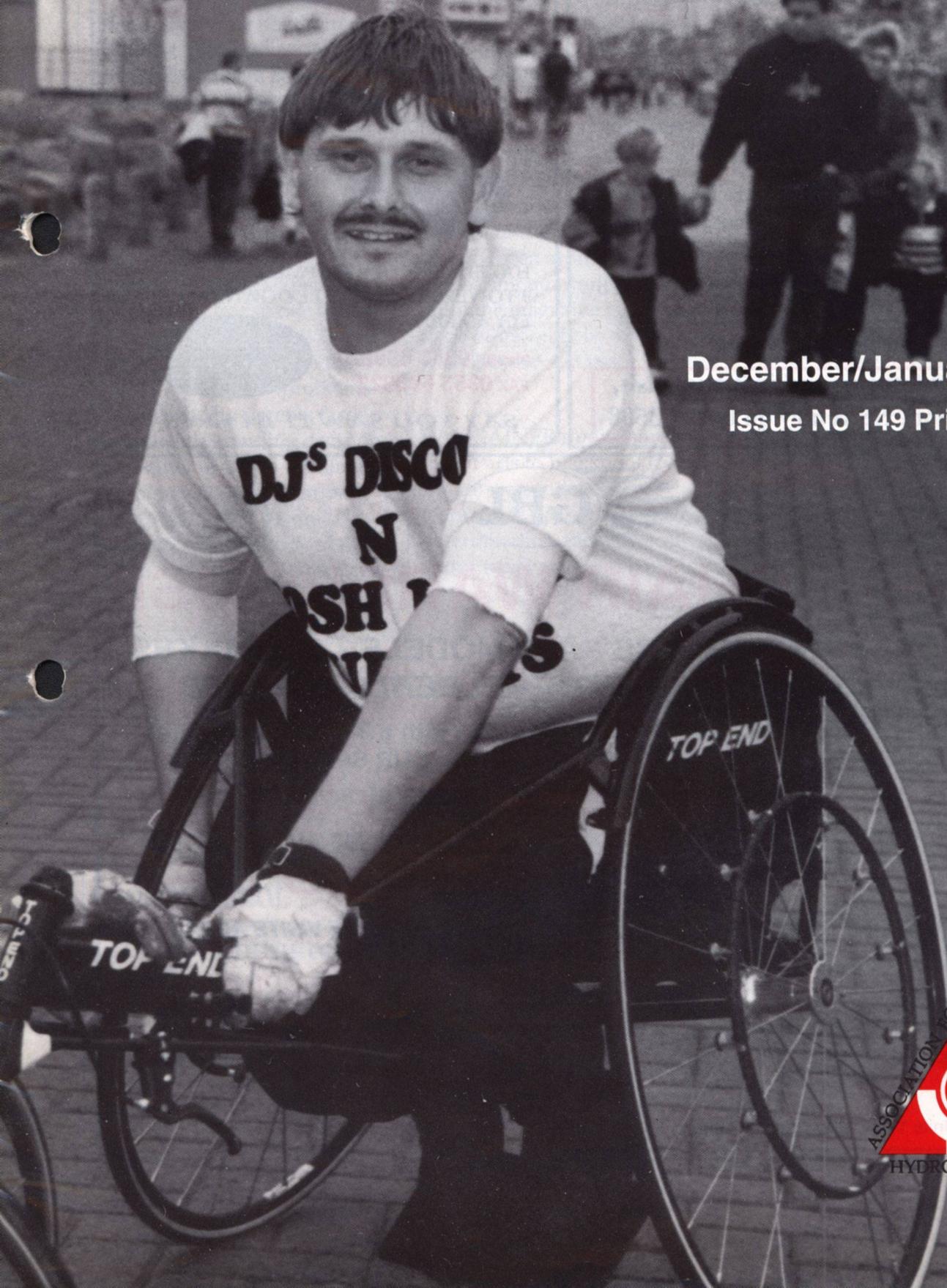


Link

The magazine for people with
Spina Bifida and/or Hydrocephalus

December/January 1994

Issue No 149 Price 80p





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Comment

AS CHRISTMAS approaches, thoughts turn inevitably to the newborn. Many of our past dreams and future hopes are bound up in our children, and there can never be a comfortable time to think about what parents go through when those hopes and dreams are cut short - when their baby dies. That there is support available and that life does, somehow, go on, is made clear in our feature on bereavement (pages 19 - 26). We have not covered, in this issue, the particular problems encountered by parents faced with the heartrending decision of whether or not to terminate a pregnancy because their baby has a particularly severe disability. We will look at the factors involved at a later date.

IT'S GOOD to be able to welcome a new publication dealing with disability issues, particularly when the first edition is as professionally put together as *Chariot* (see page 18). Although the production team are targeting a readership in the North West, nationwide interest in the venture has already been aroused. Appearing quarterly to begin with, the magazine is intended to go bi-monthly by 1995. We wish it every success.

RAY GAINER's epic journey from Paris to Blackpool (pages 14 -16) was, indeed, first featured in *Chariot*. His dogged determination and physical endurance have succeeded in

getting him in to the *Guinness Book of Records* and in raising much-needed funds for the school where he was once a pupil. Eighteen marathons in as many days - it's a terrific achievement.

A LESS encouraging note is struck by recent changes in Government legislation affecting home adaptations and access to work; and in a Home Office - sponsored study purporting to re-define the role of charities in the context of Care in the Community (pages 7 and 9). LINK will continue to keep readers informed of developments in these areas.

Jeanette Dixon

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ASBAH is a registered charity

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Front cover: Ray Gainer, triumphant at the end of his gruelling 18-day trek.

(See "Marathon Men", page 14)

ASBAH bucked the trend when overall receipts from the BBC *Children in Need* Appeal fell from £21m to £17m last year - because our applications for a share of the proceeds produced better-than-ever results on all fronts.

Our biggest grant - for £24,000 - was presented by BBC *Look East* newscaster Kim Riley to wheelchair-user Joanne Daily, from Little Downham, near Ely, at a presentation in Norwich. This money will be spent by ASBAH on grants for aids and adaptations to youngsters throughout England, Wales and Northern Ireland, and compares with grants of £18,000 and £15,000 in previous years.

ASBAH also succeeded in winning extra grants totalling £6,750 from *Children in Need* for projects based on our two regional offices, covering London and the South East and Northern Ireland.

Also pictured, from left: regional fundraiser Deirdre Pawsey, publicity manager Tony Britton and fieldwork manager Teresa Cole.

Children in Need



ASBAH Gala Concert

OUR patron, HRH The Duchess of Gloucester, meets 13-year-old Eleanor Foley after arriving at a gala concert held in aid of ASBAH at Cambridge Corn Exchange.

Eleanor presented a posy of flowers to the Duchess, who then joined us for a programme of music by Mozart, Mahler and Mendelssohn given by the English Chamber Orchestra - conducted by ASBAH president Jeffrey Tate.

Eleanor, from Alconbury Weston, near Huntingdon, is the daughter of Cambridgeshire ASBAH chairman Terry Foley and his wife Gaynor, who are also pictured.

After the concert, Her Royal Highness and Jeffrey Tate mingled with guests at a reception held in the Corn Exchange. Stephanie Gonley, youthful soloist in an exquisite performance of Mendelssohn's *Violin Concerto*, also joined the gathering.

Tony Britton

“TOO LITTLE, TOO LATE” SAYS ASBAH

ASBAH has joined forces with the National Childbirth Trust to condemn the Government's latest attempts to tell women about the link between folic acid and the risk of having a spina bifida baby.

Early in November the Government announced a leaflet and poster campaign to publicise the need for women to eat a diet rich in folic acid before becoming pregnant. These will be distributed to GP's surgeries, but the Government has no plans to take the message direct to women themselves.

Health ministers in England, Wales, Northern Ireland and Scotland announced other measures, including writing to all health professionals asking them to bring folic acid to the attention of their patients and providing details of foods rich in folic acid for display in doctors' surgeries.

Since the Medical Research Council's study linking lack of folic acid to neural tube defects,

the results of which were published two years ago, more than 4,000 pregnancies have been terminated because of these conditions, and more than 250 babies have been born with severe spinal problems. Most would have been prevented if the mothers had been eating food enriched with folates.

Since the beginning of the year ASBAH, which has no money for campaigning, has issued leaflets to almost a million women with the help of Kelloggs and Marmite.

The Government has promised a major education drive, but last week announced only a poster and leaflet campaign, centred on GP's surgeries. It has no plans for a press campaign.

“This is far too little, far too late,” said Andrew Russell, executive director of ASBAH. “Here is a marvellous opportunity to reduce dramatically the incidence of spina bifida and the Government is just throwing it away. All their

campaign amounts to is the hope that a woman will see a poster in her doctor's surgery.”

ASBAH and the NCT are mounting a press campaign to get the information about folic acid to women via women's magazines and national newspapers.

NCT director Suzanne Dobson added: “It really should not be left to voluntary organisations, with their meagre resources, to do the Government's work for them.”

The results of a survey to test women's awareness of folic acid were published in *The Lancet* last month. Of 613 women making their first visit to an antenatal clinic at Leeds General Infirmary, only 15 (2.4%) had increased the folic acid in their diet before conception.

