

Link

Association for Spina Bifida and Hydrocephalus/ASBAH

July/August 1988

Issue Number 117

30p

Association for Spina Bifida and Hydrocephalus (ASBAH)
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 Cheques payable to "ASBAH"

Young People with Spina Bifida and/or Hydrocephalus — Learning and Development (1985) <i>Leonie Holgate</i>	£1.60	FACTSHEETSup to 10 copies free Translations of fact sheets are available into Bengali, Gujarati, Hindu, Punjabi and Urdu, and into Welsh. Please send at least 30p postage
The Handwriting of Spina Bifida Children (1979) <i>Joan Cambridge, E. M. Anderson</i>	£1.60	VISUAL AIDS Slide sets and notes (12 slides) Living with Spina Bifida £8.62 inc. VAT
Spina Bifida and You — A Guide for Young People (1985).....	£3.50	Video — Training video on Hydrocephalus (May 1987). Contact Information dept. for details of hire or purchase.
Sex for Young People with Spina Bifida or Cerebral Palsy (1984).....	£1.75	MAGAZINES LIFT — for members of young ASBAH (LIFT).....Free Causeway — for contributors to ASBAH's work.....Free
Children with Spina Bifida and/or Hydrocephalus at School.....	£2.50	LINK SUBSCRIPTION
Life & Death-thoughts on bereavement (1983).....	75p	UK.....£3.30 Europe and Overseas Surface Mail.....£4.80 Air Mail.....£10.80
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General leaflet.....	13p	
Housing: general advice for young people.....	Free	
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Editor's Note

The changing nature of LINK

From time to time it's good to take a fresh look at something with a view to improving it and injecting it with a new vim and vigour. That's what I'd like to do with LINK. I think it needs a new style and a new 'shape'. What do you think?

As I've said until I'm blue in the face, LINK is your magazine. Without you it wouldn't exist at all (and not to put too fine a point on it, I'd be out of a job).

Please do give some thought to the content of LINK in particular. What kind of regular articles and columns would you like to see? What subjects would you like covered from time to time, and from what angle? Do you think we should have more regular outside contributors? Would it be useful to have more leisure articles, features on people, medical items?

The choice is yours. I'll be most disappointed if you don't take it. I aim to make the magazine enjoyable, readable, useful and thought-provoking. Times change, views and ideas change and I want to make sure that LINK is keeping pace with them all. Over to you.

Conference

See page 5 for details of the conference. September will soon be here so do contact Susie Dobson as soon as possible to book a place.

A sense of purpose

And the experience of one family trying to do the best for their handicapped daughter forms the basis of an article. With the support of relations and people in the village where they live they are trying an alternative therapy programme. It's a long slow road, but one that is giving them a sense of purpose, and some small signs of progress.

Sue Gearing, Editor

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FRONT COVER:

Proud mum, 21 year old Joanne Bates with her beautiful baby. Joanne who has spina bifida lives with husband, Steve, in Yeovil.

Photo: Ken Richards (ASBAH counsellor).

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Link

is published by ASBAH (The Association for Spina Bifida and Hydrocephalus).

Contributions to LINK by way of letters, news, photographs, articles and opinions are warmly welcomed. The closing date for the September issue is August 20. Send to the Editor, Sue Gearing, at 22 Upper Woburn Place

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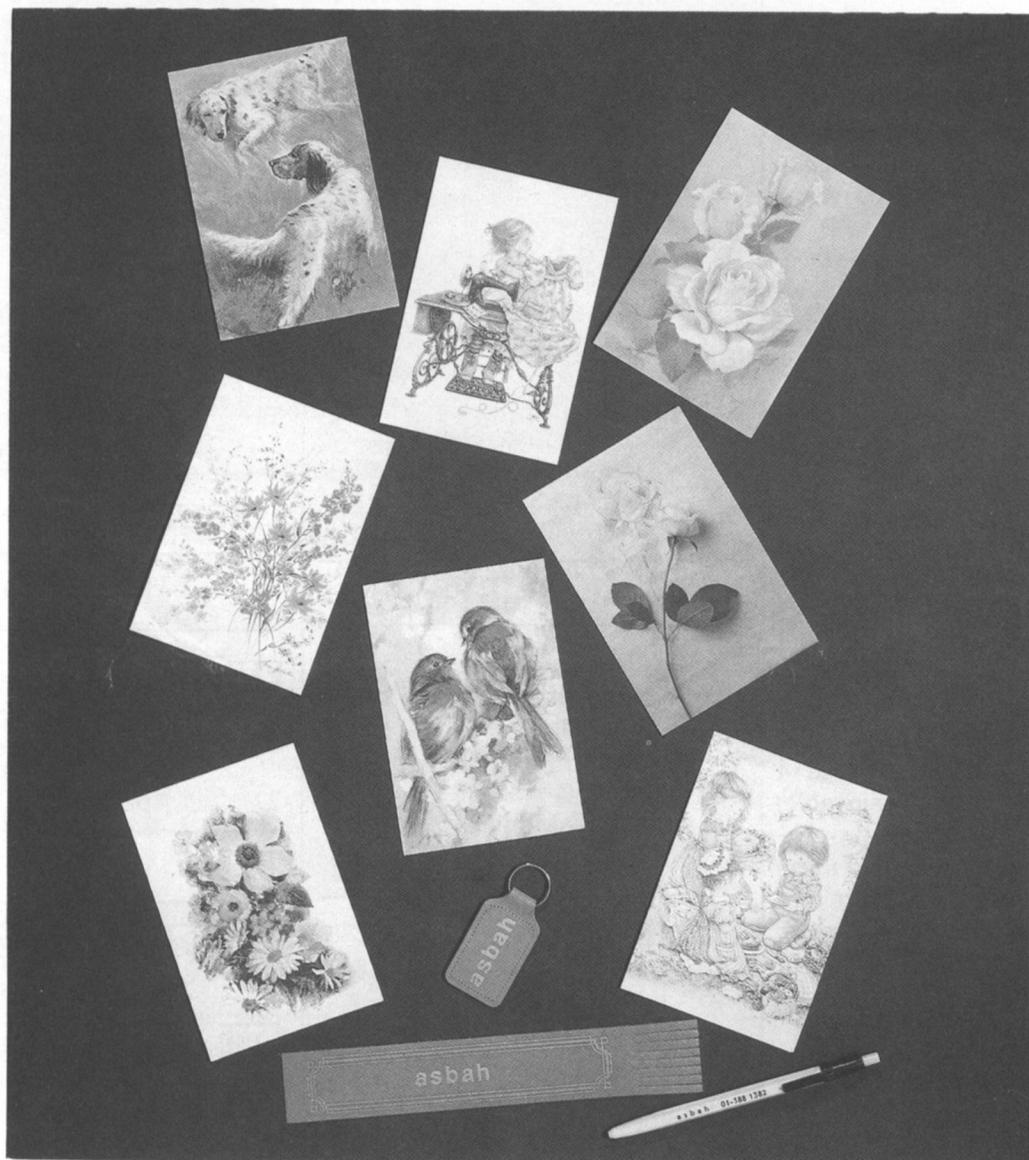
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Whilst every care is taken to ensure accuracy of information published in LINK, the publishers can accept no liability. Opinions expressed in articles are not necessarily those of ASBAH

SPECIAL BARGAIN - BUY EARLY while stocks last

ASBAH GIFTS (ideal Christmas stocking fillers)

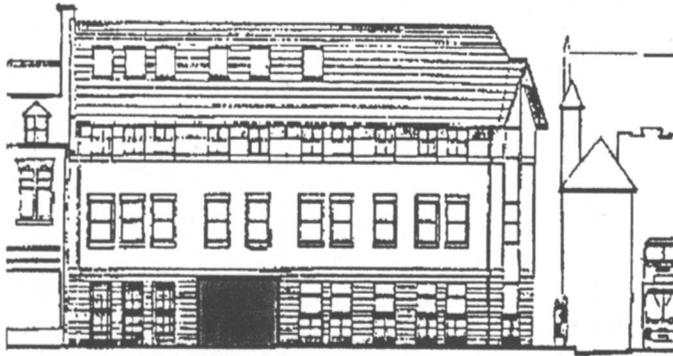


- Notelets:** Pack of assorted cards (with envelopes)..... 50p per pack
Biro: Blue and white 'asbah' pen (blue ink).....25p each
Key ring: Red leather, gold embossed key ring50p each
Bookmark: Red leather, gold embossed bookmark.....50p each

Add 25p postage per order. For bulk orders, postage may have to be increased. (Contact Joan Chapman in the ASBAH Appeals Department).

Send cash or postal order payable to 'ASBAH' with order.

Send to: Mrs Joan Chapman, ASBAH Appeals Department, 22 Upper Woburn Place, London WC1H 0EP.



The proposed new ASBAH offices

ASBAH plans new offices in Peterborough

Peterborough Development Corporation has put ASBAH in touch with a developer. After preliminary meetings he is willing to change his planned offices to take account of ASBAH's needs.

There will now be a self contained office for ASBAH of about 10,500 sq ft. Planning permission has to be reapplied for, as the original plans were for three separate units. The completion date we are working toward is July/August 1989.

The increase in space of about 3,00 sq ft will enable an expansion of the telesales operation to provide the money to take services through to the 1990s.

We are working on finding a new tenant for the present offices. If anyone wants 7,000 sq ft at an exorbitant rent in central London, please contact us!!!

ASBAH CONFERENCE

University of Southampton
Friday Sept 2 - Sunday Sept 4, 1988
Children with spina bifida and/or hydrocephalus - grown up

Papers, discussions and workshops on

- Housing and housing benefit
- Social support
- Self image and relationships
- Independence and self care
- Education and employment
- Social and medical provision for adolescents
- Research

Although not yet finalised, the cost will be about £55 plus VAT.

