on the Agenda, *in full or summary form, are available from: The Disability Unit, The Adephi, 1-11 John Adams Street, London, WC2N 6HT. Telephone 071-962 8033.*

At last... an adult

Maddie Blackburn, ASBAH research fellow, describes a new feature of London life.

IN THE second of four articles about her ASBAH fellowship, Maddie Blackburn describes some of the work of the new adult disability service at the Chelsea and Westminster Hospital. This new service was established in 1991 by Dr Richard Morgan, a consultant physician with a specialist interest and commitment to providing and co-ordinating medical care for disabled adults, particularly those with spina bifida and/or hydrocephalus.

Some results of one year's evaluation of the service involving 86 young adults with spina bifida and/or hydrocephalus are reported. Currently 164 disabled adults use the service and new referrals are regularly received.

INTRODUCTION

I would like to begin by thanking all the young people, families and ASBAH who assisted with this project. I am particularly grateful to Dr DJ Richard Morgan and Dr Martin Bax for their assistance.

In the 1960s, the legendary names of Lawson and Forrest were as significant to those attending Westminster Children's Hospital in London for surgery, as to audiences who at the time may have listened to the lyrical piano music of Flanders and Swann. Messrs Forrest and Lawson were deeply concerned that the Sixties infants whom they nurtured and cared for throughout their childhood and adolescence should continue to receive specialist help, when required, in their adult years. Their views were shared by many specialists around the United Kingdom who were concerned that specialist health services should not cease after 16 years. Dr Martin Bax and his research colleagues reported in 1989 that many disabled adults had infrequent access to specialist medical and health care after 18 years, although problems did not necessarily cease and, all too frequently, new concerns arose. They also noted that the health of these young adults often deteriorated on leaving school, making the continuity of services all the more important (1).

Until recently, the absence of specialist adult health services have required many young adults to remain under the care of paediatric specialists, albeit frequently at their own request. Years of treatment and regular hospital visits have established close bonds between health professionals and families. Furthermore, Messrs Lawson and Forrest, in the absence of an "adult" specialist alternative were reticent to discharge young people from their care.

In 1990 Dr Richard Morgan was invited and agreed to set up and head a new specialist service for adults with spina bifida and/or hydrocephalus. The service operated at first from an out-patient clinic within the former Westminster Hospital and was staffed by Dr Morgan, hospital nurses and clerical staff.

What is the purpose of this service?

To provide optimum care, continuity and consistency of service in an adult (hospital) setting, initially for people with spina bifida and/or hydrocephalus.

How does it differ from a children's specialist service?

Essentially, young people are seen at their choice, either independently, or with their carers, by a team of specialists. Advice and care is provided by health care specialists who have particular knowledge and expertise in caring for adults with spina bifida and/or hydrocephalus.

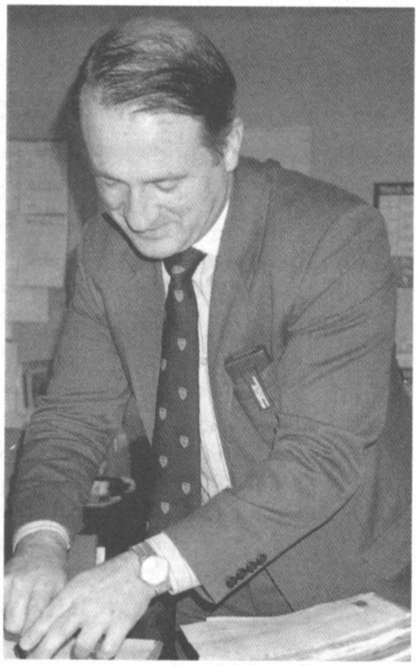
Who was involved at first?

Dr Morgan, a consultant physician, and hospital nursing staff.

Jane Williams, a former continence adviser with ASBAH who attended a monthly paediatric clinic with Dr Morgan and his paediatric specialist colleagues. At this clinic, young people over 18 years were introduced to Dr Morgan and formally transferred

ASSESSMENT, SUPPORT

disability service



Dr Richard Morgan

from paediatric to adult services. A leaflet describing the new service and emergency contact numbers was given to all young adults and their families on their first visit.

Maddie Blackburn joined Dr Morgan at the end of 1991, initially to assist as a specialist health visitor adviser and subsequently to evaluate and monitor the development of the new service.

What happens at the transfer clinic?

Dr Morgan receives referrals from the Chelsea and Westminster Hospital paediatric services and other hospitals, both within and outside the region. The physician's role is to act as coordinator of medical services, referring as and when necessary to adult urologists, neurosurgeons, orthopaedic and health care specialist services within the hospital.

Who is involved now?

The success of any new initiative depends as much on the individuals who work behind the scenes as those working on the front line. Debbie, Dr Morgan's secretary, as well as arranging appointments and transport, often provides a comforting ear to families until appropriate help, advice or information can be sought from other members of the team. Jane, the out-patients' clerk, tries to ensure that appointments run smoothly and punctually, despite the pressures and constraints of a changing and demanding new health service.

To combat the limitations of a conventional out-patient setting, the team established an adult day multi-disciplinary assessment centre which celebrated its first birthday in May 1994. This meets monthly and is staffed by the following:

- Dr Morgan, who has the expertise to manage the breadth of general medical problems which arise in people with complex needs. He provides the focal point for overall supervision and aims to provide consistency, continuity and confidence within the service.
- Associated support from consultant urologists, orthopaedic surgeons, neurosurgeons and geneticists for technical advice and management of specific problems.
- Hospital nurses, both within the out-patient and assessment units.
- Continence advisers, both urinary and bowel specialists, from ASBAH and other agencies.
- A specialist health visitor - Maddie Blackburn.
- A disabled living adviser from ASBAH, usually Caroline Berkley, attends the monthly clinic. Leonie Holgate, another DLA with ASBAH, attends on specific issues related to hydrocephalus.
- A clinical psychologist.
- An occupational therapist.
- Physiotherapists.
- Technicians for urological, neurological and orthopaedic investigations.
- Radiographers, to achieve liaison with imaging, radio isotope departments.
- Wheelchair/appliance advisers.