“If this sample represents pregnant women in UK, and perhaps elsewhere, a major programme of education for professionals and the general public is needed,” concluded the researchers.

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The high jump!



IN TERMS of sheer nerve, an 81-year-old daredevil widow led the way during ASBAH's National Parachute Jump in September.

"It was one of those things I've always wanted to do," said Mrs Salome Hicks, who leapt out of a plane at 11,000 feet over an airfield at Honiton, Devon.

"I wrote to Jimmy Savile when I was 75, asking him to fix it for me to do my first parachute jump, but I heard nothing from him. He must have thought I was too old. Then, quite by chance, I saw an article asking for volunteers to be sponsored for charity in my local paper.

"It was a life's dream come true. I couldn't miss the chance and, although my GP was unwilling to sign the medical certificate, I eventually got clearance from the

British Parachute Association for a tandem parachute jump."

Mrs Hicks, who lives at Tedburn St Mary, near Exeter, did a freefall for the first 5000ft of descent strapped to an instructor before the parachute billowed out. "I don't like the wind in my face normally, but this time I was prepared to grin and bear it."

Over 100 people were sponsored to jump for ASBAH and The Children's Society using parachute centres across England in August - but bad weather forced the postponement of many jumps.

Organiser John Rogers is laying plans for next year's National Parachute Jump to take place for the same two charities on 17 and 18 September - the closest weekend to the anniversary of the Battle of Arnhem, when thousands of Allied parachutists and gliderborne troops landed in Holland.

In 1994, he intends to involve many more people who want the thrill of a first parachute jump at up to 23 parachute training centres.

If you are interested in taking part, or know a friend who might be tempted, contact: John Rogers, 10 South Close, Alverstoke, Gosport, Hants PO12 2PS. Tel: 0705-523740.

• PLAYTIME •

The Handicapped Adventure Playground Association is a national charity which promotes play opportunities for disabled children and children with special needs. It runs five adventure playgrounds in London and has a National Information Service.

The HAPA Journal is published three times a year and includes articles on play and disability issues, suggestions for activities, news of other organisations and projects and relevant publications and events.

Also available is a 13-minute video featuring the summer playschemes at two of the HAPA playgrounds. This introduction to HAPA's playwork for disabled children could be useful for groups setting up similar projects or for teaching purposes.

The Information Officer, HAPA National Information Service, Fulham Palace, Bishop's Avenue, LONDON SW6 6EA. National Information Line: 071 731 1435 voice/minicom

PLANET (Play Leisure Advice Network) is a national information resource on play, leisure and recreation for children, young people and adults with disabilities. The project is a partnership between Mencap, Save the Children and The Spastics Society.

Its resource centre in Hertfordshire offers a display of equipment, reference libraries of books and videos, together with viewing facilities, a multisensory room and a small shop. For those unable to travel to the centre, Planet offers an "outreach" service, travelling to any part of the country to make their information and ideas accessible to a wider audience. There is also a programme of open days for consumers, parents and professionals.

Mrs Jayne Gillard, Project Administrator, PLANET c/o Harperbury, Harper Lane, Radlett Herts WD7 9HQ. Tel: 0923 854861 ext 4384

Charities challenge advice to government

A CONSTRUCTIVE debate on the efficiency and effectiveness of the voluntary sector is to be welcomed in the changed, and still changing, economic climate. But the recently published Centris report (sponsored by, among others, the Home Office at a cost of £175,000) has been widely condemned as seriously flawed by academics and charities alike. Nicholas Hinton, Save the Children director, called it 'privatisation by any other name'.

The main recommendation of the study entitled, *Voluntary Action*, is that charities should be split arbitrarily into two groups - those delivering services and those with campaigning roles.

The not-for-profit service deliverers should aim to survive on winning government contracts to supply the services, and be rewarded by tax breaks for exceeding 'agreed' performance

targets (similar to the system currently followed in France).

The campaigners - the 'real' voluntary sector, according to the report - should lose their charitable status and depend on their ability to generate donations, thereby keeping their independent voice.

Andrew Russell, ASBAH Executive Director, said the report showed a dangerous misunderstanding of the work of many charities. ASBAH, for instance, was a service which had received no government funding for some years but had been able gradually to expand its services, yet we keep the freedom to set our own agenda.

"The report now suggests that service-providing charities must become more like the statutory sector, lose our charitable status and work through contracts to other people's agendas," said Mr Russell.

"This ill-thought out drive to force different types of organisations into a mould defined by government will, if pursued, result in a loss of the valuable voluntary efforts of able individuals, and the loss of services and equipment to disabled people."

It would be better, he suggested, to preserve the tax exemption of charities and to require service-driven charities to raise part of their funds from voluntary donations rather than contracts.

The author of the report, Barry Knight, describes his work as a "personal vision designed to stimulate debate". And a spokesman from the Research and Planning Unit at the Home Office commented: "The report does not have any official status."

Whatever happens, ASBAH will continue to speak out on behalf of our members and those we serve.

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: (081) 449 0475
Regional Co-ordinator: Gina Broughton.

Northern Ireland

73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (0265) 51522
Regional Co-ordinator: Meta Harvey.

Rest of England and Wales

National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (0733) 555988

Medic Alert

Advertisements for emergency bracelets appear from time to time in the press and it is true that, in an accident or other situation where a patient is unable to communicate, they can alert the medical professionals caring for you to a hidden condition such as hydrocephalus or epilepsy or an allergy, for example to adrenalin or penicillin.

The Medic Alert Foundation was founded in America in 1956 by Dr M Collins after his daughter almost died from a reaction to a sensitivity test for tetanus antitoxin. The Foundation is now international with affiliates established in 22 countries; over three million people worldwide are members.

A registered charity, it is the only internationally recognised medical identification system that has to be endorsed by doctors - one section of the application form has to be completed by your GP. The bare facts are engraved in a few words on a bracelet or pendant, further details are stored on computer. In



an emergency, doctors or other medical professionals can access this information by making a telephone call.

The cost, which includes lifelong membership of the Foundation, ranges from £30 for a stainless steel bracelet to £260 for a solid 9ct gold neck pendant. Members can update their computer record at any time.

Medic Alert, 12 Bridge Wharf, 156 Caledonian Road, LONDON N1 9UU. Tel: 071 833 3034.

Switching on to books



Dame Catherine Cookson, who has been voted 'Author of the year 1993' by members of the National Listening Library.

Illness, accident or disability, whether temporary or long-term, can tend to isolate a person from the mainstream of life. It's easy for boredom and loneliness to set in. Talking books offer hours of entertainment and pleasure to those who find a conventional book inappropriate.

For a small annual fee, National Listening Library supplies both a suitable tape player and an unlimited supply of unabridged talking books. Postage (both ways) is free and the membership costs just £25.

The current range of titles runs to more than 3,000, covering not only classical and popular fiction but also biographies, archaeology, history, politics, country life and sport; foreign language books are also available.

The books are recorded by professional readers who include many well-known actors. Recently, Derek Nimmo read his autobiography *As the Actress said to the Bishop*.

The tape players are specially designed to be very easy to use and the tapes themselves are on long-playing cassettes, capable of playing for up to a maximum of 12 hours, to avoid constant tape-changing.

National Listening Library has members all over the country, some in their own homes, others in hospitals, residential and care homes, and special schools. On joining, each member receives a comprehensive catalogue of all the talking book titles, with the name of the reader and a brief description of each book. Members are also kept in touch with the organisation by receiving an annual report and an illustrated newsletter.

For more information: National Listening Library, 12 Lant Street, LONDON SE1 1QH (Tel: 071 407 9417)

The beginning of the end for DFGs?

NEW upper limits for the payment of Disabled Facilities Grants will come into force in England and Wales early next year. In England, the limit for mandatory grants will fall from £50,000 to £20,000; in Wales, the figure will be £24,000.

The new maximum rates for mandatory grants will come into force on 14 January and be better targeted, Housing Minister Sir George Young announced in reply to a written Parliamentary Question in November.

People most affected will be the most severely disabled requiring substantial alterations and additions to their property.

Mike Ellison, policy and monitoring officer for Care and Repair, the charity which co-ordinates voluntary work aimed at helping the elderly, disabled and low-income people to stay in their own homes, commented: "Although the announcement does not confirm our worst fears about the future of DFGs, it could turn out to be the beginning of the end. The minister, in carrying out his review of short-term options, has also announced that there will be no change - for the moment - in exchequer subsidy or the test of applicants' resources.

"The key phrase is 'for the moment'. There is the distinct possibility that conditions will worsen further in the future."

ASBAH has joined a group of nine voluntary organisations which have already condemned a consultation paper on the subject produced by the Department of Environment. This warned of a possible Government cash-squeeze on Disabled Facilities Grants.

The cash squeeze could, in the longer-term, lead to local authorities being given complete discretion in the awarding of DFGs and having the freedom to run their own means tests, delaying applications from a maximum six months to two or three years, cutting mandatory grants further or abolishing DFGs altogether.