The conference runs from 5pm Friday until after lunch on Sunday.

For more information please contact Susie Dobson at ASBAH national office.

Research Society Elects New President



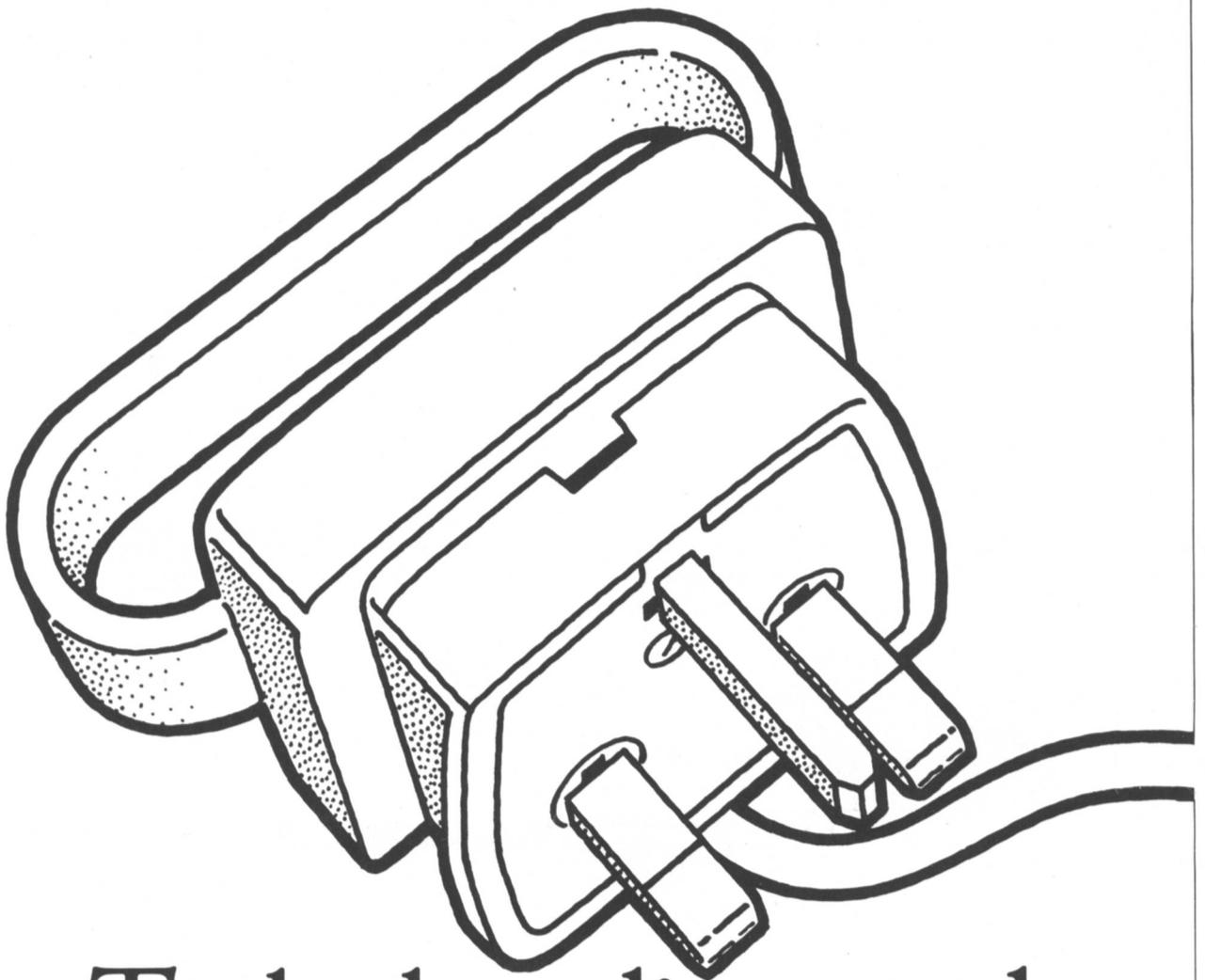
At the Thirty Second Annual General Meeting of the Society for Research into Hydrocephalus and Spina Bifida (SRHSB) ASBAH's Executive Director, Miss Moyna P Gilbertson MCSP FBIM, was elected President on the retirement of Professor Hugo Andersson of Gothenburg.

Before joining ASBAH more than eleven years ago, Moyna Gilbertson enjoyed a distinguished career as a physiotherapist, her last position before leaving the National Health Service for the Voluntary Sector was as Group Superintendent

Physiotherapist, the Hospitals for Sick Children, Great Ormond Street, London. Under her leadership ASBAH has grown both in size and in stature and is now a recognized source of expertise and experience throughout the world. A fact that has been recognised by this very important appointment as President of the SRHSB - this is the first time the post of President has been held by a 'non medical professional'.

The Society for Research into Hydrocephalus and Spina Bifida, established in 1957 has always recognised the wide variety of professionals concerned with spina bifida and hydrocephalus in its membership. Psychologists, educationalists, nurses and therapists, as well as physicians, surgeons and scientists make up the more than 300 strong membership drawn from all over the world. Recently some parents have been elected to membership.

Sponsoring research is a main objective of ASBAH and close links have existed with the Society ever since ASBAH was formed in 1966. Indeed, our founder Chairman, Professor R B Zachary, was President of the Society from 1964 to 1967. Other past Presidents of the Society have included some of the worlds most eminent authorities on spina bifida and hydrocephalus.



To the handicapped it's a world of difference.

Simple-to-use electric appliances and controls can help disabled people enjoy easier, more independent lives.

The plug adaptor shown above, for example, enables arthritic hands to secure a grip more readily.

We can advise you on this and other aids for the disabled and the elderly, such as modified cooker controls, time switches for electric blankets and lights, and switches that can be operated by a walking stick or an elbow.

For the severely handicapped, electricity also contributes to a range of equipment

controlled by minimal movement, including air switches, operated by a light touch of finger or toe.

There are fuller details in our free "Making Life Easier for the Disabled" booklet.

Just send the coupon to Pat McNally and she'll be pleased to send you a copy.



To: Pat McNally, Electricity Publications, PO Box 2, Feltham, Middlesex. TW14 0TG.

Please send me your "Making Life Easier for the Disabled" booklet.

Name _____

Address _____

Post Code _____

Local Association
Round-up



Barnsley

Glen Haigh (above) has reason to look pleased. He is being given a cheque by Barnsley Council to pay for a new sports wheelchair to help him as he progresses as a promising athlete. His sport is weightlifting, which he only took up a couple of years ago but which has already proved to be something that occupies much of his spare time and puts his talents to good use.

At his first attempt, he could not even lift the bar without weights, but was encouraged by his mum and dad, Marlene and Brian Haigh. Now he can power 90 kilos - nearly twice his own body-weight.

Glen is a member of the Stoke Mandeville British Les Auteurs sports association and recently went to France with the team where they gave a demonstration of weightlifting for French television.

Weightlifting occupies much of Glen's spare time. He works during the day at Barnsley Light Industries on assembly work.

With Glen in the photo are Barnsley Councillors Harry Wilson and Dick Shirt.

West Yorkshire

In Steven's memory

Steven Leach, who had spina bifida died suddenly in April at the age of 29, but friends in the pool league in which he played have made sure that his memory lives on.

They have set up the Steven Leach Memorial Trophy which will be presented to the winning player for the first time this year.

Steven, who lived at Pontefract, played in the Sharlston Pool League at the Green Baize club. The owner, Mr Albert Williams said "He was a wonderful lad and everyone admired his skill, competitiveness and apparent disregard for his disability".

His parents, Ronald and Mary Leach wrote to LINK, "As a family we have been members of ASBAH since Prof. Zachary first started it soon after Steven's birth in 1958."

Steven was an active lad with many interests and worked at Remploy.

"We would like to thank the Association for all the help we received during his life and at the time of his death" said his parents. They said they had been overwhelmed by people's kindness and sincerity.

More than £300 was sent to the local association in Steven's memory.



South Wales

(see photo above right)

ASBAH is delighted when it continues to receive news of children long after they have gone their own separate ways.

One such is 11 year old David Seymour. He was at Five Oaks for about four years and when the time was right and a suitable home found, he was fostered.

He is now living happily in South Wales with his foster parents, who sent us this photograph.

Sussex

Parents' breakaway

The Chatsworth Hotel in Worthing was the chosen venue for 14 Sussex Association parents who decided to treat themselves to a weekend away.

They were there for one night full board, under a 'conference package'. The weekend theme was 'Caring for the Carers'. SASBAH subsidised the cost, so parents paid only half the £30 charge plus reduction for couples.

Those who went included parents with young children, expectant parents, one granny, one single parent and two foster parents as well as parents of young people in their twenties - it turned out to be a stimulating mix.

Comments on the weekend included: "Very relaxing, yet informative and extremely useful in sharing ideas and experiences. Some more free time would be appreciated to ensure a complete break from all the problems involved with caring for our disabled daughter". "It was our first weekend away for ten years. We thoroughly enjoyed ourselves, and we hope there are many more to come. My husband felt that it was a good chance to meet and discuss with other parents, when normally he is at work".

Sussex Association secretary Margaret White commented: "We feel the weekend was a success and will be followed by others - though by popular request, we shall go for two nights next time...and where parents were unable to come because of family commitments, we shall try and free them by arranging respite care where possible...The group will be kept fairly small, however...As a result of our experience, we feel we can strongly recommend such a weekend to other local associations".

Editor's note: Are other local associations doing anything like this? It usually seems to be Sussex we hear from with new and stimulating ideas. Come on other associations, let us hear what YOU are up to!

New Education Guidelines Launched

On 29 June, HRH The Prince of Wales launched guidelines on the provision of further and continuing education for people with disabilities, entitled "Learning Options".