Where are the clinics held?

Weekly clinics are provided within a general out-patient clinic in Chelsea and Westminster Hospital.

Continued on page 20

From page 19

The monthly, all-day adult disability service is held within a large purpose built assessment unit/day hospital, located on the ground floor. This facility is used by other departments such as cardiology, haematology and rehabilitation as there are excellent assessment and instructional facilities, such as teaching continence management.

What are the differences between the two clinics?

The weekly out-patient service - This aims to see those people who are transferred either from the children's services, Chelsea and Westminster Hospital, or referred by general practitioners. Young people requiring more regular review attend the weekly service. The weekly clinics are held on Tuesday afternoons and on some Wednesday mornings.

The all-day multi-disciplinary clinic - In the absence of local facilities, some young adults travel large distances to attend the clinic. A full day appointment is offered so that young people may receive any necessary investigations, have access to multi-disciplinary medical and health consultations on the same day, without making additional visits to hospital. It is hoped such comprehensive review will reduce waiting time for certain investigations, for example ultrasound scans.

The day clinic aims to provide an annual, comprehensive health and social "MOT" as well as giving the young person greater opportunity to be involved in the planning of decisions concerning his/her care. It also aims to provide an opportunity to discuss matters, in private and informally with doctors and other health care specialists. Private, individual consultations are available for both the young person and their parents/carers.

In addition, the day clinic provides:

- Equipment - contraceptive devices and continence appliances.
- Transport/parking and some support costs.
- Wheelchair accessible canteen, toilet and parking facilities.
- Administrative and clerical support.
- Information in the form of videos and leaflets about benefits and health issues.

METHODS AND SOME RESULTS

During 1992, 86 young adults, age over 18 years, with either spina bifida and/or hydrocephalus were offered a health care assessment in a newly established out-patient clinic specifically for people with spina bifida and/or hydrocephalus. There were 37 men and 49 women (n = 86), mean age 22.9 years. Only two defaulted their appointment but later phoned for another date.

Many young patients reported complications often associated with these conditions; epilepsy, moderate to severe learning difficulties, cardio-thoracic and renal problems.

All young adults received a comprehensive medical review at their first attendance. Some routine investigations were performed on the same day. These included the regular assessment of shunt systems by x-ray, CT scan and electro-encephalograms for people newly diagnosed with epilepsy. Ultrasound scans, other urological investigations and kidney scans are sometimes performed. These were planned to coincide with the young person's visit, by prior arrangement for convenience. Many young people had complications associated with their disability which require careful monitoring and assessment. These included chronic chest deformities, chronic renal failure, skeletal pain from scoliosis, headache, epilepsy and/or behavioural problems, pressure sores and continence management. Where necessary, some young people were offered hospital admission for more comprehensive assessment or to see the adult urologist, neurosurgeon and orthopaedic surgeon as necessary. Whenever possible, hospital admissions were kept to a minimum. Many of these people have spent several years of their lives in hospital.

It is equally important to recognise the young person's social/health concerns as well as medical condition. Many social and health issues are discussed with the research health visitor and/or continence adviser. Where necessary patient referrals are made to ASBAH and/or other agencies as appropriate with the patient's prior permission. Continence advice is available during the clinic and any follow-up or referral will be arranged during the session.

RESULTS

Six young adults with spina bifida only, 48 spina bifida with hydrocephalus and 32 with primary hydrocephalus attended the clinic.

The average distance travelled to attend the service were 35 miles. Medical assessment often lasted an hour because of the complex nature of the disabilities. Of particular interest were the number of requests and concerns about shunts, continence, mobility management, as well as independence, behaviour, sexuality, contraception and benefit issues. Two patients disclosed that they had been sexually assaulted, necessitating referral at their request to both statutory or voluntary agencies. One woman, who had a myelomeningocele, and one woman with hydrocephalus attended the clinic with their able bodied children. One other woman

Continued on next page

From page 20

was pregnant and requested specific advice about disability and childbirth. Others contemplating a family inquired about genetic risks. Several people in relationships asked about contraception. Two women with hydrocephalus disclosed that they had been sexually assaulted and were referred to social services, with their approval, for appropriate support and follow-up. One man reported incidences of bullying.

Diagnoses of Young Adults

Diagnosis	(N)
Spina Bifida (SB)	6
SB/HC	48
Primary HC	32
Total = 36	

Most young adults were accompanied by parents, carers or partners. Only 10 adults attended the clinic without carers. All young people and relatives seemed to welcome the opportunity of meeting medical and health care specialists in an adult setting. Generally the proposal to continue and expand this service was welcomed.

Forty six adults attended the clinic once, 21 twice, seven on three occasions and six four times during this period. Those seen on more than two occasions usually presented with more acute medical or behavioural concerns which necessitated an earlier appointment. All other patients were usually offered annual appointments but could attend an earlier one if required.

Seven young adults were subsequently admitted to hospital for investigations and an opinion from either an adult urologist or neurosurgeon; one young person was admitted for a cystoscopy and bowel management, one for specific bowel management, two people for ventricular shunt revision, two people for pressure sore management and one person for observation assessment only.

DISCUSSION

From this initial evaluation, it was clear that over half of the adults seen had unmet needs and were pleased to have the opportunity for annual assessment. However the success of such a service not only hinges on purchasers and providers recognising the importance of making available such services. Providers must also respond to the needs of the young person and his/her family as well as work collaboratively with health care specialists both in hospital and the community.