■ In order to help campaign against further deterioration, RADAR is compiling case histories of people who have applied - successfully or unsuccessfully - for Disabled Facilities Grants. People featured must be prepared to talk to the media and be photographed/filmed as part of a campaign against the cuts.

Families who can help are asked to contact ASBAH assistant fieldwork manager Mary Malcolm, who will then pass details over to RADAR.

DON'T THROW OUT UNWANTED TRADING STAMPS, PETROL VOUCHERS OR OTHER COUPONS AS ASBAH CAN EXCHANGE ALL OF THEM FOR CASH OR GIFTS.

INSTEAD, PLEASE POP THEM IN AN ENVELOPE AND SEND TO: JOHN ROGERS, c/o ASBAH SHOP, 22 WEST STREET, PORTCHESTER, HANTS. WE CAN MAKE GOOD USE OF THEM.

ACCESS TO WORK

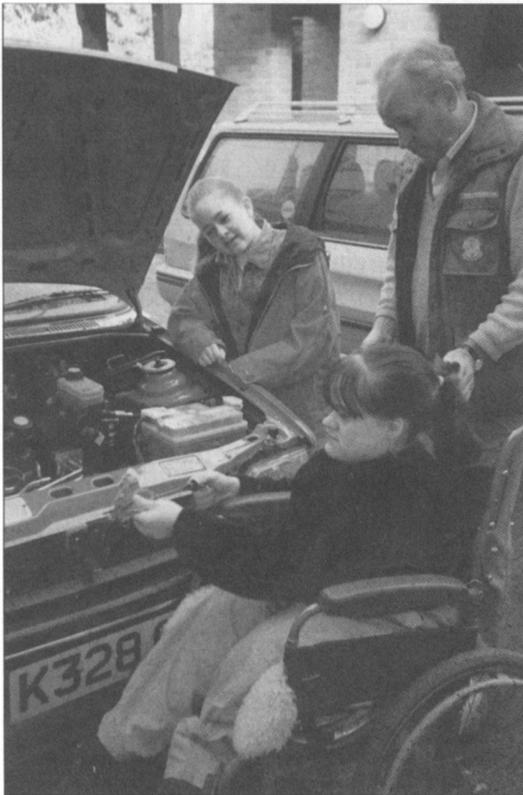
We are still awaiting details of the Department of Employment's Access to Work scheme, due to come into effect from April 1994 (*No, minister!* LINK August/September). All that is clear so far is that employers will be assumed to pay half the costs of assistance, such as adaptations to premises and equipment, for disabled workers who have been with them for more than six months. Grants will no longer be provided for "small" items (under £100) and a maximum expenditure ceiling will be introduced for each disabled worker over a five year period.

There is no convincing evidence that employers will be prepared to pay extra money to retain disabled staff. Few employers are prepared to admit that they will not help disabled workers, but the reality of the situation is very different.

The official unemployment rate for disabled people is 19%, with an enormous pool of "hidden" unemployment. Rather than penalising disabled people by cutting Access to Work, the Government should be helping them into work and off state benefits.

Employment Secretary David Hunt has so far failed to respond to the general outcry his proposals have prompted from many organisations representing disabled people, including ASBAH.

A further government announcement is expected at the end of December. RADAR are urging organisations and individuals to write to their own MP at the House of Commons, explaining how the changes will affect them. "Letter writing campaigns really do make an impact," said a spokesman. "It is vital that disabled people make their voices heard as soon as possible."



Driving Courses



Elaine Featherstone gets to grips with checking the oil, under the watchful eye of Bill Platt (far left). Michael Harrison ready for the off in the driving seat (left).

A VERY successful and enjoyable driving course was held at Five Oaks, ASBAH's residential centre in Ilkley at the end of September. It was structured so that each member of the course had two driving lessons per day, as well as classroom instruction on topics concerning the Highway Code, the financial and legal aspects of driving and the more relaxing side, such as belonging to a club. John and Helen Robinson, from Newcastle, spent an evening chatting with the young people and explaining the benefits of becoming members of the Disabled Driving Association.

The first two days of the course were spent at the Army Apprentices' Barracks near Harrogate. The parade ground, which is vast, is made available in order to practise starting the car, moving off, stopping (very important!) and manoeuvring around cones. This was done in complete safety and helped to provide the confidence towards the next step, which is driving on

the open road. ASBAH is most fortunate to have the services of two expert and dedicated instructors, Denis Sutcliffe and Malcolm Kleiman, who have cars well adapted for use by people with disabilities; they also have dual control, which is essential.

John Naudé, ASBAH's Mobility Officer, joined the young people for a day to demonstrate to those who used wheelchairs ways of loading the chairs into the car and also assisting them to make safe transfers. There was then opportunity for the students to practise, because this is an important aspect of becoming mobile and independent on the road. Bill Platt, from Five Oaks,

worked with the students throughout the week helping to increase their knowledge and independence by involving them in some under-the-bonnet maintenance, eg where to look for the dipstick, windscreen washer bottle, etc.

There was time for relaxing and forming new friendships which, one hopes, will continue beyond the course. On the final evening, a visit to a local restaurant proved a very happy way of rounding off a week of hard work and achievement.

ASBAH would like to thank both Provident Financial of Bradford, who financed all the driving tuition, and Ford Motor Company.

AT A RECENT ceremony at the Guildhall the new Lord Mayor of London, Alderman Paul Newall, gave his backing to the "Safety and Convenience" campaign on London's 5,000 buses.



Commenting on the bright new messages to be seen both on buses and at various sites throughout London, he said: "If we are all aware how accidents occur on public transport, then it will make it easier for us to adopt a safer way of travelling on buses."

All signs will be closely monitored over the coming months to ensure that the campaign is effective.

on the move ● on the move ● on the move ● on the move ●

A WHEELCHAIR athlete's plans to make it into the sporting big time could be dashed - because he will soon be unable to afford to travel to training sessions and contests.

Since obtaining the car - an 'L'-reg Vauxhall Astra - in August, he has run up so much mileage that he is in danger of exhausting his annual allowance of 12,000 'free' miles. In just three months, he clocked up over 8,000 miles.

Mark (29), who appeared on the front cover of *LINK* in April, finds the car eats up the miles while travelling round the country to qualify and compete at the highest possible levels.

He is a regular visitor to training sessions at Stoke Mandeville and Leicester and, on 8 January, hopes to motor to Bristol to see if he can

Mark wants to keep motoring

qualify for the weightlifting world championships which take place in Australia next spring.

Motability starts charging for mileage used once their disabled-motorist customers exceed set annual allowances. Mark - who has spina bifida and hydrocephalus - has already written to Motability to see if they will extend his quote of 'free' miles, but he is not hopeful that the charity will consider him as a special case.

"The Astra is a lovely car. I don't

really want to send it back but, unless something turns up soon, I won't have much option", said Mark. "I could buy myself a banger for £150, just about - but couldn't afford to repair it when it breaks down."

Lynne Young, ASBAH's fieldworker in Cornwall, has launched a local appeal to help keep Mark on the road - saying he needs £1,000 a year to meet car running costs once the mileage allowance had run out.

"If he lost the use of the car now, it would put his personal development back years. He would be devastated."

Natalie Pearse, Motability's public relations officer, said her organisation would like to be able to help but could not afford to make an exception.

TIMELY advice on the fast-growing problem of crimes against motorists - usually those travelling alone - comes in the form of a new personal safety video programme produced by Ford called *Driving Without Fear*.

The video uses reconstructions of four real-life attacks on car drivers and interviews with the actual victims involved to highlight some of the types of risk. It offers constructive guidance to motorists on how to minimise the potential dangers.

South Yorkshire Police Chief Constable Richard Wells has praised the Ford initiative. "The video programme is packed with information and I can see it having a wide influence on the motoring public - those who may be involved in accidents and breakdowns and those very few who may be involved in car crimes."

Safety concerns in various circumstances are covered, from town driving to long distance journeys, including procedures in case of motorway breakdowns. The video also emphasises the importance of planning trips

Driving without fear

carefully and of regular vehicle checks. The overall message is that by taking some basic, sensible precautions, motorists can ensure that driving remains enjoyable and safe.



Despite the spate of recent media stories with alarming headlines, serious attacks on motorists are fortunately still relatively uncommon.

"The time when we really have to worry is when they don't make headlines. That means they've become to commonplace to be news", says Diana Lamplugh, whose daughter - an estate agent - disappeared after being called out to visit a property.

A detailed information leaflet accompanies the video to reinforce key messages.

Available on free loan to groups and clubs from the Ford Video Library or may be purchased for £5.00 (inc VAT, P&P) from Ford Motor Company Ltd., Broadcast Services, Room 1/455, Eagle Way, Brentwood, Essex CM13 3BW.

Golfing boost for funds

Our Carolyn Smith Memorial Fund received a healthy boost when her mother Pat and brother Tim came into the national centre at Peterborough bringing cheques totalling £650.

Of this, £550 was raised by Tim, a presenter with BBC Radio 5, when he organised a benefit golf tournament at Telford. Pat raised the other £100 through car boot sales.