The guidelines were produced by a working party of the Prince of Wales Advisory Group On Disability (POWAGOD) which was chaired by Professor Peter Mittler CBE. Moyna Gilbertson, the Executive Director of ASBAH, was a member of the working party.

Over 270 delegates attended the Conference at National Westminster Hall in London; many were Chiefs of Local Education Authorities and others were representing voluntary organisations.

The Prince of Wales welcomed the publication of the guidelines and expressed his concern about the continuing need for improvement in further education facilities for all disabled students. However, he suggested that curricula could be adapted to the needs of the students by making classes available on the more accessible ground floor of colleges.

The Prince of Wales cited the formation of the Employers' Forum on Disability (which currently has a membership of 30 major employers) and The Open College, which will soon be launching a special bursary for disabled students, as examples of new initiatives in improving opportunities for disabled people.

He was convinced that collaboration and consultation was of the utmost importance - particularly between parent groups, voluntary organisations, teachers and employers, but, above all, with the students themselves. He expressed the hope that the discussions during the day would lead to positive action.

The Conference was chaired by Baroness Warnock. Speakers included:

Mrs Elizabeth Standen - a young woman with severe disabilities who related her experiences in overcoming prejudices in the past with regard to training and employment. She had eventually studied philosophy at university and was soon to take up a post as an Equal Opportunities Officer in the North East of England.

Mr Robert Dunn MP, Under-Secretary of State, Department of Education and Science. Mr Dunn had stepped in at short notice to replace Baroness Hooper to give the Government's viewpoint. He expressed appreciation of the work undertaken in the compilation of the guidelines. Mr Dunn emphasised that the Government's new powers of delegation under the Education Reform Bill were designed to make facilities more available to those with special needs.

Mrs Pat Twyman, Principal of Bourneville College in Birmingham, and

Mr Neil Fitton, Chief Education Officer for Cheshire.

The day ended with a panel discussion embracing wide-ranging questions submitted by the delegates. A particular area of concern was the need for the establishment of a national co-ordinating body or advisory council for special needs, a proposal which received overwhelming support from delegates.

The key principles proposed by "Learning Options" are:

Rights	Students who are disabled have the same rights of access to further and continuing education as any other citizen.
Individuality and Choice	Like everyone else disabled people have individual attitudes, abilities, preferences, likes, aspirations and fears. As individuals they have the right to make choices and decisions concerning their lives.
Support for Integration	Disabled students should be given the necessary support to enable them to have full access to the whole range of college and other training courses. For some such provision may be the only means by which they can gain access to the full curriculum. Where special courses are necessary students should nonetheless be provided with full opportunities to interact with other students in all college learning, social and recreational activities.
Confidence	Learning experiences should help students to increase their self-confidence and self-esteem. This is particularly important for those young people who have previously encountered obstacles and experienced failure.

Copies of "Learning Options" are available from:

Richard Stowell,
National Bureau for Handicapped Students *,
336 Brixton Road,
London SW9 7AA.

* Soon to be renamed National Bureau for Students with Disabilities.

Community Care

The Royal College of Nursing has strongly criticised Sir Roy Griffiths' proposals on community care on the grounds that they ignore the role of nurses. Griffiths has proposed that new 'Community Carers' be appointed, unqualified staff who would be responsible for routine domestic and personal care.

'Community Carers' is just one of the issues raised. ASBAH is currently working with the Greater London Association for the Disabled and Living Options to prepare a joint comment on the Griffiths Report.

Belt Up!

"The Safety of Children in Cars, Exhibition Day", organised by Family Forum in conjunction with the Department of Transport, on the 27th June, was an impressive start to this years 'Family Fort-night'.

In his speech opening the Exhibition, Peter Bottomley, Minister for Roads and Traffic said, "There is simply no excuse for parents leaving their children unrestrained in cars, far too many children are killed or injured unnecessarily because they are not 'belted up'. Far too few parents provide restraints, or make sure that their children always use them".

Cheadle MP, Stephen Day, promoter of the Bill to make use of child restraints compulsory (which completed it's passage through the House of Lords the same evening) Chaired the proceedings. Other speakers included Dr Gordon Avery, District Medical Officer for South Warwickshire Health Authority, and Christine Burn, originator of the 'Belt Up in the Back' campaign. An impressive range of safety equipment was on display and of particular interest was information about Hire and Loan Schemes, details of which are available from Pat Corns at the National Office.

Family Forum has now merged with The Family Policy Study Centre, 231 Baker Street, London NW1 6XE

Footwear Feeture!

During the past few months, you may have had difficulties in obtaining supplies of Adidas orthopaedic footwear - 'Adimed'. Due to these problems Adidas have discontinued this range.

However, Jane Manning Ltd have announced the introduction of 'Orthosport'. These are a range of high quality footwear with all the features of 'trainers'.

For further information please contact: Jane Manning Ltd, 1070-1072 London Road, Thornton Heath, Surrey, CR4 7ND.

Habinteg in Wales

In June Habinteg H.A. opened it's first Welsh scheme. Thomas Court, Wrexham is an integrated estate of 35 dwellings which is completely accessible to wheelchair users. There is also a 24 hour emergency help service included in the scheme.

LIFT Your Views

A committee is to be established to examine the services that ASBAH provides for young people with particular reference to LIFT's future development.

The committee will be chaired by Austin Crowther, member of ASBAH's Executive Committee and a founder of LIFT. He would welcome LINK reader's views on LIFT.

You can write to Austin c/o ASBAH, 22 Upper Woburn Place, London WC1H 0EP.

Adaptations Booklet

The Department of the Environment has produced a manual called "Adaptations for People with Disabilities". Aimed at professionals, the book documents 22 detailed case studies of disabled people and their housing circumstances. The book attempts to assess the "successfulness" of adaptations carried out. It can be purchased from HMSO for £17.50.

Abortion (Amendment) Bill

Mr David Alton's Private Members Bill proposing amendments to the Abortion Act 1967 received it's third reading in the House of Commons on May 6th 1988. The Bill ran out of parliamentary time and so was not voted upon by MPs. Mr Alton requested additional time for MPs to continue the debate and vote and was refused. Therefore the Abortion Act 1967 remains unaltered.

ASBAH, along with many other organisations concerned with disability issues, had opposed the time limit of 18 weeks. This time limit has no scientific basis and lacks compassion as it would deny many of our parents access to antenatal diagnosis presently available to detect spina bifida and/or hydrocephalus. This decision was reached after much discussion and thought by our Medical Committee. It reflected ASBAH's continuing belief that support, information and advice should be available to all parents and individuals regardless of personal opinion - a belief endorsed by Council.

ASBAH received letters both supporting and condemning our opposition to the 18 week time limit. Some said that the choice of decision to terminate a pregnancy due to fetal abnormality was a matter of personal conscience and circumstance. Others believed that abortion was wrong and that there were no, or very few, justifiable reasons to allow such a choice by parents. Mr Doug Endersby, a long standing member of the Association felt that ASBAH should be lobbying in favour of the Alton Bill. As a result of his personal views Mr Endersby resigned from the Executive Committee. His great efforts will be missed.

We are always pleased to have members views on this, or any other, topic of concern.

The Association supports all people with spina bifida and/or hydrocephalus and their families whatever their personal view may be.

Honeylands is a family support unit which has developed within a District General Hospital paediatric service. The unit has gained an international reputation for its flexible and inter-disciplinary approach to working with families of handicapped children and for its philosophy of active partnership with parents.

The Honeylands' services are based upon a survey of consumer needs within the Exeter Health District and on a commitment to work together in the best interests of handicapped children. It has important lessons for a wide range of agencies (not only within the child health services) in terms of planning, providing and developing a flexible system of family care following the birth or identification of a handicapped child.

Honeylands provides a service for all children with special needs and developmental delays, as well as for those with specific disabilities. Children with physical, mental and sensory handicaps use the same facilities, and the integration of special needs has not provided any difficulties.

Honeylands is itself committed to integration within the wider community and frequently supports mainstream services in accepting children with a wide range of disabilities and special needs. Treatment, therapy and services for family relief (including respite care) are firmly linked at Honeylands and local parents appear to have more confidence in and make more effective use of services because of the continuity of care.

Honeylands' parents can use services (including respite care) 'on demand', once the initial referral has been made. Many families have emphasised the importance of linking respite care and good quality day care and other services. Their satisfaction with Honeylands is shown in a recent evaluation of consumer satisfaction with the provision offered. Parents have particularly welcomed the 'key-worker' approach - with the use of 'home therapists' for very young children with difficulties and disabilities.

Parents play a major role in assessment and are seen as partners, not only in the development and care of their child, but in managing the unit and determining future directions.

HONEYLANDS

A FLEXIBLE & COMPREHENSIVE CARE SERVICE FOR FAMILIES OF HANDICAPPED CHILDREN

By Philippa Russell, Principal Officer of the Voluntary Council for Handicapped Children.

At Honeylands in Exeter there is an ever-ready, kindly and knowledgeable team and pleasant facilities so that no family with a handicapped child should ever feel lonely or at a loss to know where to turn. Because the full range of support is provided at Honeylands, professionals from many different disciplines meet each other here, and in an informal and friendly surrounding get to know much better the whole family situation and need.

The centre was set up by Professor Frederic Brimblecombe, Exeter's first paediatric doctor, in the 1950's. He became aware that there weren't adequate resources to help children with handicaps, and initiated a study of their need in the East Devon area. Once identified, the next step was to meet those needs, and so Honeylands came into being, and has flowered over the years to become an invaluable 'second home' to handicapped families in East Devon. What a pity that all areas can't have a Honeylands of their own.

Sue Gearing, Link Editor

Local professionals can also use Honeylands not only to gain sufficient confidence to work with a child in community services, but to share their own skills and abilities.