Every young person offered an appointment attended the clinic despite distance and transport difficulties. In the absence of local provision, it appear that many families are prepared to travel to Chelsea and Westminster Hospital in order to receive health care in an adult setting (see table on page 22).

The service has highlighted the sexual vulnerability as well as inadequate sexual knowledge of some young adults, particularly those who are sexually active and may seek further information. The need for both bowel and urinary continence advice and management is strongly indicated.

CONCLUSION

It is inappropriate to care for young adults over the age of 18 in a children's out-patient setting. The medical, social and emotional requirements of this group differ enormously and necessitate the skilled knowledge and expertise of a variety of specialists in adult services in order to monitor, advise and provide health care intervention where necessary.

It is hoped that the Adult SB/HC clinic will continue to expand and develop its services. The successful management of disabled adults is dependent on collaboration and co-operation between health care

Continued on page 22

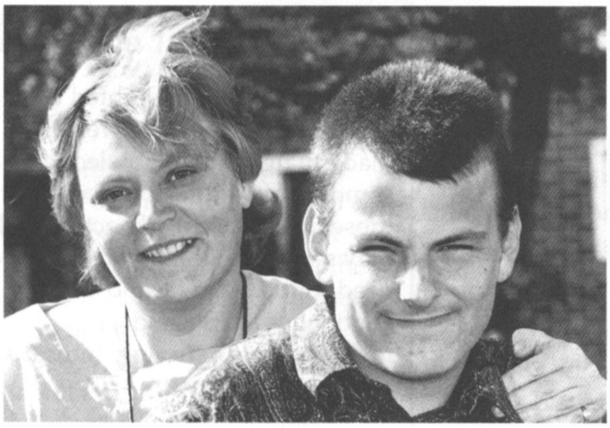
A place? Ask your doctor

IF YOU would like to use the adult disability service described in this feature, you should be aged 16 or over and have spina bifida and/or hydrocephalus.

Most importantly, you must also:

- **Ask your family doctor to consider referring you to Dr D J R Morgan at the Chelsea and Westminster Hospital.**
- **Even if you have been a patient at the former Westminster Children's Hospital or in the children's department at Chelsea and Westminster Children's Hospital, then again you must ask your family doctor for a referral letter.**
- **The same applies if you live outside the district (in particular, outside London).**

For further information or advice about the service please contact Debbie (Dr Morgan's secretary), tel 081-746 8146 or Maddie Blackburn, tel 081-746 8629.



Mum forms self-help group

WORRIES about health and personality changes in her son since the detection of a Dandy Walker cyst in his brain has led Hampshire mother Heather Jury to set up a Dandy Walker support group.

"My son, Stuart, has had eight operations this year and he is having personality problems and mood swings. After his fifth time of going into hospital, we decided in desperation to see if we could share the burden with other families who are in similar situations", said Mrs Jury.

She has already joined forces with another family met through Southampton General Hospital and hopes to make contact with other families in the area and further afield. They would particularly value the experiences of people in older age-groups who had DW cysts.

The support group idea is supported "100 per cent" by their consultant at the hospital, says Mrs Jury.

Stuart had a Spitz Holter valve fitted after being born with hydrocephalus and, until a year ago when the valve stopped working, was doing well.

One particular worry at the moment is that his school want to put Stuart in for his GCSEs but his parents think he has been too ill lately to be able to cope successfully with the stress.

Mrs Jury says the symptoms of Dandy Walker cyst are similar to hydrocephalus, but are often far more subtle.

Families and people with DW cysts interested in offering each other mutual support can write to Heather Jury at 28 Tichborne Way, Rowner, Gosport, Hants PO13 OBL.

■ A Dandy-Walker cyst occurs when the roof of the fourth ventricle in the brain fails to perforate - the cavity of the fourth ventricle becomes distended with trapped CSF and balloons out to form the cyst. It is a relatively rare condition which is not always easy to detect. Patients with Dandy-Walker cysts need treatment, usually by inserting a shunt, if the dammed-up CSF within the ventricle is causing raised pressure.

From page 21

specialists and young adults and their families.

Our paediatric surgeons recognised that it was inappropriate to continue caring for adults aged over 18 in a children's setting. Our preliminary evaluation suggests that certain functional problems continue and the increasing psycho-social demands of this group necessitate an adult service provided by specialists who are able to advise adults with complex needs in safeguarding and achieving optimum health. Further evaluation is indicated from this initial study.

REFERENCES

1. Thomas A, Bax MCO, Smyth D, The Health and Social Needs of People with Disabilities (1989) Ch 3. Blackwells Scientific Publications.

2. Blunn RW, Resnick MD, Nelson R, Germaine A, Family and Peer issues among adolescents with spina bifida and cerebral palsy (1991) 88: 280-285.

Maddie Blackburn has been signed by publishers Butterworth/Heinemann to write a book on sexuality and disability, aimed at professionals and consumers. The book should be in the shops in summer or autumn 1995.

Satisfaction with new all-day adult disability service (1993-4)

Comments	*Number*	*Total*
Think service is useful	**58**	**60**
Think service should be provided locally	**13**	**60**
Happy to travel to C&W	**57**	**60**
Service could be improved	**10**	**60**

Total = 60 written evaluations (total patients = 80).

Adult Clinic for People with Spina Bifida and/or Hydrocephalus. Pilot Patient Sample (1992)

Patients	*Nos*	*%*
Men	**37**	**43%**
Women	**49**	**57%**
Total	**86**	**100%**

Numbers of patients currently known to service as of 30th June 1994 = 164.

LAUNCH OF BEREAVEMENT TRUST

A FAMILY'S Grief is the title of a one-day conference organised next month by The Child Bereavement Trust.

The trust, featured in the December '93 issue of *LINK*, cares for bereaved families by training and supporting the professionals who help them.

The conference, on Friday 23 September at the Moat House Hotel, Northampton, aims to support and train all professionals who care for families and themselves as carers.

