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Association for Spina Bifida and Hydrocephalus/ASBAH 20p July/August 83

- ★ Day of Action
- ★ Sheltered Industrial Groups
- ★ 70 years with spina bifida
- ★ Embryology
- ★ Answering Service
- ★ Housing opportunities
- ★ Leisure ideas

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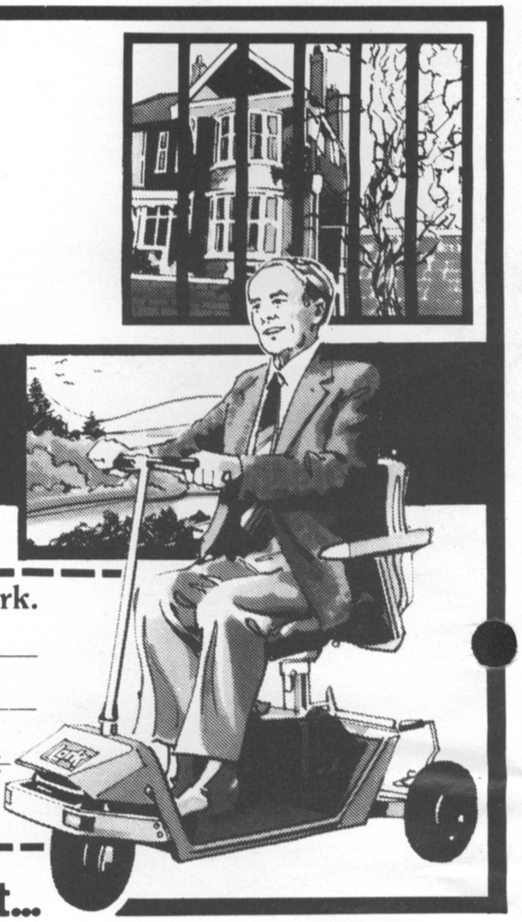

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Association for Spina Bifida and Hydrocephalus/ASBAH

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Tavistock House North,
Tavistock Square,
London WC1H 9HJ.
Registered Charity No. 249338
Tel: 01-388 1382/5

Patron:
HRH The Duchess of Gloucester

Chairman: Mr D M Bryant

Hon Treasurer: Mr R H Smith

ASBAH has an experienced staff ready to help with any problems relating to those with spina bifida and hydrocephalus.

Executive Director:
Miss M P Gilbertson, MCSP

Finance Director:
Mr F G Armour, FCA

Appeals Director:
Miss Judy Kay, MIPR

Services Director:
Mrs B Newman

Disabled Living Advisers;
Miss Mary Barton, MCSP
Miss Andrea Robinson, SRN, SCM, HV
Miss Mary Small, DIP COT, SROT

Fieldwork Co-ordinator:
Mrs T Cole

Project Leader at Five Oaks, Ilkley, Yorks.
(Tel: 0943 609468):
Mr Jim Stanton

Information Officer:
Miss B Holland

Link Editor:
Mrs S I Gearing

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Campaign calls for end to discrimination against women

ASBAH is one of over 50 organisations campaigning to end the discrimination against married and co-habiting women when it comes to the Invalid Care Allowance and "Household Duties Test" for HNCIP (The Housewives Non-Contributory Invalidity Pension).

Last year a week of Parliamentary Action was held in July and received considerable support from Members of Parliament and wide coverage in the media.

In their election manifestos, the Labour Party and SDP/Liberal Alliance pledged to extend the ICA to married and co-habiting women and to abolish the "Household Duties Test" but the Conservative Party, now the Government, gave no such commitment. However, Ministers in the last Parliament agreed that the benefits did discriminate against married and co-habiting women and basically it was a matter of costs: the estimated cost of extending ICA is £60M (nett) and of abolishing the "Household Duties Test" £250M (nett). These figures can be disputed: for example they do not take into account savings on the cost of administering the test nor the millions of pounds carers are saving the country in social services and residential care. However, the basis of the campaign is that the benefits discriminate against women and this fact by itself should make them a priority for action.

The ICA/HNCIP Steering Group is organising more days of action this month — July, the third anniversary of the National Insurance Advisory Committee's review of the test recommending it be abolished or phased out. The plans are for:—

8/9 July	Lobbying MPs in their constituencies, use of local media, publicity events, eg picket of social security office.
13 July	Presentations to the Prime Minister of a cheque for her to sign giving ICA and HNCIP to the women presently denied it. Demand to the Trades Union Congress and Department of Employment to investigate "wages and conditions" of carers. Press conference at the House of Commons.

It is important that Members of Parliament, *especially new MPs,* know the strength of the feeling on this issue.

If you would like more information about the campaign, about organising local activity and an information pack please contact Raewyn Stone, RADAR, 25 Mortimer Street, London W1N 8AB (telephone 01-637 5400) or Amanda Jordan, Spastics Society, 12 Park Crescent, London W1 (telephone 01-636 5020).

Raewyn Stone, Co-ordinator ICA/HNCIP Steering Group

COVER PHOTO: The camera has captured a fond farewell between two young people who became friends on a short independence training course. Sarah (left), aged 10, is being seen off by Luisa after a mini independence course last September run by ASBAH at Hilary House, Friston, near Aldeburgh, Suffolk.

What do you think of your car?

THE INSTITUTE of Consumer Ergonomics (ICE) is undertaking a research project for the Department of Transport, to investigate the problems which disabled and elderly people may have in getting in and out of ordinary cars. The results of the research will be used to help manufacturers to design suitable cars, and to enable disabled drivers and passengers to select a car which will allow convenient access.