Carolyn - remembered as a vivacious, friendly colleague - had been married for a few months only when she died suddenly in September 1991 at the age of 28. She first joined ASBAH as accommodation officer in June 1986, leaving in July 1989 to return to college. She rejoined for a short while as a fieldworker until her marriage.

At the request of her family, a fund was set up in her memory to be



used to help young people with spina bifida and hydrocephalus achieve independent accommodation. The first donations were made by family and friends in place of flowers at Carolyn's funeral, and some extra money has been received since then.

Because the fund is limited in size, use so far has been restricted to

residents in ASBAH housing schemes. Typical payments so far have been from £50 to £250, to help purchase equipment or minor adaptations.

Pictured, from the left: Pat and Tim Smith, and two of Carolyn's former colleagues - fieldwork manager Teresa Cole and disabled living services manager Rachel Stanworth.

Good news from Kent

PLANS for a £420,000 housing scheme in the Medway area for young people with spina bifida and/or hydrocephalus have been kickstarted by Kent ASBAH - which now has almost a fifth of the money needed.

Donations totalling over £71,000 have been banked since the scheme was mooted about a year ago. Discussions are under way about possible sites in Gillingham, and Sanctuary Housing Association has put in a bid for the rest to the government-funded Housing Corporation.

If the bid is successful, project chairman Sue Patten says the aim is for building work on the 10-bed sit scheme to start next April and for it to be up and running in 1995.

The scheme will provide 10 individual bedsitting rooms with en-suite facilities and communal rooms, on level ground close to the town centre and public transport. Gillingham Borough Council have drawn the partners' attention to a number of sites in its area, but sites in other Medway towns are not ruled out.

Sue Patten said Medway had been chosen because a large number of Kent ASBAH families lived in the area. Also, very few of their 139 young people aged 16 and over were known to be living independently.

It is hoped that most residents will spend a year or two living in the scheme as a "stepping stone" towards independence. Training and guidance in daily living skills will be given by full-time staff and volunteers.

Lady Swinfen, president of Kent ASBAH, hosted an official launch at the beginning of October. The local Association has made great efforts to identify new money for the project so as not to erode the fundraising base for existing activities.



Hydrocephalus Network News

Acquiring Hydrocephalus as an adult

The next issue of Hydrocephalus Network News will be distributed with the February/March edition of LINK. But here is an update of what is happening.

This study day, held in late November at ASBAH House, proved both enjoyable and informative for those who attended. A range of issues was explored. Bernard Williams, a Consultant Neurosurgeon, explained the medical facts about Hydrocephalus and, after Rachel Stanworth (DLS Manager, ASBAH) had discussed the differences and similarities between those who acquire hydrocephalus later in life and

children who have the condition at birth, there was a break for lunch. In the afternoon, Jackie King's "personal view" of hydrocephalus provided much that people could identify with; Mary Malcolm (Assistant Fieldwork Manager, ASBAH) gave a rundown on the benefits available and the day ended with an "any questions" session.

"I met so many people and found everyone so friendly and helpful."

"we attended the study day with an open mind.... to obtain an understanding of the problem, to listen and learn."

"there was a great feeling of camaraderie."

Funded by BBC Children in Need for families living in ASBAH's South East Region

Spina Bifida and Hydrocephalus study weekend.

For under 5's their parents and their siblings

Saturday 26 March 1994

Sunday 27 March 1994

The venue is likely to be in Hertfordshire. Topics covered during the study weekend will include; mobility; continence; behaviour; medical matters; education/statementing; claims and benefits.

With time for fun!!

*For further information contact
Lynn Thomas, ASBAH House, 42 Park Road,
Peterborough, PE1 2UQ. Telephone 0733 555988*

Hydrocephalus Study Day - Saturday 16 April in the Chester area.

*More details about content,
speakers and precise venue in
the next issue. But
make a diary
note now.*

ADVANCE NOTICE '94



MARATHON MEN



*Over a marathon a day for
18 days from the Eiffel Tower
to the Blackpool Tower!*

by Ray Gainer

It all started way back in August '92 when, as a member of Southport Pirates basketball team, we played a friendly against Forways in Atherton near Manchester. At the match, I met up with my mate Mike Pyke who, like myself, had been a pupil at Mere Oaks Special School. We decided that we wanted to raise money for the school, but we wanted to raise it by doing

something unique which had never been tried before and which would be a huge challenge to us both.

In 1988, Mr Steve Redford from Leigh, near Manchester - the birthplace of myself and Mike - completed the first ever attempt by an able-bodied runner to run from the Eiffel Tower in Paris to the Blackpool Tower in England.

He set a world record and it was registered in *The Guinness Book of Records*.

Steve's record inspired us to become the first-ever self-propelled wheelchair athletes to undertake this same run. We felt that this would be our way of showing that people with disabilities can compete alongside their able-bodied colleagues without any special provision being made. The only difference between Steve and ourselves was that our wheelchairs were our legs. We would require just as much stamina and determination as Steve needed, to undertake this long endurance event.

The run took Mike and I twelve months to prepare and, on August 20th 1993, our journey to Paris began. We took with us a support team which included our drivers Jack and Brian, who took the role of team manager as well; two physiotherapists Cathie from Walton Hospital and Heather from Arrowse Park Hospital; and Pauline, Mike's wife, who took the role of carer.

Our first destination was Portsmouth, where we intended to stay because it was from there that we would be sailing to Cherbourg. P & O European Ferries, who had sponsored the run, had agreed to give free passage to the entire team and all our vehicles.

By the evening of August 21st, we had reached Paris and started to get ready for the start of the run on Monday.

Our plan was to complete over 500 miles in eighteen days, to reach Blackpool on the 9th September 1993, coinciding with the 25th anniversary of the school's opening. To achieve this, we needed to complete the equivalent of a marathon per day for 18 consecutive days. It was imperative that we reach our first target of Cherbourg, 217 miles away, on the 30th August 1993 because that's when our ferry sailed.

We had the full co-operation of the Mayor of Paris, and the French police gave us the go-ahead to use the route to Cherbourg supplied to us by the RAC. This route was the N13 which is the most used dual carriageway, apart from the motorway, from Paris to Cherbourg. We only had a very small cycle track alongside the main road to push on and, at times, when the cycle track ran out, we were pushing with the traffic on the actual road itself.

Most of the time, cars and heavy transport vehicles moved to give us room. We were spotted by a travelling circus who used their CBs to inform truckers travelling between Paris and Cherbourg to look out for us and pass us with caution, which they did.

A day later, on a very good stretch of road, we found ourselves reaching speeds of about 25 miles per hour. It was at this point while going downhill, that my whole brake assembly, including my brake pads, fell off my 'new' racing chair. I had suddenly become a runaway with no brakes! Being a novice with no idea of the correct emergency procedure, I panicked. I jammed my right hand into my right rear wheel, hopefully to pull me into the side of the road and stop me toppling over. The chair did eventually stop but I got a burn on my right hand for my troubles. I was relieved that I had not received any more serious injury.

The other thing which occurred was my steering collapsed, and I seemed to get all the punctures. But after pushing up some huge hills - one being over two miles long - we arrived in Cherbourg in the afternoon of August 30th to catch our overnight ferry. (Only 286 miles to go when we reached Portsmouth Ferry Port).

We started again at around 9am pushing along the route snaking up England to Blackpool. The support crew did a great job of going ahead of us and checking the route before we arrived. They



Ray Gainer, Steve Redford and Mike Pyke finally reach Blackpool.

stopped at predetermined points at about three-mile and five-mile intervals so we could get water but more importantly for me was that I needed lots of physiotherapy on my legs because of stiffness and cramp., from being strapped into my racing chair for long periods of time, which I was not used to.

Mike seemed to cope better than I because he was an experienced racer. Though he coached me, which was really only achieved during the actual run, I suffered with blisters on my hands. I had never previously attempted any marathons and, to suddenly attempt 18 consecutive marathons, was proving too much for my hands.

September 8th was the highlight of the run, because we passed through the centre of our home town Leigh. It was here that Steve joined us to complete the final few days.

The reception we received passing through Leigh was great. The local people all came out to cheer us on. After a photocall, we continued to Mere Oaks Special School, arriving by early afternoon. We

stopped briefly to meet the Mayor and Mayoress, and were cheered on our way by the whole school.

When the final day came, it came with a vengeance. We'd had great weather for the last 217 days but it had to happen - it poured with rain. This made it very difficult for us to push, particularly coping with the hills from Charnock to Preston. Worse was to come, when we lost our support team and we took the wrong road.

It seemed ages but fortunately, after a detour, we met up with the team who were beginning to get very worried about us.

Undaunted, we carried on to the Tower where a brilliant welcome awaited. Family, friend, the press and even Jim Davidson, the comedian, were there to welcome and congratulate us.

The run, which had started at the top of the Eiffel Tower and ended at the top of Blackpool Tower, was a world record and will be entered in the Guinness Book of Records - 503 miles completed, with an average of 27.9 miles miles per day, over 18 days.

In conclusion, it was a very demanding event for both of us to complete. We pushed ourselves to the limit doing this run, but it was all worthwhile when we saw those kids' faces at the school.