The programme includes:

☛ Understanding Grief - keynote speech by Dr Colin Murray Parkes.

☛ The Needs of the Family - by Janet Doyle, Regional Nurse, Palliative Care, Oxford & Anglia Regional Health Authority.

☛ Siblings Grief - by Dr Richard Wilson, Consultant Paediatrician, Kingston Hospital.

☛ The Needs of the Dying Child - by Dr Jim Kuykendall, GP, HIV/AIDS Facilitator, Ealing and Hammersmith FHSA.

The cost of registration is £40 including VAT and all refreshments. For further information contact *Mr G Rivas, SMA Nutritition, Dept of Postgraduate Education, Huntercombe Lane South, Taplow, Maidenhead, Berks, SL6 0PH. Telephone (0628) 660633 extn 4330.*

New Director

David Phillips (47) has been appointed new director of the Holiday Care Service. He had previously worked at the English Tourist Board looking after the *Tourism for All* campaign.

Management changes at ASBAH

FOLLOWING the departure last month of our Disabled Living Services Manager, the Executive Committee has brought forward changes in the way ASBAH runs its services.

The post of DLS Manager has now been deleted with a view to unifying our fieldwork and disabled living services departments later this year. Instead, a new services manager will be in post from 12 September, who will manage existing services staff and co-ordinators,

Her name is **Miss Millie Rollinson**, who has a social work background and has worked for the Spastics Society for 17 years, most recently as a community manager in their Eastern region.

Teresa Cole, presently fieldwork manager, will be appointed senior services manager from 1 October, with specific responsibilities for new service development (including the START assessment and training team) and for assisting the executive director with approaches to local authorities and health services.

Rosemary Batchelor has been appointed disabled living services co-ordinator in addition to her work as a disabled living adviser. She will be the line manager for DLAs who are not 'regionalised'

The process of developing our regions continues. Instead of two regional teams, ASBAH should have four by the end of the financial year. **Mary Malcolm**, assistant fieldwork manager, has been appointed regional co-ordinator of our new Eastern region from 1 October. Julie Llewellyn, one of our nurse DLAs, and secretary Becky Sewell will work with Mary.

The Eastern region office will be at ASBAH House, Peterborough, and it will cover Lincs, Cambs, Leics, Norfolk, Suffolk, Essex, Herts, Beds, Northants and Notts.

The other new region - covering the area east of the Pennines from South Yorkshire to the Scottish border - should be in existence by the end of the year, depending on finance. The co-ordinator will be **Joan Pheasant**, in addition to her work developing the new START team.

Employment leaflets from ASBAH

TWO information sheets for employers have been published by ASBAH - to help people with spina bifida and hydrocephalus find and keep work.

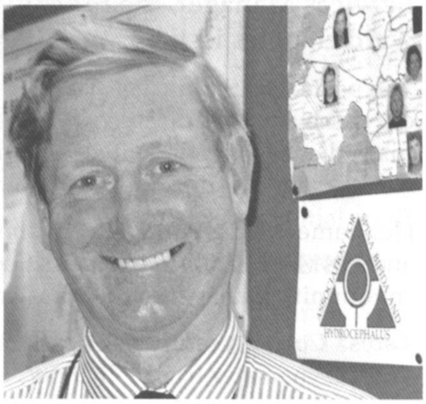
Notes for Employers (Info Sheet No 9) aims to reassure prospective employers that people with hydrocephalus make willing members of staff, providing they are helped to settle into a new job and given well-structured supervision.

Access to Work for an Employee with Hydrocephalus (Info Sheet No 12) addresses some of the hidden needs of workers with hydrocephalus and urges employers, where appropriate, to consider applying for a support worker under the Employment Service's new 'Access to Work' scheme. It also advises on how to set up a well-structured working environment, even if a specialist support worker is not obtained.

Copies are available from the Information Department, ASBAH House, 42 Park Road, Peterborough PE1 2UQ, when a contribution towards printing and postage would be welcomed.

SPECIAL NEEDS EDUCATION CODE OF PRACTICE

Tribunal job for ASBAH Education Adviser



EDUCATION adviser Peter Walker *(pictured)*, who has worked for ASBAH for four years, has been named as one of 79 locally-based lay members of the new Special Educational Needs Tribunal. This will hear appeals from parents unhappy about local education authority decisions on the assessment or statementing of their children.

The tribunal, which begins work on 1 September, will hold hearings as near as possible to parents' homes. Schools Minister, Eric Forth, says appointing locally-based lay members will make this possible.

"The Tribunal is a key part of the action being taken to provide for children with special needs," said Mr Forth.

"We have recently published a Code of Practice giving practical guidance on how to identify and assess special educational needs. The Tribunal is being set up for parents who cannot agree with the LEA on the decision taken and it is completely independent."

Mr Walker spent 30 years in teaching before joining ASBAH and was head of three primary schools in Lincoln, Coventry and Sheffield. His last school had a unit for physically disabled pupils.

Each appeal will be heard by a tribunal of three, headed by a lawyer chairman and with two lay members who between them have knowledge and experience of special educational needs and local government.

Mr Walker, who deals annually with over 100 statements of special educational needs, commented: "The keynotes of the Tribunal will be informality, speed of decision, impartiality and user-friendliness."

Mr Walker will still represent families at appeal but will not be able to adjudicate on appeals involving ASBAH or its clients.

"Parental choice remains something of a fiction. Parents can express a preference for a school for their child but even in the new Code of Practice local education authorities retain the get-out clause, "effective use of resources", as an excuse for sending children elsewhere," he added.

MAIN POINTS FROM CODE OF PRACTICE

The new Code of Practice includes:

- Information about the school-based stages of assessment and provision.
- The procedure for a statutory assessment of special educational needs.
- The provision of a statement of statutory educational needs.
- Details for assessments and statement for under-fives.
- Advice about the conduct of annual reviews.