In addition to the full range of child health services, Honeylands provides a variety of services. Playgroups and holiday playschemes not only offer developmental play opportunities for disabled children. They also involve siblings, family members and volunteers from the local community. Respite care is available on a daily or overnight basis on demand.

A toy library provides access to a range of play activities at home. All services are co-ordinated by a team and parents can work closely in planning their own child's programmes. Honeylands has close working relationships with the LEA and can play a major role in helping parents understand and participate in Section 5 assessments under the 1981 Act. A major concern for future work is the transition to adult life and the need to develop better services for disabled school leavers. A study of disabled school leavers in the Exeter area* identified a range of unmet needs and is being used to plan better services and to avoid the fragmentation and confusion which characterised children's

services before Honeylands began.

Most importantly, Honeylands is a tribute to the ability of committed professionals like Professor Frederic Brimblecombe, and the present paediatrician in charge, John Tripp, and their colleagues to develop services which genuinely reflect and value parents' views and which change and grow in response to local needs.

The development and evaluation of Honeylands has shown that services based upon individual programmes do work. Parents do not abuse or over-use services to which they have access on demand. They feel that integration of assessment, treatment, therapy and support services is essential in meeting the day-to-day needs of families and children who have disabilities and special needs.

**The next LINK will carry a report about the development of services in the area following the report, which was featured in LINK Sept/Oct 1985.*

'HONEYLANDS - developing a Service for Families with Handicapped Children', by Frederic Brimblecombe and Philippa Russell. From the National Children's Bureau, 8 Wakley St., London EC1V 7QE. Tel: 01 278 9441

THE FAMILY FUND

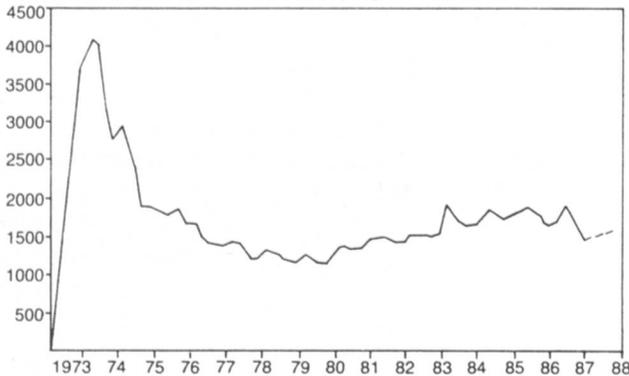
One of the sources of financial help available to families with a disabled member is the Family Fund, who have proved very helpful whenever our field workers make approaches on behalf of the families in their area. We felt that LINK readers might be interested in some of the statistics and details of how the Fund is working.

THE FAMILY FUND

The Family Fund provides financial support for families in the UK with severely handicapped children. It was established in 1973 in response to the public outcry about children damaged as a result of the drug thalidomide being taken during pregnancy. This government fund is unique within the benefits system because it is administered independently by the Joseph Rowntree Memorial Trust in York. The Fund gives modest grants to families for items which might help to relieve the burden of caring for a severely handicapped child and is intended to complement other statutory provision. Families may apply for and receive help more than once.

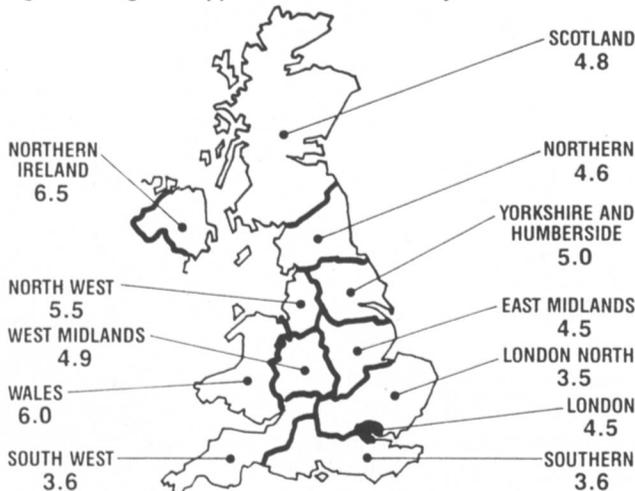
SPRU has responsibility for maintaining the Family Fund data bank, a coded record of all applications to the Fund. This responsibility includes the production of administrative statistics and liaison with research workers who want to utilise the wealth of information available.

Figure 1: Number of families applying for the first time



By the end of 1987 the Fund had distributed £57 million to 80,000 of the 100,000 families who have applied. Figure 1 shows the number of new Family Fund clients per quarter over a period of 15 years. After an initial burst of activity the number of new applications fell until 1980 and then started to increase again. Present indications are that new applications may be beginning to level off. The figure also illustrates the seasonal nature of application to the Fund with greater activity in the spring and summer.

Figure 2: Regional applications to the Family Fund



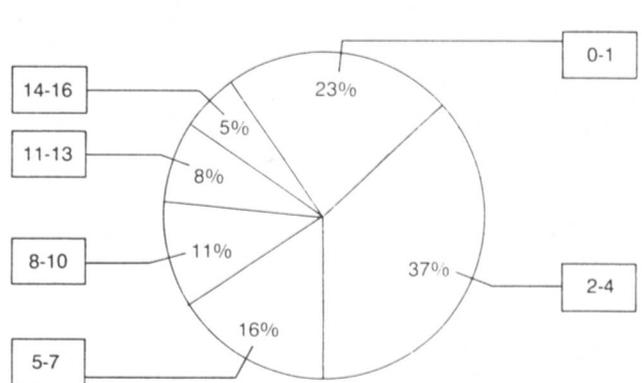
Region

The overall rate of application to the Family Fund is 4.6 per 1000 population under 16. Figure 2 shows the regional variation of applications with Northern Ireland having the highest rate in application and London North having the lowest.

Age

For several reasons the age of the child at application is variable. Spina bifida and other handicapping conditions are clearly evident at birth. Others, such as muscular dystrophy, cystic fibrosis and non-specific mental handicap only become evident, or severely handicapping, later in childhood. In addition, not all families apply to the Fund as soon as they know about the child's disability. Some children are, of course, disabled as a result of accidents. At present more than half of new applications received are on behalf of children under four years of age as Figure 3 shows.

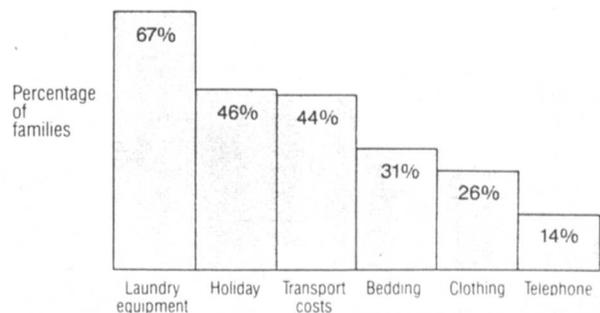
Figure 3: Age distribution of recent applicants to the Family Fund



Types of Item

The Family Fund has discretion to give a grant for virtually anything but in practice most of the help given falls into standard categories. Figure 4 shows that two thirds of families have received laundry equipment, just under a half have received help with a holiday and a quarter have received a grant towards the cost of clothing.

Figure 4: Items received by families



Dorothy Lawton

Source of Figures: The Family Fund

Our thanks to Cash and Care, the newsletter of the Social Policy Research Unit at York University, for letting us use this information.

ASBAH'S FIRST MOBILITY WEEKEND

One weekend in May nearly 50 young people with spina bifida and/or hydrocephalus attended the first ASBAH weekend of mobility at the Ludwig Guttmann Sports Centre at Stoke Mandeville. It gave the opportunity to learn and develop new skills towards a greater level of individual mobility. There were also sessions on education, training and employment, housing, personal relationships and transport. Being a new project, it also provided a valuable lesson for ASBAH staff members in organising and running such an event.

One of the most important lessons of the weekend was that being in a wheelchair does not mean that you always have to be 'pushed around'! Central to this are confidence, skills and a wheelchair that can be easily manoeuvred.

It is one of the greatest indictments of statutory provision for the disabled that DHSS chairs are almost wholly unsuitable for people's needs and can, in many cases, constitute a barrier to independent mobility. Many of those who attended, took the opportunity to try out lightweight wheelchairs and to discuss what type of chair would most suit their lifestyles.

Our thanks to physiotherapist, Owen McGhee with assistant Kay Owen, who masterminded the mobility sessions, and to all volunteer helpers. Comments from those who participated, or those who would like to join in next time, would be gratefully received by us.

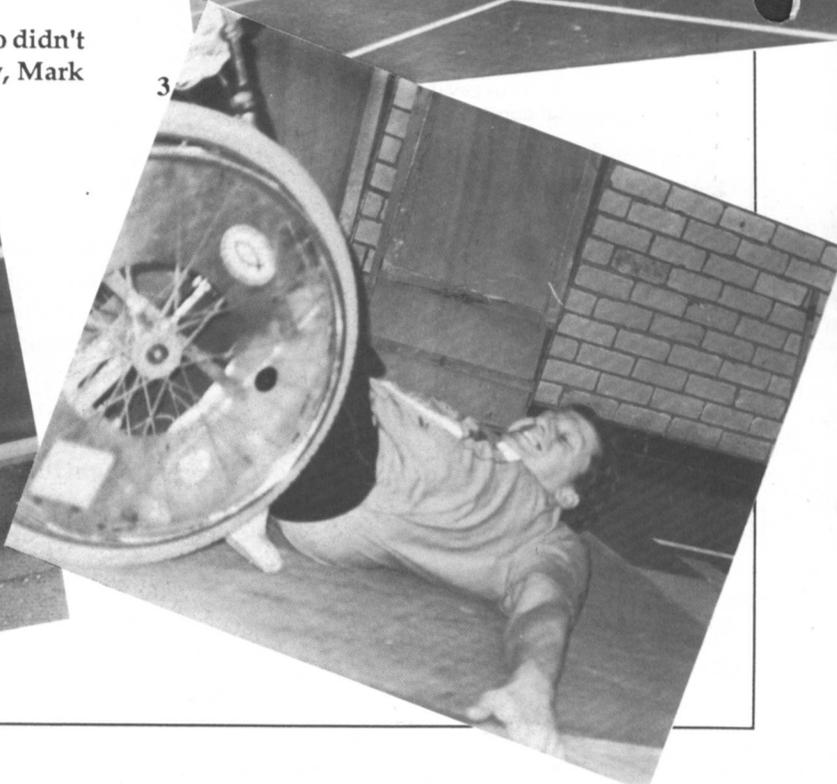
Phill Watson and Ian Laker
ASBAH Disabled Living Advisory Department

1 - Jon Harvey demonstrates how to negotiate a ramp, watched by Owen McGhee

2 - Ian Laker, one of ASBAH's Disabled Living Advisers on the slalom course

3 - John Naude ends the slalom in fine style!