Ray Gainer, who only started his newest sport Wheelchair Tennis in May of this year, became the 1993 British National Wheelchair Tennis Champion and has also just become the French Open Tennis Champion (both at his first attempts). He is also the only person with spina bifida in Europe to hold an unrestricted Private Pilot's Licence, and has also completed all flying training and pass all written examinations, but awaiting final flight tests, for the issue of a Commercial Pilot's Licence.

Mike Pyke has coached Ray in wheelchair road racing over the past 12 months in preparation for this unique Paris to Blackpool Wheelchair Run. He is an experienced and established wheelchair athlete for both road racing and track racing. Mike has completed the London Marathon on eight previous occasions and, in June of this year, regained his British national 200-metre and 400-metres wheelchair track titles, at the British Wheelchair Sports Foundation National Games held at Stoke Mandeville. He is now currently ranked number one in Britain for this major national event.

The purpose of undertaking this run was to raise money for Mere Oaks Special School in Wigan, for children who have various disabilities. The money raised is to be used to pay for special equipment and fund projects planned by the school, for the benefits of all pupils.

Donations welcome, payable to The Mere Oaks Twin Towers Account. Registered charity number 504264. Ray Gainer, tel 051 924 9742 - Mike Pyke, tel 0942 883728, after 6pm.

Events 1994

Saturday, 15 January

ASBAH Study Day 'Are there choices in adulthood for the person with spina bifida and/or hydrocephalus?', Banstead Mobility Centre, Carshalton, Surrey, 9.15am-4.30pm. Fee £6 includes ploughman's lunch. Overview - Leonie Holgate, ASBAH disabled living adviser; housing speaker - Vicky McNicol, regional appeals manager, John Grooms Association for Disabled People; employment - Mark Gilbert, Disability Employment Officer, Hampshire; mobility - John Naudé, ASBAH mobility adviser. Chances to test wheelchairs, adapted vehicles. *Jerry Crowsley, 141 York Road, Woking, Surrey GU22 7XS, tel 0483 763984, before 31 December.*

21 - 25 February

Residential Development Course, organised by Surrey ASBAH and Surrey PHAB, course for 16 young people aged between 12 and 18 with spina bifida and/or hydrocephalus, Felbury House, Holmbury St Mary, Dorking, Surrey. Cost, including full board, £250 per person. Bookings, with deposit of £50, by 15 January. *Mrs Pat Reynolds, Director of Phab Services, Surrey Phab, Felbury House, Holmbury St Mary, Dorking, Surrey RH5 6NL*

Saturday, 19 March

'The Cost of Incontinence', one-day multi-disciplinary conference organised by Derby and District ASBAH, Post Graduate Centre, City Hospital, Nottingham, 9am-4.30pm. Fee £15. *Anthea Hewitt, 20 Burley Hill, Allestree, Derby DE22 2ET, tel 0332-841893*

24 - 30 April

Intensive L-driving and road handling skills course for young people with spina bifida and /or hydrocephalus, Five Oaks Centre, Ilkley, West Yorkshire. *Sarah Peet, tel 0943-603013.*

Saturday, 11 June

"Moving into adulthood: working towards a positive experience", a conference for people with spina bifida, Nottingham. *Mary White, 0629-580297.*

17/18 June

Mobility Roadshow, King's Hall Complex, Belfast. *David Patterson, Assistant Director (Transport), Disability Action, 2 Annadale Avenue, Belfast BT7 3UR. Tel: 0232-491011.*

5 - 8 July

2nd National Congress, British Association for the Study and Prevention of Child Abuse and Neglect, theme - 'Working in Partnership'. Bristol University. *Details from BASPCAN, 10 Priory Street, York, YO1 1EZ*

18 - 24 September

L-driving and road handling skills course for young people with spina bifida and/or hydrocephalus, Five Oaks Centre, Ilkley, West Yorkshire. *Sarah Peet, tel 0943-601013.*

The User's Guide to Intermittent Catheterisation

Gillian Hunt, Robert Whitaker and Pippa Oakeshott
 BMA: Family Doctor Publications £2.50 (plus 50p p&p)
 (Bulk Orders: 10 for £20; 25 for £47.50; >25 £1.85 each)

Intermittent catheterisation means passing a narrow tube into your bladder to empty out all the urine several times a day. This puts the bladder under your control, helps to keep you dry and safeguards the kidneys.

It is well worth trying intermittent catheterisation. Unlike an operation, nothing permanent is done so it can always be discontinued if no longer needed. If successful, the benefits may be enormous.

Intermittent catheterisation has transformed the lives of people who have bladder problems associated with spina bifida, spinal injuries or disease, prolapsed disc, multiple sclerosis or diabetes as well as in other conditions in which there has been difficulty in emptying the bladder.

Drawing on 18 years' practical experience, the authors have written the first authoritative book on the subject. Extremely clear and useful, it describes the methods and discusses the difficulties and how to overcome them. Each section is clearly illustrated.

Gillian Hunt MB BChir and Robert Whitaker MD FRCS work in the Urology Department at Addenbrooke's Hospital, Cambridge. Pippa Oakeshott MRCP MRCGP lectures in General Practice and Primary Care at St George's Hospital Medical School in London.

Family Doctor Publications Ltd., PO Box 118, LONDON WC2N 5BG.



Gene therapy week

One of the issues to emerge from Gene Therapy Week (15 - 19 November) was the worry expressed by patients, researchers and doctors that treatment for genetic conditions might be threatened by the patenting of human genes.

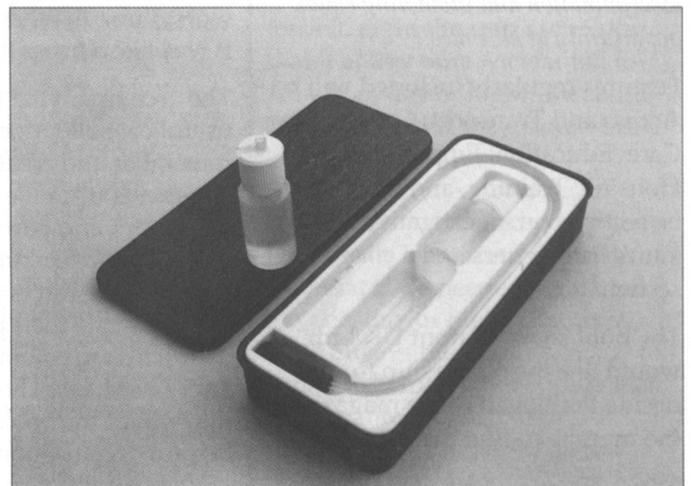
Ann Hunt, Chair of the Genetic Interest Group (an umbrella group of voluntary organisations concerned with genetic disorders) gave voice to the widespread concern: "The gene is a basic part of the human body. Quite apart from the ethical and moral objections that we have to the notion of anyone being allowed to own rights over something which is a fundamental part of all of us, we are also very concerned that this trend to patenting will slow down or even stop the development of gene therapy."

The general consensus was that human genes should be excluded from patentability and that commercial interests should not be allowed to over-ride the wishes of patients and those who support them.

PRODUCT NEWS

Beambridge Medical have come up with a new product which they feel could benefit users of intermittent catheters.

Their "Bridge Catheter Case" (recommended price £7.99) offers the advantage of carrying out the procedure of intermittent self catheterisation without the need to locate a wash hand basin. The manufacturers claim that it solves storage problems for those using the same catheter for more than one procedure; it can also double as a soak tray which will allow the catheter to be immersed in water before use.



Further information: Steven Mochrie, Beambridge Medical, 17 Findlay Drive, Keens Lane, Guildford, Surrey GU3 3HT. Tel: 0483- 234393



A new magazine dealing with disability issues has been launched in the North West.

It has three main objectives. In the words of its editor, Christine Pickthall:

The first is to offer to the disabled community throughout the North West, an opportunity to come together to share our problems and express our concerns about the everyday frustrations, hopes and successes of living with a disability.

The second is to show by example that although we are all members of a distinct group that we are, first and foremost, individual and that our experiences are personal and individual to us.

Thirdly, that we use CHARIOT as a voice to express our shared common experiences thus raising levels of awareness, drawing attention to discrimination and promoting equal opportunity at all times.

Features regularly included will be Access and Transport; Community Care; Education; Employment; Housing; Training, and there will be sections on investigative journalism, letters and a classified section.

The publishers, Output UK Ltd., would like the readership to decide the slogan of the magazine (no more than five words).

To receive your first copy telephone FREEPHONE 0800 318958

When Our Baby Died.

A video about grief for parents and families.

Grieving after the death of your baby. *Accompanying book.*

Video: £14.99; Book: £5.00. P&P: £2.50

*Professional Care Productions Ltd.,
1 Millside, Riversdale, Bourne End, Bucks SL8 5EB.*

REVIEW

Of all deaths, the death of a baby is especially hard to accept: parents often feel overwhelmed by grief and very isolated and this extremely sensitive video seeks to help them feel less alone and to understand more about their feelings. A number of couples of different social and ethnic backgrounds talk about their experience of loss, how it affected their relationship with each other, while the feelings of surviving siblings and grandparents are also explored. One little girl, who was six when her brother died, illustrated how responsible young children can feel for events they don't understand: "The worst feeling was really me because I'd actually felt it was me who'd made Ricky die. When I'd actually kissed him, his heart started disappearing."