The 1993 Act requires school governing bodies to:

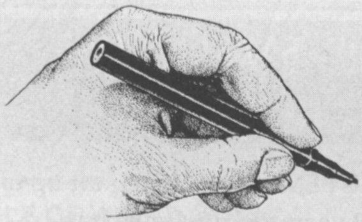
- Publish information on their special educational needs policies.
- Report annually on the implementation of those policies.
- Have regard to the Code of Practice.

Schools must implement the Code from the beginning of September but the way they do this will vary. Precisely what schools do will vary according to size, organisation, location and the nature of their pupil population. Registered inspectors, who will monitor and evaluate the impact of the Code, will consider these points when looking at a schools' provision.

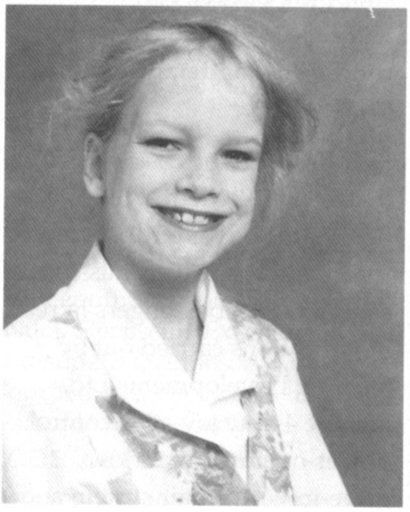
Local Education Authorities must also have regard to the Code. It explains how they can effectively fulfil their statutory duties, for example, in meeting time limits. Some aspects, however, such as the issuing of 'notes in lieu' of statements, are advisory, but this advice cannot be ignored.

The Code emphasises partnership with parents and, wherever possible, with the child during school-based and statutory assessment. It highlights the importance of inter-agency co-operation when considering the special education needs and provision for a child.

The voluntary sector has a key role in supporting parents during statutory assessment and in contributing advice to the statement. A voluntary sector adviser may be appointed as a 'named person' who can give information and advice about the child's special education needs.



Letters



Sarah Wassell: thanks for your help

I felt that I just wanted to drop a line to say that we took our five-year-old daughter Kylie to Florida this year. She has hydrocephalus and has two shunts inserted.

The flight took nine and a half hours and, apart from the normal ear-popping experiences, she was fine. We all had a super time and I would like to say that, if you have the chance ever to go, do TAKE IT!

I must add though that we did take out extra holiday insurance in case we needed medical care.

Mrs G Pratten
Cleethorpes, South Humberside

Editor's note: do see your doctor if you are worried about fitness to fly. ASBAH's disabled living services department, tel 0733 555988, can also offer advice on the subject and on holiday insurance.

WE WOULD like to thank Mr Peter Walker and his wife for visiting us to help us choose the most suitable school for Sarah to transfer to in September 1994.

We visited three schools: the local comprehensive which is old with lots of steps and is split into two levels, no facilities for children with special needs (physical disabilities) existed; the second school was a Roman Catholic school, much smaller but still with steps and no special facilities; the third was a large comprehensive school in another area. The facilities were great, everywhere there were ramps, large waiting areas outside classrooms, special toilet and shower facilities for children with special needs and, above all, a full-time nurse in attendance, and a fully trained special needs co-ordinator.

Sarah will be going to the third school - Old Hall Comprehensive School at Kimberworth, Rotherham, South Yorkshire. Well done, Rotherham Borough Council, for providing these facilities. Although Sarah will have to travel further to school which is out of our area, she is looking forward to the transfer as this school will offer her freedom to move about on her own without the worry of all the steps at the other school, and the opportunity to meet other children with special needs.

Mr Walker is very kind and helpful and knew what to look out for like the condition of the steps floor surfaces, handrails and the policies of schools many things which we had never thought about. Thanks, Mr Walker.

My advice to parents would be don't choose the nearest school first go but have a good look round other schools and see what facilities they have to offer your child. I would also advise parents to go and visit other schools the year before their children are due to transfer to make sure there are enough places available.

Sarah and I would also like to thank ASBAH for providing Sarah with a Panasonic laptop word processor and printer. Sarah is learning how to use these and this letter is being typed on the word processor. We are having a lot of pleasure learning how to use them. Once again a great big thank you from Sarah and myself. We find all the articles and literature we have obtained from ASBAH very useful. Sarah has hydrocephalus and other disabilities and will be 11 years old in August.

Sarah Wassell and Mum,
Rotherham, South Yorkshire

FORTHCOMING EVENTS

Wednesday, 14 September

Hydrocephalus Study Day, McKinney House, Musgrave Park Hospital, Belfast, speakers include Dr Nan Hill (consultant paediatrician, Royal Belfast Hospital) and Mr Thomas Fannon (consultant neurosurgeon, Royal Victoria Hospital, Belfast), Rosemary Batchelor (Hydrocephalus Network co-ordinator, ASBAH). ***ASBAH Regional Centre, 73 New Row, Coleraine, Northern Ireland BT52 1EJ, tel 0265-51522.***

Thursday, 15 September

Hydrocephalus Study Day, details as for 14 September, except the venue changes to Library HQ, Omagh, Northern Ireland.

FORTHCOMING EVENTS

Saturday, 17 September

Hydrocephalus Study Day, Eastpoint Centre, Thornhill, Southampton. Speakers: Dr I Sugarman (St Mary's Hospital, Portsmouth), clinical psychologist Steve Dorner, ASBAH disabled living adviser Leonie Holgate. Fee £6.50 *Details: Liz Clayton, ASBAH fieldworker, tel 0734-724013*

Saturday, 24 September

ASBAH AGM, Peterborough.

27 - 29 September

Naidex International '94, Wembley Conference and Exhibition Centre, London.