4 - At the start of the weekend, four participants who didn't know what lay ahead!. Left to right: David Henley, Mark Pitts, Diane Melham and Troy Sloper.



Trying to help Helen

Helen was five in June. She was born with hydrocephalus and is severely handicapped with floppy limbs and poor eyesight. Despite spending a considerable amount of time going backwards and forwards to the local hospital for physiotherapy, speech therapy etc., her progress was very minimal.

When Helen was three, we visited special schools with a view to her starting some form of education. However, after listening to an item on television about a child who was on a programme designed by the British Institute for Brain Injured Children, I started to think that maybe something similar could benefit Helen. At that time we had a new addition to the family and we were anxious that he did not suffer by our efforts to help our daughter.

Whilst waiting to go to the British Institute, we were given the address of the Kerland Foundation in Bridgewater, Somerset. Their programme of exercises is individually designed to suit each child's needs and is carried out for fifteen hours each week which seemed to be more practical for us. After a lot of thought we finally went to the clinic in March 1987 and came home with the daunting task of finding people to help us, getting equipment made, and also getting the programme underway.

A year later we are still working. We have not seen any miracles, although to us each minor achievement is like a miracle. Helen is making slow progress. After four months on the programme she could roll from her tummy to her back - quite an achievement when she would not even lay on her tummy without complaining before commencing the programme. She is now so strong that her grandparents can hardly hold her when she wriggles! Her head control and eyesight have improved significantly. She

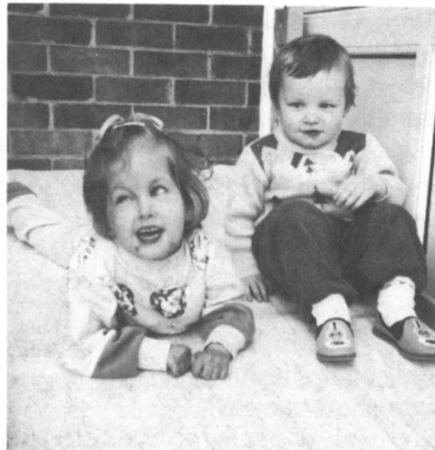
Mrs Jan Diggins of Colchester in Essex is not claiming that the programme of exercises that her daughter Helen has each week is having any miraculous effect. Indeed, she admits that progress is slow. But she felt that other LINK readers might be interested to hear of their experiences with this alternative method of treatment which they have embarked upon in the simple hope that it might help her in some way.

There is so much publicity about the Peto Institute in Hungary, but the costs of pursuing this method of treatment can be astronomical and may not be suitable for the child in question. For this reason Mrs Diggins writes about this alternative programme. It cost the family £320 for the initial two day visit to the clinic, and about every 6 months there is a follow-up assessment at the clinic for a day which costs £160. Simple wooden equipment for use in the 'patterning' programme at home was made by a local carpenter for about £100.

Obviously each child is an individual and the programme will not suit everyone. Indeed it isn't everyone who would be able to find a dedicated and constant team of helpers. The Diggins family have been lucky in this respect. They live in a small village and people have rallied round. Of the 20 original helpers, there are still 13 who give about one to two hours of their time each week. The others have had to give up because of moving from the area or other personal reasons.

There are more than 25 units in this country practising conductive education, as well as alternative therapy centres, and ASBAH does advise you to seek independent professional advice before proceeding with any of these. They can be costly and may not suit your child, your lifestyle or your expectations. ASBAH would like to point out that it has, at this stage, no personal experience or knowledge of the work of the Kerland Foundation.

Later this year we hope to have a full report on the work at Peto following the forthcoming visit there of a member of ASBAH's Medical Advisory Committee.



Helen makes her way down the ramp, one of the pieces of equipment which had to be made for the programme, watched by brother Philip.

is also more alert, understands much more and is now trying very hard to move along the floor.

We have 20 dedicated helpers from the village who responded to our plea for help and to whom we will always be very grateful. Some days Helen cries a lot, and I am sure the helpers -

'patterners' as we call them - will be come despondent, but they still return the following week to carry on. We have been back to the clinic once and the exercises were then changed, and we will shortly return again for further assessment.

Life is hectic and there are times when we think we must be mad but we are trying to help our daughter achieve her full potential. We know that we may not see any great improvements for all our efforts but we will have tried.

Philip is now an adorable two year old who copes well with our routine.

I do not know how long we will continue with the Kerland programme. I guess as long as we can see some results and have people willing to help us. Perhaps I will write again in a couple of years to give you an update on our progress.

**Jan Diggins,
Alresford, Colchester, Essex**

Not the end of the world -

My name is Lorraine. I am the mother of five children. Andrew 8, David 6, Peter 5, Christina 4, and Katie Louise, 11 months.

Christina was born in August 1982 with spina bifida. This is the story of her life and of our lives with her from her birth. I felt we should share with others what joy she has brought into our family and how she has enriched our lives with her lovely little personality. Her presence in our family has helped to bring out the best in each one of us. As you will see, being disabled is not the end of the world, but the beginning of a very good life.

CHAPTER 1: Christina's first month

David looked very serious. So did the nurse. I thought that everyone was concerned because baby had opened its bowels as it was born, but this wasn't the case. The nurse, whose face was very red, told us that it was a girl, and that there was a problem with her back. At this moment I was afraid to ask if I could hold her. She looked so beautiful and I couldn't be sure whether to be happy or sad. There were so many feelings churning inside me, but I had no way of letting them out. I am a shy person and never like to make a fuss. The nurse cleaned up Christina a little, dressed her back and put her into a cot.

Christina had been born at 6 pm, just 45 minutes after the first contraction. She was 8lbs 3ozs at birth and looked big inside the incubator.

David left to tell his parents and to telephone mine. I knew then that he was much more upset than he was showing me. Over the last two or three years we had spoken about having an abnormal child and he had said that he simply wouldn't be able to cope with that happening to him. But, he did. I think that he had been able to cry a little.

I was so tired and worried about all the events that had taken place and which were to come. At midnight the paediatrician came with the young

doctors to look at Christina. He asked me if I knew what was wrong with her. I replied that I didn't, only that there was something wrong with her back. He then told me that the condition was called spina bifida and that Christina would need to have the wound in her back closed as soon as possible in order to prevent any infection; and would I agree to this operation being performed? I naturally agreed, and it was arranged for the morning.

The worst part was when Christina was wheeled down the corridor and out of the ward. I felt so helpless. There was nothing I could do. I knew that she had to have this operation. All I could do was to wait and pray for her return from theatre.

At long last she was brought back to the ward. They had put her back into the incubator; she was very pale and had a drip into her little arm and for the first time she was actually lying on her back. The sister explained that being on her back would allow the blood vessels to seal. Christina seemed to be alright, although in some discomfort.

Hydrocephalus

Well, the day of Christina's operation was almost over but we had just begun. Sister had told me that Christina would probably develop hydrocephalus, and explained to me what it would mean...we had jumped over one hurdle only to realise that there would be more to

Christina spent the night crying on and off, and in the morning was gen-

The diary of the first four years of CHRISTINA who has spina bifida and hydrocephalus, written by her mother

tly turned over by the sister. It was the first time that I saw her back since the operation. It was dark red, black and blue with little stitches dotted here and there. I then fully understood the problem that the surgeon had faced. He came back later that morning to check her back and to look at the



Christina, about three months

pupils of her eyes as this would indicate if any pressure through hydrocephalus had started. Her head had been measured the previous evening and now the surgeon discovered that there had been an increase in the size, and informed me

that Christina had hydrocephalus. I was so glad that I had at least been prepared for this by the sister, so the shock was not too great. The surgeon said that he would have to draw off some of the excess fluid and told me that she was too small to have a shunt fitted. The fluid was successfully drawn off the following day.

Christina's spinal cord had been damaged leaving her incontinent. This meant that she had to have her bladder expressed every four hours by the nurses. I would have to learn at some time how to do this, but had to admit I wasn't too keen! It looked so

continued on next page

- the start of a new one



Christina at about two years

difficult and I was concerned that I might hurt her. That was one of the bridges to cross later. As days went by Christina's back would weep a clear fluid and we were not sure if it was spinal fluid or healing fluid. It turned out to be healing fluid much to our relief. Christina's back took about two and a half weeks to heal.

Now the next hurdle was to have a shunt fitted. Christina had a cat scan and it showed that the ventricles in her head, which are little canals that carry fluid, were large enough to insert the shunt. The surgeon decided that Christina could now be operated upon since she was strong enough. She had been fed from birth on breast milk which I had expressed, and then fed from a bottle. I wasn't allowed to handle her, but by propping up the bottle on a little pillow in the incubator she was able to take the milk. All this was rather awkward, but well worth the effort involved, and I'm convinced one of the reasons Christina was now ready for the shunt to be fitted. Once her back had healed I was then able to feed her quite normally. We were then bonded together properly for the first time and what joy there was in being able to hold and cuddle her.