The reasons for the loss vary - the couple may have had a miscarriage or terminated a pregnancy because of abnormality; their baby may have been stillborn or have died soon after birth; or the death may have come later - a cot death or as a result of illness or accident. One mother of twins speaks movingly of her difficulty in mourning her lost son while his brother lives - feeling she can never be totally happy or completely end her grieving - and of the support she found in meeting other bereaved parents and exploring her loss with them.

Inevitably, this is a moving video but it is also positive in that it enables couples to share how they have coped and, it is hoped, help someone else to come to terms with their own loss. The construction of the video allows it to be shown in short sections without losing sight of the overall theme and for this reason it could be extremely useful for the training of professionals. It ends with the telephone numbers of several relevant organisations who may be contacted for further support. This seems highly appropriate, given that some viewers may find the memories evoked by the film extremely painful. As one father says: "It was the worst thing that happened in my life. I actually felt the pain in my heart. It was like a lump that you couldn't get away."

The accompanying booklet could be read in isolation but it is a very useful consolidation of the film with a very sensitive section on how to remember and create a memorial for the lost baby, interspersed with comments from the featured parents. It is acknowledged that grieving is hard work and parents are urged to "care for yourself" through a series of basic exercises and relaxation techniques while the pages on children and grief are full of simple ideas for helping even quite young children to communicate their pain. For example, an outline of the body with the instruction to colour in the parts where you feel sad-blue; scared - black; angry - red, etc. There is a list of appropriate story book for children at the back of the booklet along with contact addresses for a number of helpful organisations.

The standard of presentation of both video and booklet is extremely high and both will be of great value to professionals, bereaved parents and their relatives.

Remembering

Jason

by Joanne &
Jeremy Banks

THROUGHOUT our time on SCBU the staff were magnificent in their support. They gave us comfort through our tears, spent time talking our worst fears through and created a 'family' environment which Jeremy was made to feel a vital part of as the father of Jason. Without their support we would have been so lonely and lost in our distress, so abandoned. They gave me time alone but I always knew that they were there and Jeremy was assured he could ring anytime during the night to check on Jason if he wanted to or even sleep in the unit to be near his son.

We were asked if we would like Jason christened and we said we would but at the time he was doing quite well so it didn't seem an urgent requirement. We now regret we didn't have him christened when he was better, he would have had a proper ceremony instead of hasty baptism minutes before he died.

I really don't think there can be anything more horrifying than to have your own baby breathe his last breath in your arms. Fortunately the sister in charge that night rang us in time for us to get to him before he died. It had been my first day home.

We were surrounded by the nurses who had cared for him and the doctor, all giving their support and sympathy which helped us enormously and also made us feel that our little mite was important to them too, that he had been genuinely loved by others as well

as by his mummy and daddy. It meant a great deal to us that the nurses were able to shed tears with us, that as the care givers they didn't need a stiff upper lip or some kind of professional stoicism. It helped us both to let our own feelings go in that most harrowing of moments.

One of the nurses baptised Jason as I held him. We weren't regular church goers but it was vital to us that he had this baptism. I am so glad that the nurses remembered it as it was the last thing on my mind at that time.

Time alone

After Jason had died the sister in charge gently suggested we might like to take Jason into one of the rooms where we could be alone with him. I was hesitant about this, I wasn't sure if it was the right thing to do, whilst deep in my heart I just didn't want to let him go. Fortunately they had the experience to know that this would be a good idea for us and we were encouraged to spend some time alone with him. This time we spent alone with our baby was one of the most important and precious times for us. At last that awful feeding tube was removed, at last the oxygen mask wasn't needed, at last I could cuddle, kiss, and hold my baby with no tubes or monitors, no worries of anything further happening to him. He was

released from his misery and I could carry him out of the hot nursery, my baby and me together at last.

Jeremy and I grieved so deeply for our little boy, we took photos and felt we didn't want to let him go but the cooler he became the more we were able to accept that he had truly left us. The staff checked on us about every twenty minutes, respecting our privacy but also showing us that they were still there supporting us. Eventually they came to bath and change his clothes and asked me if I would like to do it. I decided I wanted to do everything I could for him. I had never bathed him, I wanted this one chance, he was my baby, I would care for him until the end. After I'd bathed him the nurses offered us a lovely white robe to dress him in. He looked so serene and peaceful, as if asleep, in his cot.

Before we left the SCBU that terrible night the staff assured us that if at any time we wanted to see Jason, day or night, we could come down and they would bring him to us, that was very reassuring, it meant we didn't have to feel we'd said goodbye to him for the last time. They also said that if we needed to talk to anyone, day or night, that they were always there for us, ready to listen, to help, either by 'phone or if we wanted to visit. Our important connection with the SCBU did not end after Jason had died, their support continued and we were especially touched when so many nurses came to Jason's

funeral. We have since been back to visit Jason's 'home' on Special Care and had home visits from the unit's bereavement counsellor.

After Jason's Death

The desolation we felt after our baby had died was without measure. How can the taking of so young and fragile a life possibly be justified? Grief is a strange and powerful animal and its full force was upon us, throwing up its terrible mix of emotions: shock, misery, anger, resentment, guilt, desperation, confusion. We desperately needed someone experienced to listen to all these feelings, this was where the hospital's bereavement counsellor was our saviour.

Family and friends provided plenty of sympathy but they had no real idea of quite what we were going through. Family were almost too involved to help and friends, once over their own shock, would underestimate the extent of ours. We needed to talk to someone who we trusted, whose support was totally consistent, who understood all the emotions we talked about, however strange some of them may have seemed to us. A counsellor, by not being family or friend, was someone to whom we could say exactly what we liked without wondering what she may think. We were able to be totally honest with Jenni and ourselves - something which we learnt is so important to working through grief, something often difficult to do with a friend. For instance I was able to tell her how much I resented my friends who had babies, how badly I wanted to dig up my baby's coffin and hold him again. I could cry endless tears without fearing any embarrassment from her, without fear of platitudes, knowing that at the end of it she would explain the good I had done myself, the positive side of the 'griefwork' I was doing. We could also smile and laugh with her, knowing she understood. We were still suffering terribly - where a friend

may have thought, 'they're smiling, they must be over it now'.

The counselling sessions were carried out in our own home which helped us. They were landmarks that we worked towards. By the time we reached them I had plenty to say and much emotion to pour out. Jeremy would sometimes think he could cope without being there as being busy in the office kept his mind away from his grief. Afterwards he would be amazed at how much he had indeed needed to share. Jeremy and I also learnt much from each other at this time. We would both reveal thoughts and emotions that for some reason we hadn't actually discussed between us. It helped us to understand each other better and to bring us closer together in our grief.

Finding our feelings

After every counselling session we felt we had learnt so much about ourselves and what we were going through. Jenni listened to everything we had to say and helped us to identify for ourselves the underlying feelings that may have been hidden by the confusion of grief. She didn't push ideas on us, or tell us how we felt. She helped us towards our own conclusions, finding our own feelings, so that in the end we were actually helping ourselves. This was so important to us, it helped us to get through when she wasn't there, helped us to realise that we were grieving through our own hard work and that in the end we would be able to survive.

Some of the most valuable things we learnt at this time were that nothing we felt or thought, however bad, was wrong. We needed to know this. When we felt so bad that we thought we were going out of our minds with grief we were comforted to learn that this feeling was normal and allowed. The extent of the fear was then subsequently lessened. We learnt we could expect to have some bad days again and need not

fight against them. So much of this time was concerned with the 'letting go' of our baby. We were guided, for instance, over the difficult and painful task of putting away the cot and the baby clothes. We were pleased to learn that there was no right time to do this, we had to do it in our own time, whatever felt right for us.

There were so many occasions, because we had lost a child, that triggered further grief. Our own birthdays missing the cards we would have had from our son; Christmas where everyone had their families around them; Mother's day and me a mother without her baby; and ultimately of course the anniversary of Jason's birth and death. We found we wanted counselling support through all such events, especially Jason's anniversary when I was horrified to find myself feeling so bad that I feared. I had made no progress at all over the year. My parents sent us some flowers but there were no cards from what would have been Jason's friends, no birthday party, it was as if to others he had never existed and I was heart broken all over again. The best thing that happened that day was a card from the SCBU which the nurses had signed, we were so touched that they had remembered him, our little boy.

A new life

When I became pregnant again with our second child we were frightened that counselling would end; fortunately this was not the case. Knowing that there was another life inside me only further confirmed that Jason was really gone, I had to accept this would be a new life, a different life, that Jason would not be coming back. I kept thinking back to the last pregnancy and how I felt. We were so glad that we had decided that it would be unwise for me to get pregnant again at the same time of year as last time. The pregnancy would have been so much harder and having a new baby around Jason's anniversary would have



The authors, Joanne and Jeremy Banks with their new daughter Francesca.

been unbearable for us and totally unfair to Jason.