Saturday, 8 October

Hydrocephalus Study Day, organised by North Wales ASBAH, Gogarth Special School, Nant-y-Gamar Road, Llandudno, Gwynedd, 9.30am-3.30pm. Speakers include: Paul May, consultant neurosurgeon, Alder Hey Children's Hospital, Liverpool; Leonie Holgate, hydrocephalus adviser, ASBAH. Cost £5 each. *Mrs Lynn Thomas, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel 0733-555988.*

Tuesday, 11 October

RADAR conference, 'Consultation, Collaboration, Co-operation & Communication: disabled people have rights' - on subject of Community Care and Provision of Services under Section 2 of the Chronically Sick and Disabled Persons Act 1970. BT Centre, London. Fees: sliding scale £60-£85 (some subsidised places available for disabled people on low incomes). *Jill Clarkson/John Keep, RADAR, tel 071-250 3222.*

21 - 22 October

'One Life' international conference, organised by BOSK (Association of the Motor Disabled and their Parents) with Union Européene des Associations de Spina Bifida and Hydrocephalie (UEASBH). Venue: Leeuwenhorst Conference Center, Noordwijkerhout, The Netherlands. *BOSK National Office, P O Box 457, 2051 CL The Hague, The Netherlands, tel + 31 70 350 0554, fax + 31 70 354 0834.*

12 - 19 December

Project Phoenix Trust overseas study tour for the disabled: Venice, with a visit to Padova, *Mrs V Saunders, 56 Burnaby Road, Southend on Sea, Essex SS1 2TL, tel 0702-466412 .*

16 -19 July 1995

Annual Mobility Roadshow and 'Ideas into Action', the 7th International Conference on Mobility and Transport for Elderly and Disabled People, Transport Research Laboratory, Crowthorne, Berkshire. *Conference details: Paddy Payne/Louisa Rogers, Baltic Conventions, The Baltic Centre, Great West Road, Brentford, Middx, TW8 9BU, tel 0181-847 2446.*

14 -16 September 1995

'Fast Forward into the Future' , 8th International Congress of the International Federation for Hydrocephalus and Spina Bifida, The Collaroy Centre, Sydney, Australia. *Details: SBH Conference Secretariat, GPO Box 128, Sydney NSW 2001, Australia.*

SMALL ADS - FOR SALE

ALVEMA pushchair, suit up to 10 years old. Includes tray, shopping backet, full harness and cape. £400 ono. Good condition. For details, phone 0709-547913.

ELSWICK Envoy Special Saloon (based on BL Metro), blue fibreglass body, petrol engine, 998cc, automatic transmission, can carry two passengers in rear, modifications carried out by Steering Developments Ltd include 4-way joy-stick control, power-operated rear door, drive-in wheelchair system and seat-belt adaptation, nine-way beeper, electric handbrake, extended gearshift and push-button start/ignition. Registration Number B399 BJW, first registered August 1984, very low mileage. Excellent condition. Executor's sale. Located Peterborough. Offers invited. Tel Paul Wootton, ASBAH, tel 0733-555988, if interested in viewing or bidding.

BARRATT Jewel electric wheelchair in excellent condition, £1,475 ono. Tel: 0442-235769.

VAUXHALL Astra Max rear entry vehicle for transport of wheelchair/powered chair passengers in situ. This vehicle is specially adapted with joystick controls, power steering, vacuum brake, electric front windows, ancillary controls, can be switched to normal driving when required. H reg., 1600cc, Blue, 23,000 miles. £9,000 ono. Tel: 0903 745831

HOLIDAY ACCOMMODATION

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

ISLE OF WIGHT ASBAH

Fully equipped, wheelchair-accessible, 2-bedroom holiday chalet, sleeps 6 + cot. Clubhouse, indoor heated pool, shop, etc. Site overlooks sea. Own transport advisable. *Details: Mrs P Burnden, 36 Sherbourne Avenue, Binstead, Ryde, Isle of Wight PO33 3PX. Tel: 0983-564604.*

NEW FOREST

Fully equipped caravan designed for wheelchair access throughout, sleeps 5-6, club with indoor pool, shop etc, sited at Bashley Park. *Contact: Joan Searle tel: 0705-376816*

NEW MILTON HAMPSHIRE

Fully equipped, completely wheelchair-adapted, self-catering, 2-bedroom chalet. Sleeps six. Excellent all-year round site, indoor and outdoor pool and superb facilities. All 100 yards from chalet. Near to New Forest and Bournemouth. Bookings taken to November. Also similar property at Millendreath in Cornwall. *For details, contact Mr P Cash tel: 0425-72055.*

LOOE, CORNWALL

Fully equipped, self-catering bungalow. Sleeps six, site near sea with easy access to beach, shop indoor pool and camp facilities. Easily accessible for wheelchairs. *Details: Mr P Cash, tel: 0425-72055.*

SHERBORNE, DORSET

B&B en suite, ramped accommodation, colour TV with beverage tray, twin beds, central heating, armchairs, own key, from £17 per person per night. *Tel 0963-250857.*

WESTGATE-ON-SEA, KENT (GREENWICH ASBAH)

Semi-detached bungalow available all year round. Since bought in 1976, we have added new lounge/diner, summer house in garden, shower/toilet room for latest wheelchair hygiene and gutted kitchen, installing disabled facilities for wheelchair use. Also bathroom/toilet, 3 double-bedrooms to sleep 8, plus cot. Full central heating, colour TV, drive-in takes 3 cars. Westgate has 2 sandy bays with wheelchair access and toilets. NO steps anywhere and low off-season rates. *Doug Endersby, 12 Veda Road, London SE13 7JF, tel 081-690 0342.*

mar y sol

TENERIFE

Wheelchair-accessible apartments. Heated pool with hoist. Restaurant, poolside bar. Equipment hire. Ring today for video and cheapest prices on flights and accommodation.