It was time for Christina to be prepared for the operation. The surgeon explained that sometimes the shunt picks up an infection and might need to be removed and another put in its place, but that this generally happened within ten to fourteen days of the operation.

It was a lovely day so I took myself for a walk in the park nearby. It felt so

strange to be back outside. How easy it is to become used to a hospital ward, forgetting that outside the world continues to go on. I stayed a short time and then returned to the hospital to wait Christina's return.

A few days after the operation the surgeon was so pleased with her that he said that if the cat scan showed that all was well he could see no reason not to be able to return home. What sweet music to my ears!

Going home

So, at long last, the day came for us to leave the hospital. Prior to Christina's birth we had decided, with David's parents, to sell our house and buy a hotel near Newquay, and to start a Christian community. We had hoped that our fourth child would be born before the move, but this obviously didn't happen. Whilst I was in Plymouth hospital, David had to pack our belongings, and move house himself, as well as helping his parents move. It was an exhausting time for all, but it went relatively smoothly.

As we were getting into the car I was aware how much Christina was going to need to be protected. We took this opportunity to tell the boys that they must be careful with Christina because of her back. They accepted this and seemed to understand, without a sign of jealousy.

I felt so happy during the journey home, enjoying being a family once more. David and I had become much closer through all our trials of the past month and we were aware that we would need to help each other in the months to come.

CHAPTER 2: Getting into a routine

Routine with Christina and the boys became second nature and life was much easier than I had thought possible - not easy though, just easier than I had feared it would be.

Andrew had started at the local village school at St Mawgan, and had settled in happily whilst David and Peter spent endless time playing in the field or in the garden, often with

the family dog Rusty, joining in the games. Christina was making good progress all through this time.

Christina had a few urine infections in the first months, and I remember dreading the first one. The staff at the hospital had warned me what to look for - 'fishy smelling urine' and 'darker than usual'. One morning I expressed her as usual and found that the urine was indeed darker than usual and smelling 'fishy'. I took a sample of the urine to the doctor and after tests it was found to be infected. Antibiotics were prescribed and in a week it was completely cleared. How relieved I was that I had been able to recognise the symptoms.

Faith

The first few months of looking after a disabled child are a time of learning. I used to miss things like her toes not being able to grip my finger when placed under them. This caused me much sorrow which Christina seemed to sense. She looked at me with her large brown eyes and smiled, which made me very thankful for her beauty. I have been lucky to have faith as my strength. My parents had done a good job bringing me up in a christian home. It must be difficult for those bringing up a disabled child without any faith in God to help support them. I am truly grateful to my mum and dad for passing on their faith to me.

Christina was already four months old and very interested in all that was going on around her. She seemed always to have this enormous, gummy smile on her face and all who came to Holy Trinity House fell in love with her. During the day she spent most of the time asleep or playing on the floor in the family lounge, always watched and guarded by nanna Maria. When she was bored on the floor we would pop her into a bouncer chair, where she could sit and watch all that was going on. The boys were always there to talk to her, and to play with her. I could see that they were a great encouragement to

continued on next page

Not the end of the world *continued*

her and the main reason for her impatience to get up and go and to be like them, and get into the same mischief.

CHAPTER 3: Progress towards walking

When Christina was about six months old she started going to the physiotherapy department at Truro City Hospital Assessment Unit. Her physiotherapist was Janine (Jan). Christina got on very well with Jan from the first time they met.

She did lots of exercises to build up strength in her back and legs. The first sessions lasted about half an hour and were gradually increased to about an hour. Christina progressed very well and Jan was pleased with her. After a short time Jan introduced Christina to exercise on a skateboard-like contraption which had a belt fixed to it. The idea was to lay Christina on the board, belt her on to it, thus leaving her in a position to learn to crawl. She certainly didn't enjoy this. However, Jan's patience and perseverance were eventually rewarded as Christina started to use the skateboard by pulling herself along with her hands. She later learned that when she pushed with her legs she could move much faster. Her legs were quite weak at this time but the more she exercised, the stronger they became.

Jan was really pleased with her progress and when Christina was about one year old decided that it was time to try something new for her to exercise on - a very sturdy baby walker. It wasn't too long before Christina mastered this, realising that Jan was wanting her to walk. Slowly she lifted one leg and put it down and although not actually covering any ground was getting used to the concept of walking.

At home David and I would encourage Christina to walk and soon she found that when she used both legs at the same time she was able to make the walker move forward. She was like a little kangaroo propelling herself along. It was so comical. After a few months of 'cheating' in this way we managed to get the message across that we wanted her to use one

leg at a time and slowly she started to walk properly in the walker.

CHAPTER 4: Back to hospital

Only eight weeks after Christina's birthday she began to be very irritable and nothing either I did or David did was able to please her. Even the boys when playing with her or talking to her somehow seemed to upset her. She would scream at the top of her voice and then cry.

She was hot and was running a very high temperature by 7 o'clock when I decided that I must telephone the doctor to seek his advice, and he agreed to come immediately. I was aware deep down that there was something seriously wrong with her and was mentally packing a suitcase ready to go off to hospital. I thought that it might be something to do with the shunt. The doctor examined Christina and found that her temperature was considerably higher than normal, felt the area on her head around the shunt, and then asked if I had given her any medication. I pointed out that she had had her normal medication and also calpol to bring the temperature down, which had been a wise thing to give.

The doctor decided that Christina must, as I had feared, go to hospital as it was quite possible that the shunt was either infected or blocked; and then telephoned Trelisk Hospital at Truro to advise them that we were coming. There followed a mad dash to pack that bag that I had earlier packed mentally and thinking all the time of Christina's beautiful, curly hair which had just got a reasonable length and which was likely to be shaved yet again if there was a problem with the shunt. I thought then how trivial losing a few curls would be compared to losing Christina.

We arrived at Truro hospital about thirty minutes later and were soon admitted to the newly opened children's ward. A lady doctor examined Christina and decided to withdraw some cerebral fluid from the shunt



Aged 15 months.. one month after the operation to remove the shunt

and also took a sample of blood from her hands for testing. Results showed that she had meningitis.

The main problem at this stage was the fact that Christina was no longer a little baby but now 14 months old and certainly not in a mood to lay still and allow some stranger to stick needles in her head! She screamed and fought for nearly an hour before eventually, with the aid of myself, two nurses, and the doctor, the necessary samples were taken. Mr Gossman came to do his rounds and soon arrived at Christina's cot. Seeing that she was not well at all, he decided to operate the following day.

Scan

Mr Gossman went to see Christina after the operation and seemed happy with the way that it had gone. He told me that he had removed the shunt from the front of her head and had inserted a similar thing into the back of her head. He again promised to keep her under observation and said that once the meningitis had cleared they would replace the shunt. So it was just a question now of waiting for the meningitis to clear and apart from the fact the Christina was not at all happy about the drip in her arm, which had to remain there for ten days, we needed to watch very carefully to monitor any sign of fluid building up in her head.

One day Mr Gossman was on his rounds and said that he would like Christina to have a cat scan as he thought that she might be able to do

continued on next page

without a shunt being fitted.

The following day I waited for the results, feeling very nervous. I should have trusted more though, Mr Gossman was smiling and told me that he did not think it was necessary to insert another shunt as Christina was only producing a little excess fluid - not enough to worry about. I was elated, although the reality of it all took some days to sink in.

I picked Christina up and cuddled her thinking how good it felt now without the drip. She felt so precious to me. Her hair had started to grow, little stubbles pricked at my face. It would soon grow and the important thing was that soon we would be able to go home.

CHAPTER 5: **Trying something new**

Christina was picking up from the operation quickly and soon started to attend physiotherapy once more. Jan was pleased with her even though the meningitis and subsequent operation, as well as three weeks in hospital, had set her progress back somewhat. She was trying hard and starting to catch up.

Each morning at home, after giving Christina breakfast, I would sit her in the walker, and she would travel all around the kitchen, just behind me all the time, checking to see what I was doing. The kitchen floor had lino on it making it much easier than carpets.

As Christina grew bigger Jan tried her with a rollater, which is a little like a walking frame with front rubber wheels. At first Christina was not too keen on it, she liked to stay with what she knew rather than experiment with new things. However, with the help and encouragement from Jan she soon began to exercise with it. We took it home with us and I was gradually able to get Christina to use it in the way that Jan had shown us, and little by little she started to co-operate with me although she was always glad when it was set aside. When we were unable to practice with the rollater we would pop her into the walker, using that as an exerciser.

It was often difficult for us to spend time with the children at Holy Trinity House, as we would normally have done living in a private house. David



Christina walking, aged 2

found this particularly hard as we often had a lot of people staying there, or some kind of event would be set up which meant that we would be working from 7 am until 9 pm. After much prayer and thought, we decided, when Christina was about 17 months old, that we should leave Holy Trinity House and establish a family home once more.

We moved to Par and soon, with Andrew and David Jnr already at school and enjoying it, settled down to new routines. But problems began to show.

CHAPTER 6: **Another operation**

About the middle of July I noticed that yet again Christina was becoming very irritable, screaming at the boys, even when they were helping her. This was quite out of character for Christina who was always full of fun and laughter, especially when her brothers were in attendance. I wondered what it could be. Not one of the symptoms that I had been warned to look for were occurring, but she was undoubtedly not her usual self, and also off her food. I decided to keep a check on her, and the next day she seemed to be back to normal again. However, the following day she was irritable and no one could placate her. As it was coming up to the weekend, and we had an appointment for the

Monday to go to Plymouth for a scan we decided to wait.