As it was this new pregnancy was filled with enough worries for us to work through: would this baby have the same problems as Jason, would it have a different problem, would it live? As the pregnancy progressed and numerous scans proved normal we began to accept more and more that indeed we would be having a healthy baby and that it wouldn't be Jason, that it could never be Jason. This was something we continued to cover in our counselling sessions which were now about every six weeks.

When our second baby, Francesca, was born healthy and normal Jeremy and I were over the moon but we had no idea how terrible would be the rekindling of grief over Jason. We felt relieved that our new baby was a girl because she looked exactly like her brother and though devoted to her we were torn apart longing for our dead baby. Why oh why had he been denied life when she was alive and kicking? How could it have happened? Why wasn't Jason with us too? Again we desperately needed to talk our emotions through with someone who would

listen and understand. It was vital to me that the feelings of guilt I had about being low and depressed after such a happy event were accepted.

Again we were assured that we were behaving quite normally by feeling desperate and sad after what we had been through. We were able finally to understand that only now as our second child was born could we 'let go' some more of our grief for our first baby. Now that we had a baby to keep, to hold, to nurture, only now did we know the full extent of what we had lost.

Support for parents

When a new baby dies the way parents are emotionally cared for will affect them deeply. JENNI THOMAS, a bereavement counsellor, writes about her work.



"And can it be that in a world so full and busy, the loss of one weak creature makes a void in any heart, so wide and deep that nothing but the width and depth of vast eternity can fill it up!"

Charles Dickens (Dombey and Son)

On the Special Care Unit at Wycombe General Hospital, parents can live near their babies and be involved in all aspects of their care. Sadly this can include their baby's death. Those parents have taught us that they and their families need a great deal of time and help in saying "Goodbye". The way these parents are helped to approach their baby's death will affect their mental well-being in years to come. They are facing one of life's greatest traumas, and the

effects can be devastating. We have also learnt that our support may need to continue long after the baby's death.

How can neonatal staff best offer this kind of support? And how can staff themselves be helped to deal with their own feelings when a baby dies?

One of the ways Wycombe Hospital has chosen to help bereaved parents and the staff who work with them is by employing a

bereavement counsellor. This is the work I do. I was appointed to this counselling position in 1986.

The care givers

While much of my time is spent with bereaved parents, often in their homes, I am increasingly involved in supporting and training staff in the counselling skills they need when working with families of babies who die. I offer guidance on the practical things that staff may do in helping parents to get to know their baby.

Perhaps even more importantly, I encourage the doctors and nurses to draw on their own self awareness, and develop their existing counselling skills. I see my role as enabling them to use these skills by sharing with them what parents have told me helped or hurt them in hospital. It is important not to lose sight of the fact that the staff who nurse the baby are the people the parents turn to for emotional support.

Our feelings

The death of a baby is one of the most painful experiences any parent can suffer. It is also painful for us, the staff, to come close to these parents and to witness their grief. If this work is to be done well it cannot be done from an emotional distance.

To help the staff to deal with both the emotional and the practical side of caring for bereaved parents, I have recently written a book, *Supporting Parents When a Baby Dies*. The book emphasises the importance of the care-giver, pointing out to staff that their life experiences will affect how they feel at these sad times. We have found, as staff who are helping grieving parents, that we need to acknowledge our own feelings. We also feel the pain and loss when a baby dies. To have a stoic 'professional' approach to death means putting aside our human side and this can make it more difficult for parents to say or even recognise what their own needs are.

The booklet encourages staff to draw on their own experiences and responses, commenting, "we tend to turn away from looking at painful things, yet it is only in looking into ourselves that we can grow and help others". We, the care-givers, need permission to have feelings. On the SCBU we are fortunate in having a Senior Nurse Manager who recognises the emotional needs of the staff, and saw as a priority the setting aside of a staff room. Our room is close to, but away from, the stresses of the Special Care Unit. It is comfortable and attractively furnished and is also used for our staff support meetings.

Hospitals can be frightening places, and parents may not think of, or know, what they can do for this, their child, before or after its death. We learnt from one mother who herself had to remain on the adult ITU the enormous importance of having some form of contact with her baby. He was being ventilated on the SCBU and we were unable to care for them together. This mother asked that he be nursed on her nightdress. Although she was unable to touch or speak to him, she was able to give him something that smelt of her. In the months after his death this brought her great comfort.

Double room

Parents are given the choice of remaining with us in the double room after their baby's death, a time to bath and dress their child in clothes of their own. For some parents to stay overnight after their baby's death and have the baby in bed with them, or close by in the clip on cot, can give them precious time and memories.

When a twin dies, or is dying, we are aware of the complicated feelings the parents may have, and their need to care for both of their babies. We have found this to be particularly important when a twin is born with severe abnormalities.

Our parents have found that the

The Compassionate Friends

The Compassionate Friends was founded in 1969 when the Reverend Simon Stephens (the Chaplain at the Coventry and Warwickshire Hospital), introduced two newly-bereaved couples to each other. He witnessed the therapeutic value of the resulting friendship, based on the mutual understanding of their heartbreak and sorrow.

Membership of *The Compassionate Friends* is open to all parents who have suffered loss of a child, of any age and in any way. The national committee (all bereaved parents and including regional representation) meets five or six times a year. The AGM is held during a residential weekend, when talks, discussions and group meetings also take place. There is a network of County Contacts, across the UK, who co-ordinate enquiries received, put parents in touch with each other, and liaise with local TCF committees to organise meetings.

The organisation has reached out to many overseas countries including the USA, Canada, South Africa, Hong Kong, Australia, New Zealand, Switzerland, Israel and Holland.

Initially the organisation was administered from members' homes. However, with the increase in membership, this became impractical and the office was opened in the centre of Bristol in 1984. With the growth of public awareness of TCF's work in supporting bereaved parents and their families, it became necessary to employ a full-time Office Administrator in 1986 and, subsequently, additional staff.

The Compassionate Friends produces a **range of leaflets** and a quarterly **Newsletter** containing many articles and letters written by members. Two issues are sent free to newly-bereaved members, and thereafter an annual subscription covers printing and postage. The Newsletter is also available on audio cassette.

The Compassionate Friends has accumulated an extensive **Postal Library** of books on bereavement which parents and those working in the caring fields may borrow. Journals, articles, video and audio cassettes are also available.

Many referrals come from doctors, social workers, health visitors and clergy. Some parents make contact with TCF by telephone either to the National Office or to their County Contact. County Contacts, who have generally been bereaved for more than two years, will send relevant leaflets and a copy of the Newsletter, and give details of local meetings.

Some parents prefer to maintain contact through correspondence, and will carry a sympathetic letter around with them to read and re-read when they are feeling low.

The Compassionate Friends offers help through befriending, as distinct from counselling. Befriending is a more informal relationship, and is complementary to the counselling that may be needed by some parents.

The original aim of *The Compassionate Friends* was to be a self-help group of bereaved parents offering friendship and understanding to each other and this will remain its primary purpose.

**TCF National Office, 53 North Street, Bristol BS3 1EN .
Tel: 0272 539 639 (Helpline); 0272 665 202 (Admin)**

special bereavement sign for the door gives them the privacy they need to express their feelings, without fear of being disturbed. We explain to the parents that it is a "feelings" sign.

This time together must not be hurried, it is all these parents will have as memories to last a lifetime.

After the baby's death some parents leave the unit quickly; they may regret this decision later on. One of the ways we have helped at this time is to tell parents that their baby will remain with us on the unit for some hours - they may then choose to return.

Siblings and grandparents

Sometimes parents return with other children and grandparents. This may be the only opportunity that brothers and sisters have of holding their baby. We have learnt that this is very important, although parents may be deeply worried that showing their grief will seriously disturb their children. With help and reassurance from the staff we have

included children who have then been able to share in the sad feelings, and have fewer fantasies about hospitals and death. Psychiatrists Emanuel Lewis and Stanford Bourne at the Tavistock Clinic believe that some of the effects "occur later following a subsequent pregnancy or in the next generation of children when they grow up".

Family photograph

The suggestion that a photograph as a family can be taken is often appreciated. This and many other photographs and keepsakes are a crucial focus on the mourning in the months ahead. If fathers and mothers take days in making the decision to see their baby again, it is important to spend time with them gently explaining how their baby will look, and feel, after going in the mortuary.

Going home

Couples who have taken their baby home after its death have found this time together helped them to accept the reality of what

had happened. They were then more able to "let go" of their hopes for this, their child. It can also be a time for careful planning of the one event as parents that they are able to arrange, their baby's funeral.

Over the years staff have become more aware of the importance of their own responses when a baby dies. We have tried to foster a sense of openness; for example, staff first names are used throughout the unit, and other special care patients are told and share in the grief when a baby dies.

As doctors and nurses we are taught to try and make things better, to take away the pain. In death it can seem that we have failed, as if we've been defeated by death, although it is not due to any lack of care or skill. One way for staff to cope with this sadness is to be able to look back and to know that we did everything we could to help and support the family. It can be rewarding to know that we have done a very difficult task as well as we possibly could.