ALGARVE - PORTUGAL

Wheelchair-friendly luxury villas with swimming pools or mini-hotel with adapted rooms. ***Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX. Tel 0753-685718.***

SUNNY TENERIFE OR SCENIC NORTH WALES

Beautiful, accessible Mar Y Sol complex, Los Cristianos - heated pool/hoist/transport. Also luxury self-catering bungalow (sleeps 4/5), Mold, Clwyd. ***Brochures - Lynne James Ltd, 28 Gleneagles Road, Gt Sutton, Sth Wirral L66 4NF. Tel 051-339 5316.***

LINK Rates

Editor: Liz Cawthorne

Published by **ASBAH**,
ASBAH House,
42 Park Road,
Peterborough PE1 2UQ
Telephone: 01733 555988.

LINK SUBSCRIPTION
6 EDITIONS – 12 MONTHS

UK	£4.80
Europe and Overseas Surface Mail	£7.50
Air Mail	£15.00

All payments should be made in Sterling.

Classified 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* (October) sent to the Editor by Friday, 2 September.

Display Rates on application, from the Publicity Manager.

DIRECTORY OF LOCAL ASSOCIATIONS

BARNSLEY
Mrs Marlene Haigh
3a Birk Avenue
Kendray, Barnsley
S Yorks S70 3AE

BEDFORD
R C Simmonds
The Oaks, 16 Parkstone Close
Bedford MK41 8BD

BOURNEMOUTH, CHRISTCHURCH & DISTRICT
Mrs G Lanning
23 Seaway Avenue
Christchurch, Dorset
Tel: 01425 273 255

BRISTOL & DISTRICT
Mr G Egan
64 Rookery Road
Knowle, Bristol
Tel: 0117 977942

BUCKS & EAST BERKS
Mrs Margaret Humphreys
15 Brackley Road
Hazlemere
High Wycombe
Bucks HP15 7EW

BURY & BOLTON
Mr David Clyne
51 Cuckoo Lane
Whitefield
Manchester M25 5WQ
Tel: 0161 798 7804 (after 4pm)

CALDERDALE
Mr A L Crowther
12 Elm View,
Huddersfield Road
Halifax HX3 0AE
Tel: 01422 341497

CAMBRIDGESHIRE
Mrs D Thorn
58 Howland
Orton Goldhay
Peterborough
PE2 5QY
Tel: 01733 235139

CHESTER & DISTRICT
Mrs P Ithell
34 King Edward Street
Shotton, Deeside
Tel: 01244 811074

COVENTRY
Mrs N Newman
11 The Earls Court
Cheylesmere
Coventry CV3 5ES

DERBY & DISTRICT
Mrs A Hewitt
St Merryn
20 Burley Hill
Allestree, Derby DE3 2ET
Tel: 01332 841893

DUDLEY, WOLVERHAMPTON & SANDWELL
Mrs Lorna J Wootton
14 Leveson Road
Wednedfield
Wolverhampton
West Midlands WV11 2HF
Tel: 01902 738724

ESSEX
Mrs R McCarthy
26 Brixham Gardens
Ilford, Essex IG3 9AX
Tel: 0181 594 1852

GLOUCESTERSHIRE
Mr J Cormack
28 Pickering Road
Cheltenham
Gloucester
GL53 0LB

GRANTHAM
Miss Caroline MacCallum
3 Wentworth Drive
Grantham, Lincs NG31 9QQ
Tel: 01476 66085

GREENWICH & DISTRICT
Mrs M Mears
29 Wellmeadow Road
London SE13 65Y
Tel: 0181 244 3526

HAMPSHIRE NORTH, W SURREY & S BERKS
Mrs Liz Selby
Buryfields House, Buryfields
Guildford, Surrey GU2 5AZ
Tel: 01483 571736

HAMPSHIRE SOUTH
Mr S R Baker
12 Moorings Way, Southsea
Portsmouth, Hants POY 8QW
Tel: 01705 819 075

HERTS & S BEDS
Mrs S Riseborough
45 Frankland Road
Croxley Green
Herts WD3 3AS

HUDDERSFIELD
Mr Steven Bolton
41 Fieldsway
Kirkheaton, Huddersfield

HULL & DISTRICT
Mrs G D Brown
233 Cranbook Avenue
Hull HU6 7TX
Tel: 01482 857 165

JERSEY, Channel Islands
Mrs Joy Thomson
Belles Roches Cottage
Valles des Vaux
St Helier, Jersey C.I.

KENT
Mrs S Stevens
6 Croftside, Vigo Village
Meopham, Kent DA13 0SH
Tel: 01732 822985

LEEDS & BRADFORD
Anna Waddington
Mullion Cottage, Main Street
Hawksworth, Guiseley
West Yorks LF20 8NX

LEICESTERSHIRE
Mrs A Twomlow
29 The Crescent
Market Harborough
Leicestershire LE16 7JJ
Tel: 01858 432967

LINCOLN & MID LINCS
Mrs P Malson
"Pinfold", Chapel Lane
North Scarle, Lincoln LN6 9EX

LINCOLNSHIRE SOUTH
Mrs P Mason
67 Boston Road
Heckington, Sleaford, Lincs

LONDON N WEST
Mrs H Prentice
37 Milton Road
Hanwell, London W7 1LQ
Tel: 0181 579 4685

LONDON SOUTH
Mrs S Cudd
15 Woodvale Walk, Elder Road
W Norwood, London SE27
Tel: 0181 761 2400

MIDLAND
Mrs Diane Britt
Stanton House
54 Stratford Road, Shirley,
Solihull, West Midlands B90 3LS
Tel: 0121 733 7810