I told Mr Gossman about Christina's behaviour before the scan and then waited for the results which would show us what was happening to her. Apparently, the fluid was building up in her head and whilst there was no immediate danger, he felt that it would be wise to link up the shunt again. I can't say that we were too surprised. It was arranged for Christina to have the operation a week later, which would give me the opportunity to arrange things at home for the family.

There was no change in Christina's condition during that week although we were pleased when the day came round for us to go off once more to Plymouth hospital. She had the operation just a couple of days later and it was totally successful.

*Part two of
Christina's story
will continue in
the next issue of
LINK - Sept/Oct.*

holidays

● Broadlands Explorer

This is a specially designed 52 seater boat with a hydraulic wheelchair lift, special toilets and a rest room where medication can be administered privately. Since it was launched last July, the Explorer has carried over 3,000 passengers including disabled and elderly people, as a result of a growing awareness of the problems experienced by disabled visitors to the Norfolk Broads.

For more details of their day and half-day cruises, contact Broadland Passenger Craft Ltd., Wroxham, Norfolk, NR12 8UD. Tel: 06053 2527

● London at a price you can afford

Ten of the rooms at the Tara Hotel have been refurbished and adapted for visitors who are disabled. There are specially equipped bathrooms, helpful electronic equipment, as well as widened doorways. Two have extra equipment for very se-

verely disabled guests - bath hoists etc. Eight other rooms next to the adapted ones are linked by communicating doors and intercom for able-bodied members of the family, friends or escorts

The London Hotel for Disabled People Ltd., a registered charity which raised money for the rooms, made sure that the design and adaptations were done in consultation with disabled people and occupational therapists.

Through the visitors' club which costs only £1 per year - set up by LHDP - these rooms can be booked at a generous discount: £35 per person per night (normally £63) for a single room, and £50 (normally £76) for a shared room. All prices are inclusive of VAT and continental breakfast.

The hotel is situated in central London - in Scarsdale Place, Kensington, W8 5SR - an ideal base from which to explore the best that the capital has to offer.

For further information on the Visitors' Club, contact the John Grooms Association, 10 Gloucester Drive, Finsbury Park, London N4 2LP. Tel: 01 802 7272.

● Access in Israel

Pauline Hephaistos Survey Projects, which produces Access guides, has recently published an updated version of Access in Israel. Written for the disabled visitor, it covers all the main tourist sights, as well as giving details on accommodation and access.

It is available from Pauline Hephaistos Survey Projects, 39 Bradley Gardens, West Ealing, London W13 8HE. Please enclose with your order a donation of at least £3 to cover costs.

● Bahamas bound

The Jubilee Sailing Trust has released details of an exciting opportunity for physically disabled and able-bodied people to crew a sailing ship together on short voyages around the Bahamas. The specially built square rigged sailing ship the Lord Nelson has a programme of 10 one week voyages, starting mid October this year and ending in April next year. The cost is about £1,000 which includes the flights out and back to Grand Bahama. The voyages start from Freeport.

For more details contact the Jubilee Sailing Trust, PO Box 180, The Docks, Southampton SO9 7NF. Tel: 0703 631395.

Reporting from Scotland

In the last LINK, in the three pages of local association news, we carried an interesting story/caption about a young man from Scotland, Gordon Rainey, who works as an international directory enquiry operator. By putting the story where we did, we certainly didn't mean to imply that Scotland is one of ASBAH's local associations. We should, of course, have separated it in some way.

As requested by the Scottish Spina Bifida Association we are now happy to print verbatim the apology they suggested:

"We apologise for the misleading information on page 8 of LINK issue no. 116 (May/June 1988) where an item about Gordon Rainey, of Irvine in Scotland, conveyed the impression that the Scottish Spina Bifida Association is one of ASBAH's "Local Associations". This is, of course, quite wrong, since the Scottish Spina Bifida Association, founded in 1965, has

always been an autonomous, self-financing, independent Scottish Voluntary Organisation, which seeks to improve the quality of life for those of all ages in Scotland with spina bifida and/or hydrocephalus and/or allied disorders. We trust this clarifies the position of the Scottish Spina Bifida Association".

A voice to be heard

Gordon Clarkson (right) has got himself into a position where he is able to make sure that the local 'powers that be' think more about people with disabilities.

Gordon who has spina bifida has recently been elected as a district councillor in Edinburgh - the city's first disabled councillor.

Gordon said "I will use my position to make sure the council does not forget about the disabled. It is not something I will go on about con-



stantly, because I am interested in other things, but I have a voice for disabled people and I intend to use it".

Photo: Edinburgh Evening News

Newslines NEWSLINES Newslines

● The Greater London Association for Disabled People (GLAD) has produced a comprehensive guide to the numbers of disabled people in London.

It analyses the different sources of information and definitions of disability. It estimates that about 10% of the population in London is disabled.

Single copies are available free on receipt of a large stamped addressed envelope. Bulk orders can be supplied - prices will be quoted on request.

Available from GLAD, 336 Brixton Road, London SW9 7AA. Tel: 01 274 0107.

● Tunstall Telecom, a company involved with communications, has recently released details of its national caring awards scheme, which is now in its eighth year. The awards scheme, split into the two categories of Individual and Organisation, seeks nominations from people deemed to have improved the quality of life for elderly and disabled people.

The winner of the Individual award will receive a holiday up to the value of £1,000. The Organisation award winner will be given a cheque for £5,000 to be spent on a nominated project designed to improve the lives of elderly and disabled people. The closing date for nominations is September 30 this year.

Details from Tunstall Telecom Ltd., Whitley Lodge, Whitley Bridge, Yorkshire DN14 0HR.

● A vehicle design featuring an unmatched degree of passenger access has been announced by a firm based in County Durham. The vehicle, the result of extensive design work and consultation with the Dept. of

Transport's Disability Unit and the Transport and Road Research Laboratory (see feature on pages 20/21), has many features previously thought to be impossible with conventional vehicle designs. Among its features are a single-step of under 12" to the interior, extra wide doors and a flat interior floor.

For product details contact Barry Connor, City Vehicle Engineering Ltd., Hackworth Industrial Park, Shildon, Co. Durham DL4 1HF

● The British Computer Society (BCS) has launched a two year project to harness the use of information technology so that many working disabled people can be more creative and productive. The project will concentrate on employment, to allow the Society to find the best way of demonstrating to employers the relationship between information technology and disabled people.

The BCS hopes the initiative, spearheaded by Prof. Stephen Hawking of Caius College and GEC Computer Services employee, Geoff Busby, who are both disabled, will be taken on board by employers throughout the country.

Details from the BCS, 13 Mansfield Street, London W1M 0BP. Tel: 01 637 0471.

● Ford dealer, Crimble of Staines Ltd. in Middlesex will be holding a Mobility Weekend on Sept 3 and 4. Representatives from the Disabled Drivers' Motoring Club and Banstead Mobility Centre are expected to

be there.

For more information, contact Crimble of Staines, 268 London Road, Staines, TW18 4JQ. Tel: 0784 59311.

● The London Museums Service has published a new access guide to London museums.

For a copy contact the London Museums Service, Barbican, London EC2Y 8AA.

● British Rail has brought out an updated version of 'British Rail and Disabled Travellers' leaflet which gives general details of facilities currently available to make rail journeys easier for disabled passengers.

Copies of the leaflet are available from principal BR stations and travel centres.

● Six posters which depict the integration of disabled people at work have been produced by Photo Co-op. The co-op's aim is to educate both employers and the public that disability does not necessarily present obstacles to employment. The posters come in two colours, size A2, and are laminated in a plastic seal. A full set of six costs £15.

Available from the Photo Co-op, 61 Webbs Road, London SW11 6RX.

● The Commonwealth Institute in London has produced a leaflet outlining facilities that are available for disabled visitors.

For a copy contact the Commonwealth Institute, Kensington High Street, London W8 6NQ. Tel: 01 603 4535

● The Disabled Living Foundation is running a one day course on 'Electric and Manual Wheelchairs'.

The course, which will look at which wheelchairs are best suited to individual needs, will be held at the Foundation, which is in London, on December 7 or December 8.

Full details on this and other DLF courses from the Disabled Living Foundation, 380-384 Harrow Road, London W9 2HU.

● The Disability Unit at the Dept. of Transport has new telephone numbers: These are 01 276 5255 /5256. The address is still: Disability Unit, Room S10/21, Dept of Transport, 2 Marsham St., London SW1P 3EB.

● Contact A Family, the organisation for parents of children with special needs, launched its nationwide 'Contact Line' link-up service last month.

The organisation hopes that by having this facility, it can reach a greater number of families who are isolated.

Details from Contact A Family, 16 Scrutton Ground, London SW1P 2HP. Tel: 01 222 2211.

● East Midland International Airport has published a leaflet outlining facilities for disabled people.

For a copy write to the Airport at Castle Donington, Derby DE7 2SA

● Toys for the Handicapped is an organisation which can supply toys for disabled children and young adults. It also publishes a free catalogue.

Contact Toys for the Handicapped, 76 Barracks Road, Sandy Lane Industrial Estate, Stourport-on-Severn, Worcs DY213 9QB. Tel: 0299 827280.

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MAVIS will steer you in the right direction!

The Mobility Advice and Vehicle Information Service, known affectionately as MAVIS, opened in December 1985 at the Department of Transport's Road Research Laboratory at Crowthorne in Berkshire.

The Department decided to set up its own centre, initially on a two year pilot basis, to expand the services already provided to people with disabilities and to find out the most effective way in which advice of this kind, could be provided throughout the country.

The Centre, which is part of the Department's Disability Unit, has a staff of three: a consultant driving adviser, who assesses the needs of people with disabilities; an administrative manager; an administrative assistant. They provide personal advice and information through individual assessments of disabled people who visit the centre and they also provide a comprehensive information and advice service

From an article by Ann Frye, Department of Transport Disability Unit that appeared in *The Independent*, the internal magazine of the Civil Service



Advice and demonstration for a client at MAVIS

on all aspects of transport and mobility by letter or telephone - soon to be enhanced by the setting up of a computerised information data base.