Jenni Thomas is currently working for the Oxford Regional Health Authority as Facilitator for Maternity and Paediatric Bereavement Services. In this role she is training and supporting Health Care Professionals throughout the Region. As a result of this work it has become increasingly clear that if doctors and nurses are to work closely with bereaved parents they, too, need support and training. Pictured below is a training day session for professionals, designed to help them develop their understanding of grief and grieving, to look at their own feelings about loss and understand how these can affect their ability to care. The training also enables them to gain some insight into parents' very varied feelings when their baby or child is dying or has died, to develop their understanding of parents' and families' needs, and to learn how to help parents make informed choices. They learn communication and counselling skills and how to review, evaluate and develop their own practice.



When Jamie Isard died his mother Sharon felt shock and disbelief - she describes it as a physical as well as an emotional pain. Writing a letter to her son helped her greatly in the grieving process. She shares that letter with LINK readers in the hope that it might help other parents and also because she does not want Jamie to be forgotten.

LETTER TO JAMIE

I JUST wanted to write a letter to you to tell you how much we wanted you in our family. It took us 12 months to conceive you - and your brother Nicky, who's five, was the first person we told. He wanted to do everything for you! Your dad and I decorated the nursery and I spent a day in the attic with Nicky sorting through his old toys for you.

Everything was going well until I had a scan at 34 weeks and the hospital told us you might be born with hydrocephalus - water on the brain. But a larger hospital said there was an 80 per cent chance they'd be able to put a shunt in your brain to drain away the fluid.

I still worried, though. I couldn't eat or sleep and cried constantly. At 37 weeks I'd lost a stone through worry so they took me in for a Caesarean delivery. When you were born on 22 September 1992, you were rushed to a special care unit. The first thing your dad said to me was: "Sharon, he's beautiful, just beautiful." But I was frightened to go and see you. I didn't know what to expect. The next morning a nurse said: "Just come and say hello." And when I saw you, you *were* beautiful.

After that, I spent all morning just looking at you and marvelling at how perfect you were. I wanted you to have the shunt fitted as soon as possible so everything would be all right.

Nicky came in to see you then. He brought you a teddy. He gave a big smile and touched your hand - and you opened your eyes for the first time. In the afternoon the paediatrician came to your incubator, his face serious. He told us they'd done a full scan which showed you only had the bottom half of your brain. Because you couldn't breathe on your own, you wouldn't live.

That night we had you christened by the minister who married us. We cried and cried as he touched your head with water and said what a special little boy you were because you were made out of our love.

The next day they took away the things that helped you breathe and let you out of your incubator. At last I could hold you properly and it felt wonderful. I couldn't get enough of you, kissing and cuddling you and telling you how much you were loved. But it was impossible to cram a lifetime of love into those few minutes.

By early afternoon you were getting worse and I started to panic. They left your dad and me alone with you and we took it in turns to hold you. I've never seen your dad cry the way he did that day. I held you close, telling you not to fight any more as you'd already given us so much. That was when you opened your eyes again.



The rain had been beating on the window. But at 3.15 pm, as you died, the sun came out and shone right on your face and suddenly there was a rainbow in the sky. To me, it was you going to Heaven - and I felt my heart would break.

At that moment Nicky was on his way home from school with my mum and they saw the rainbow, too. Nicky loves them. I like to think that was your way of saying goodbye to him. When I saw Nicky, I put my arms around him and told him you'd been very

SANDS

(Stillbirth and Neonatal Death Society)

Members, all of whom have suffered the loss of a baby, are willing to help others more recently bereaved. Help is offered through befriending visits on a one-to-one, couple to couple or group basis. Training and study days are organised, and a newsletter is sent.

SANDS

**Argyle House,
29 - 31, Euston Road,
London NW1 2SD
Tel: 071-833-2851/2**

poorly and had gone to Heaven. He was so brave. But later, when he got to my mum's, he suddenly said, "I think I'm going to cry now, Nanny" and sobbed his heart out.

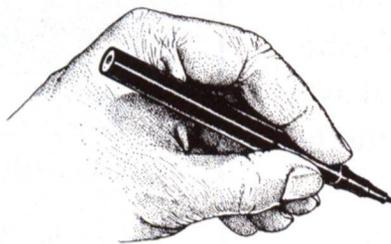
The pain I felt a few days later when I had to leave hospital without you is something I can never begin to describe. I felt as if I was outside myself, looking down on this poor family going through hell.

For the first week I couldn't sleep in our bedroom. For me that was where it all began, where you were made out of love. But your dad went out and bought beautiful ivory bed lace bed things to ease the way for me. I had to be strong for him when your funeral came round a week later. Nothing could prepare us for the sight of a tiny coffin in blue silk. I wanted to shout: "Please God, don't let this be happening to us." I wanted a doctor to tell me it had all been a terrible mistake and that it wasn't our baby who'd died.

I'd put a letter in your coffin and a photograph of Nicky, your dad and me. Your dad carried you into the crematorium and the coffin shook as he sobbed uncontrollably. We didn't invite anyone back to the house afterwards. Instead, your dad and I took a picnic to Southport beach to the place we always go with Nicky and our dog Laddie.

It was a sunny October day. We sat hugging each other and talked about what might have been. We hope to scatter your ashes there. I still ache, physically and mentally, because my time with you was so short. I'd made a space in my life ready to welcome you, but I'm left with a huge gap that's so lonely. I can still feel your lovely fluffy hair and see your beautiful face and dainty hands. You were a delight and a pleasure, Jamie. I hated to let you go. But we did have two precious days together. Thank you for fighting to give us those days.

To have given birth to you was a privilege. To have loved you was a pleasure. I love you with all my heart, now and for ever.



Letters

DAVID Fulford-Brown's letter in the last issue of LINK raised many points. It is true that society's image of disability as people sitting passively in their wheelchairs waiting for someone to come along and push them has fed a message to disabled people that they must be like the non-disabled, i.e. walking.

But disabled people are moving away from that image and recognising that they are of equal worth to their non-disabled counterparts. They have something to offer society *as disabled people*. They are recognising that they are valuable members of society and are throwing away the image that those who use a wheelchair are either "bound" or "confined" to it. The wheelchair, when seen positively, is a piece of equipment which liberates people. It means that the person can see the wheelchair as theirs to control enabling them to contribute to society.

So why would we encourage people with spina bifida to use a wheelchair? One important factor is to recognise that people with spina bifida vary enormously. Because of the nature of the disability it means some people are able to walk, with good muscle development in their lower bodies, whilst others may have paralysis from the waist down.

For both groups of people it is important to see the wheelchair as something positive. There is a great deal of training which can be given by wheelchair users and occupational therapists, for example, to show people how to go up and down kerbs, backwheel balancing, etc. For some people who have the use of leg muscles and are able to stand we would like to see them trained in how to use a wheelchair whilst they *also* develop their walking, so the walking person will have benefit of both. Should the person who walks at a later date need to use a wheelchair, then they will not feel it is a major failure.

In the sixties and seventies, a great many operations were done on disabled children in the hope that they would walk. These children have grown up with a fear of using a wheelchair - it's the last resort, the final decline. I would like to quote an example of one child I tried to help with his wheelchair skills. Let's say his name is Peter. Peter would always wear calipers, and he would struggle to put them on in the morning. His "walking" was so slow none of his peers would wait for him. He had very few friends because they were always shooting off somewhere and not prepared to wait. Now, if Peter had used a wheelchair *as well* as his limited walking, I believe he would have had the freedom to move much more freely and participate in the activities of his peers more fully.

The message is that the wheelchair is to *enable*. Yes, we live in a world where access is not brilliant, but with time and legislation things will get better. By teaching wheelchair skills, it does mean that we do not feel trapped by our own homes. We can get out and integrate, and show that disabled people are a part of society. Disabled people have a great deal to offer this world, and if you use a wheelchair what you have to offer is of no less worth than a non-disabled person's contribution. Whatever disability a person has, whether they can walk a little or not at all, there is a great deal that disabled people have to offer this society.

John Naudé, Mobility Adviser, ASBAH

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.

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Contact Joan Searle tel: (0705) 376816

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Brochure from Dept. C, Strode Park Foundation, Herne, Herne Bay, Kent CT6 7NE. Tel (0227) 360280. Reg Charity 227794

In the next issue of LINK we are planning a feature on holidays. We would like to include readers' experiences, so let us have your comments, please - the brickbats *and* the bouquets - by 12 January.

Link Holidays, ASBAH, 42 Park Road, Peterborough, PE1 2UQ

HELP FOR MAINSTREAM AND SPECIAL SCHOOLS... AND FOR THE HOME

Hydrocephalus - A Guide to Education

THIS is a reminder that ASBAH's short video is still available to buy or for hire. It concentrates on help with hand-writing, number-work and the importance of developing a partnership between school and home.

We suggest strategies that can be adopted in the classroom which, if applied with determination, can help the child become more confident.

There are inexpensive lessons here for teaching staff, care staff and every home. The author, Leonie Holgate, provides a set of notes to go with the video.

Hire for 1 week - £16.58 (inc returnable £10 deposit; to buy - £23.50 (inc VAT, p & p).

From: Information Officer, ASBAH House.

You, Your Partner and Continence

THIS training package of VHS video, handbook, audio cassette and illustrative materials is also available. Enquiries about hire charge or purchase price to Information Officer, ASBAH House.

LINK Rates

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