NORTHAMPTONSHIRE
Mrs J Cockings
45 Grafton Road
Rushden, Northants

OXFORDSHIRE
Mrs Shirley Dale
14 South Row
Chilton, Didcot, Oxon

PRESTON
Mrs S Thompson
34 Beatty Road
Southport, Merseyside PR8 6LB

ROTHERHAM & DONCASTER
Mrs Katie Hemmings
40 Bentley Road
Bentley, Doncaster DN5 9TA

St HELENS & DISTRICT
Mrs N Maddocks
236 Rainhill Road
Prescot, Merseyside L35 4LD
Tel: 0151 426 3921

SALISBURY & DISTRICT
Mrs J Renshaw
1 Phillip Court
Coronation Road
Salisbury SP2 9DA

SHEFFIELD
Mrs C Crofts
46 Busheywood Road
Sheffield S17 3QB
Tel: 01142 266033

SOMERSET
Mrs Iris Coton
3 Court Gardens, Yeovil
Somerset BA21 3LZ

SOUTH THAMES
Mr Angela Poole
133 Hamsey Green Gardens
Warlingham, Surrey CR6 9RT
Tel: 01883 627429

SOUTHAMPTON & DISTRICT
Mr A D Strong
8 Summerfields, Locks Heath
Southampton SO3 6NN
Tel: 01489 583023

STAFFORDSHIRE
Mrs J Davies
8 Oakhill Avenue
Oakhill, Stoke on Trent ST4 5NJ
Tel: 01782 45365

STAINES HOUNSLOW & DISTRICT
Mrs Pamela Page
237 Upper Halliford Road
Shepperton,
Middx TW17 8SP

STOCKPORT
Mrs J Roberts
9 Highcroft Road Romiley
Stockport,
Cheshire SK6 4PS
Tel: 0161 430 4869

SUNDERLAND
Mr J Pounder
42 Gowanburn
Sunderland
Tel: 0191 415 1725

SURREY
Mr Simon Figg
4 Brickyard Copse
Ockley, Dorking
Surrey RH5 5TJ
Tel: 01306 627572

SUSSEX
Mrs M White
Averys
Rusper, Horsham Sussex
Tel: 01293 871217

TRAFFORD & SALFORD
Mrs T Gaynor
Davis Court
Cyprus Street, Stretford
Manchester M32 8AX
Tel: 0161 865 0222 (mornings only)

WARRINGTON & DISTRICT
Mrs S Lawless
4 Astley Close, Warrington
Cheshire WA4 6RB
Tel: 01925 573708

WESSEX
Mr T Poole
123 Gerrards Green
Beaminster, Dorset DT8 3EA
Tel: 01308 862614

WIGAN, LEIGH & DISTRICT
Mrs Pat Stridgeon
24 Greendale Crescent
Leigh WN7 2LQ
Tel: 01905 676091

WIRRAL
Mrs M Appleyard
28 Stavordale Road
Moreton
Wirral, Cheshire L46 9PR

WORCESTERSHIRE
Mrs F Bourne
20 Grafson Place, Droitwich
Worcestershire WR9 8NQ
Tel: 01905 776809

YORKSHIRE NORTH
Miss Faith Seward MBE BA
45 The Paddock, York YO2 6AW
Tel: 01904 798653

WALES

Llanelli
Mrs Anthea James
61 Westland Close
Loughor, Swansea SA4 2JT

Mid Wales
Mrs J Carter
1 Meadow Road, Craven Arms
Shropshire SY7 9QY

North Wales
Mrs L D Morris
Penrhyn Arms
Pendre Road, Penrhynside
Llandudno LL30 3BY

South Wales
Mrs Brenda Sharp
4 Lakeside, Barry
S Glamorgan CF6 8SS
Tel: 01446 735714

NORTHERN IRELAND
Mr J Rippey
Long Eaves
24 Tulleywiggan Road
Cookstown, Co Tyrone
Tel: 0164 87 62290

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde
Mr John Dewhurst
40 Edmonton Place
Bispham, Blackpool FY2 0VT
Tel: 01253 592807

Cannock & Walsall
Mr Ken Hall
17 Wallhouse Street
Cannock, Staffs
Tel: 0154 35 4847

Chesterfield
Mrs K Tomlinson
23 Hathern Close
Birmington Common
Chesterfield, Derbys

Cornwall
Helen Youngman
26 Penalverne Avenue
Penzance, Cornwall TR18 2RL
Tel: 01736 51962

East Anglia
Mrs Sylvia Frost
97 Gaywood Road
King's Lynn, Norfolk PE30 2PU

Gainsborough & District
Mrs M Hawkes
10 Turpin Close
Gainsborough
Lincs DN21 1PA
Tel: 01427 616807

Isle of Wight
Mr D J S Sprake
Springfield, Town Lane
Chale Green, Ventnor I W
Tel: 01983 551234

Lancaster, Morcambe & District
Mrs Dyson
25 Royds Avenue
Heysham, Morcambe LA3 1PA

Nottinghamshire
Mrs W Purseglove
122 Chesterfield Road
Huthwaite, Sutton-in-Ashfield
Notts NG17 2QF

Rochdale
Mrs Anne Lawton
20 Spencer Street
Chadderton, Oldham, Lancs
Tel: 0161 6524487

Teeside
Mr J Gray
148 Lingfield Ash
Coulby, Newham
Middlesbrough, Cleveland

Whitchurch (Salop)
Mrs E Calder
Southfork
Sedgeford, Whitchurch
Salop SY13 1EX

OTHER ASSOCIATIONS

SCOTTISH SBA
Executive Officer:
Mr Andrew Wynd
190 Queensferry Road
Edinburgh EH4 2BW
Tel: 0131 332 0743

IRISH ASBAH
Ms Claire Gill
Hon Secretary
Irish ASBAH
Old Nangor Road
Clondalkin, Dublin 22
Tel: Dublin 0103531 4572326

Any local secretaries who require changes please contact LINK Editor at: ***ASBAH HOUSE, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733 555988***