MAVIS is open to people who have never driven before, to those who have become disabled since learning to drive and to experienced disabled drivers who just want to change their cars. Disabled people who want to travel as passengers are also catered for; so, too, are disabled drivers who want to familiarise themselves with a new car or new controls away from the public road.

Continued on next page

MAVIS continued from previous page



Static car rig at MAVIS

Before visiting MAVIS, clients must have gone through the licensing process and obtained at least a provisional driving license. This is a means of ensuring that anyone with a medical bar to driving is picked up by the licensing centre (DVLC) before they have become too hopeful about the prospect of driving.

Experience is not a requirement. Many of the clients who come to MAVIS have never driven before or even sat in the driving seat. With such clients, the first part of the assessment is made on a static rig (see above) which simulates the front half and controls of a car, and on which, strength, grip, and reaction times can be measured, seating position can be judged and a basic assessment made of a person's physical strengths and weaknesses.

The greatest asset of the centre is the wide variety of adapted cars which are available for test drive. There are currently 15 vehicles, ranging from a Mini to a Vauxhall Cavalier, including the centre's latest and most prized acquisition - a Transit van fully adapted to be entered and driven independently by a severely disabled wheelchair-bound person. Every vehicle is fitted with hand controls (from a variety of manufacturers) and other adaptations, from the simplest push/pull accelerator/brake levers to sophisticated remote steering system. Wheelchair hoists, transfer boards and swivel seats are also included in the range of equipment on display.

MAVIS makes full use of the extensive private road system available at the Transport and Road Research Laboratory. This system includes a circuit which simulates most urban driving features including roundabouts, pedestrian crossings, traffic lights and hill starts. All the cars are also fitted with dual controls so that even those with no driving experience can feel what it is like behind the wheel without any risk to themselves or other road users.

Clients at the centre can try out as many of the cars as they choose, comparing one vehicle or set of controls with another; in fact, going through very much the same process as anyone without a disability would by going around car showrooms and asking for test drives.

MAVIS and drivers or prospective drivers with spina bifida/hydrocephalus

Comment from Mrs Leonie Holgate, ASBAH's Mobility Adviser:

The service offered by MAVIS is of particular benefit to ASBAH members who have a full driving licence or to parents, relatives, friends etc. who regularly transport a disabled person in their car and wish to look at alternative vehicles. MAVIS offers an excellent service from the practical point of view, but cannot fully assess the ability to understand and control a car in complex traffic situations. Most of our young members who have hydrocephalus, with or without a shunt system, are strongly recommended to have a driving ability assessment, which MAVIS, at present, is not in a position to offer.

DVLC will often refer people with hydrocephalus to Banstead Place Mobility Centre or to one of the other centres which have medical staff involved, and who can perform a full driving ability assessment. In the list below, the asterisk * indicates those centres that can carry out the full psychological assessment recommended for anyone with hydrocephalus.

*Banstead Place Mobility Centre **
Park Road, Banstead, Surrey SM7 3EE.
Tel: 0737 351674

B.S.M. Disability Training Centre,
81 Hartfield Road, London SW19.
Tel: 01 540 8262. Ext 201

Derby Disabled Driving Centre,*
Kingsway Hospital, Kingsway, Derby DE3 3LZ
Tel: 0332 371929

MAVIS. Dept of Transport,
TRRL, Crowthorne, Berks RG11 6AU
Tel: 0344 770456

Mobility Information Service,
Unit 2A Atcham Estate,
Upton Magna, Shrewsbury, SY6 6UG
Tel: 0743 77489

N.Ireland Council on Disability,
2 Annadale Avenue, Belfast BT7 3JR.
Tel: 0232 491011

Stoke Mandeville Hospital,
Occupational Therapy Workshop,
Mandeville Road, Aylesbury, Bucks, HP21 8AL
Tel: 0296 84111

Tehidy Mobility Centre,*
Tehidy Hospital, Camborne, Cornwall TR 14 0SA
Tel: 0209 710708

Vehicles for the Disabled Centre,*
Astley Ainslie Hospital,
133 Grange Loan, Edinburgh EH9 2HL
Tel: 031 447 6271, 031 667 3398

Wales Disabled Drivers' Assessment Centre,
18 Plas Newydd, Whitchurch, Cardiff
Tel: 0222 615276 (See page 23 for details of the Show on July 23).

APPEALS NEWS

Pigeon racers once again show their support

Following our report in the February LINK, ASBAH was invited to send representatives to Doncaster to collect a cheque from the British Homing World Show of the Year.

Moyna Gilbertson, Executive Director and Douglas Jack, Appeals Director attended and ASBAH was fortunate enough to receive a cheque for £16,000 which brings to over £120,000 the total money received from our friends in the pigeon racing world over the years. Such generosity is a great encouragement to us all.

This year the Royal Pigeon Racing Association felt they would like a little 'razzamatazz' and we were able to get the assistance of Miss Yorkshire TV - Zoe Bolsover from Sheffield, who made an attractive contribution to the proceedings.

A ripping day at Ripon

The Ripon Race Day took place at the end of April and raised a larger sum than ever before. The weather has often been a source of anxiety at this event, but this year it remained dry after a little early morning snow, whereas many parts of the country had torrential rain.

The raffle draw was carried out by Richard Whiteley, a presenter for Yorkshire TV.

It has unfortunately proved necessary to abandon the proposed fashion show in Newport (Gwent)

HULL GREYHOUND EVENING

SAT OCTOBER 8, 1988

First Race 7.30 pm
Hull Kingston Rovers
Greyhound Stadium

This is a joint venture between Hull local association and ASBAH national, which we hope will generate funds for both.

For admission ticket, basket meal (chicken /scampi and chips), race card and admission to disco after race meeting, please contact Mr Philip Brown, Chairman of Hull local association, tel: 0482 857165. Ticket prices will be about £5 each.

For those interested in sponsoring a race for £200 or nominating a dog for £5, which could win you a prize, please contact Anna Khan at national ASBAH, tel: 01 388 1382.

On the shop front

Efforts to extend our charity shop base have not so far yielded any tangible result and, in fact, we are likely over the next year to reduce our existing holding by two. The shop in Fareham is in a redevelopment area and we are disposing of Swaythling (Southampton) because of disappointing trading. However, new shops are fairly firmly in prospect; two in South Wales, one in Porchester (Hants) and one in Maidstone in Kent.



Go-karting day in prospect

A new enterprise in the form of a go-karting day is being worked on, and it is hoped that it will take place at Brand's Hatch on Friday November 18, if we get sufficient entrants.

Lloyds 'veterans' take to the field

Earlier this year a football match was again played between Lloyds underwriters and brokers. The organisers decided that last year's minimum age limit of 37 was opening the door to too many immature youngsters, this year the limit was raised to 38!

Many arms in the insurance industry were twisted to supply sponsorship, and a truly magnificent total of £6,800 was donated to ASBAH, with a similar amount going to Mencap. The generosity and goodwill of our friends in the insurance industry is greatly appreciated. (See photo below).

ASBAH Appeals Director, Douglas Jack (right) photographed with Joe Lavers of U.I.C. Ltd, the organiser of the insurance football match (see story above). Douglas, on behalf of ASBAH, received cheques totalling nearly £6,500 from Joe Lavers.

Advertising

FOR THE USE OF LOCAL ASSOCIATIONS
AND OTHER READERS

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

Cheque or postal order payable to 'ASBAH'

Adverts for the next LINK (Sept/Oct) should be in by
August 15. Send to: The Editor, Mrs Sue Gearing,
The Gables, Long Lane, Wrington, Avon, BS18 7NE.
Tel: 0934 862279

HOLIDAY ACCOMMODATION

BORTH, Nr Aberystwyth. 6-berth de luxe holiday home.
Licensed site. Suitable for wheelchair users who live inde-
pendently. Details: Mrs J. Carter, 1 Meadow Road, Craven
Arms, Shropshire.

ISLE OF WIGHT. Very well equipped chalet with easy
wheelchair access at **Brambles Chine, Freshwater.** Sleeps
6. Indoor heated pool, club, shop. Details: Ring or write:
Mrs S. Gully, Old Princelett, Apse Heath, Sandown, Isle of
Wight. Tel: 0983 863354

SELSEY, Sussex. Six berth purpose built fully equipped
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Details: Mrs C. Bugden, 27 The Grove, Sholing, Southamp-
ton SO2 9LT. Tel: 0703 444921.

PRIMROSE VALLEY Fully adapted luxury caravan.
Sleeps 6. Bath/shower. Ramp. Many facilities on site;
Details: Mr J. Adams, 105 Blakey Close, Redcar, Cleve-
land. Tel: Middlesborough 472920

RYE HARBOUR, Sussex Fully equipped mobile home,
adapted for wheelchair users. Sleeps 4. Clubhouse on
site. Details: Mr P. Borthwick, 170 Hollington Old Lane, St
Leonards, E. Sussex. Tel: 0424 51145

FAIRBOURNE. Very well equipped bungalow with easy
wheelchair access. Two bedrooms. Sleeps 6. Self catering.
Five minutes from beach. Details: Midland ASBAH. Tel:
021 771 0371.

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- ♿ Try The Latest Accessories ♿
- ♿ Bring The Family ♿

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Nr. BARRY, S. GLAM
23rd JULY 1988 at 10.00 a.m.

and

POLICE HEADQUARTERS
COLWYN BAY, NORTH WALES
18th SEPTEMBER, 1988 at 10.00 a.m.

ENTRY FORMS AND FURTHER INFORMATION FROM—
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