In order to do this ICE needs to know what sort of cars are being used; whether you have any problems or difficulties getting into and out of the car which you regularly use; whether you have adapted the car in any way (for example by adding cushions, swivel seats, control conversions, etc.) and what you would look for in a new car.

If you are interested in helping with this research, or know of somebody who might, please contact ICE, *Freepost*, Loughborough, Leicestershire LE11 0BR.

Special Aids insurance scheme

THE SUN ALLIANCE Insurance Group is offering a new insurance for disabled people. Called "Special Aids Scheme For Disabled People" it covers electronic aids (whether owned or on loan) used at home, school or work, and provides "all risks" insurance, cover against fire, theft and accidental damage (including 'in transit') anywhere in Britain. Details from Sun Alliance, 12 Rickfords Hill, Aylesbury. Tel: Aylesbury 24688.

Coach for hire

ROYSTON'S COACHES has a purpose-built luxury coach for hire with an electric side lift. There is seating for 30 people, reclining seats with holding armrests and restraining straps, two tables. It is available for hire to any group or organisation anywhere in Britain.

For further information contact: Mr J Walton, Royston's Coaches, Bowesfield Lane Industrial Estate, Stockton-On-Tees, Cleveland. Tel: 0642 616696.

Gordon Perry of Chadwell Heath, Romford, Essex, winner of the first wheelchair marathon in London in the Spring receives a new lightweight training wheelchair from Ken Livingstone, Chairman of the GLC, on behalf of Downs Surgical. Also pictured is John Walker of Downs.

Integration in ordinary schools

DIANA BAILEY, an occupational therapist, has been involved in introducing an independence training programme for physically handicapped young people in an ordinary comprehensive school. She is studying the effectiveness of the programme and planning for its future use, and would be pleased for information about similar programmes for disabled students in integrated school situations.

Contact Diana Bailey, Community Occupational Therapist, Civic Centre, Huddersfield, HD1 2NL.

BBC offers programme tickets

IF YOUR ARE visiting London and would like to see a current television programme being recorded, some BBC Studios have facilities to accommodate two wheelchair users accompanied by escorts. If you are interested please contact the BBC Ticket Unit, BBC, London, W1, Tel: 580 4468, Ext 5492, giving the date you will be in town. The Ticket Unit must be informed of the name of those wishing to attend and they may be able to help with parking if you provide the vehicle registration number.

London life on 'the end of the line'

ARTSLINE is a free telephone advice and information service about the arts and entertainment scene in London. Its prime aim is to bring London's unique and varied entertainments to the notice of people with disabilities.

It will tell you things like what's accessible, how easy and close parking is, where the loos are, and whether you can get transport to and from where you want to go. Advice is available, too, about a place's attitude towards wheelchairs, and where you will need to take a companion. Artsline may even be able to help with people who would be happy to go along with you, if necessary.

It will tell you where to go for rock, or fringe theatre, ballet, Beethoven, or an exhibition of impressionist painting. It can give help too with suggestions for arts activities that you can participate in. All you do is ring: 01-625 5666.

Music makes news

THE DISABLED Living Foundation has started a Music Advisory Service Newsletter.

If you would like to receive a copy please send a large stamped-addressed envelope to Daphne Kennard, Music Adviser, DLF, 346 Kensington High Street, London W14 8NS.

Double celebration

CONGRATULATIONS to Jackie and Philip Parkinson who became the proud parents of twin daughters, Gemma and Jodie, on June 15. Jackie has spina bifida and is in a wheelchair. Her marriage last year was featured in LINK.

The twins each weighed 3lbs, and were born by caesarian section at Guy's Hospital, London — a hospital that has proved very supportive and caring to Jackie and Philip. They have even had Philip in for 'classes' in how to look after babies!

Another spina bifida mother of twins, Karen Craig of Broadstairs, Kent, has been to visit Jackie. Her twins are 18 months old — Daniel and sister Robyn.

Are there other twins born to any LINK readers?

prevention

Is the vitamin trial justified?

AFTER a great deal of discussion and hesitation, the Medical Research Council has decided to go ahead with a trial on the value of vitamin supplementation in would-be mothers who run a high risk of having spina bifida babies or similar malformations. The reason for the trial is excellent, namely that the Committee and everybody would like to know definitely not only whether vitamins are of value for the prevention of these defects but which of the vitamins are necessary and in what quantity to get the best results.

At present the evidence is from Professor Smithells and his many colleagues who in the *Lancet* in May 1983 report that they have added substantially to the number of women treated with Pregnavite Forte F. The findings of earlier research were published two years earlier.

From this it is evident that the combination of vitamins, as used, was effective in reducing the risk about seven-fold compared with the random risk for women who did not have vitamin supplements. This was based on well over a thousand women, about half of whom had vitamin supplements and half of whom did not.

It seems to me, therefore, unjustified to start a new trial by the MRC in the way it is set out. It has been said that a quarter of the women voluntarily enrolling in the trial would receive no active vitamins and, therefore, would be expected to run the risks of the untreated case, namely approximately 5%. It is not true, however, that only a quarter would run such a risk. It may be half or three-quarters. This is because they would have four groups.

One would have the multi-vitamin preparation as used by Professor Smithells and colleagues and in whom the same kind of good results would be expected. A second group, however, would only receive the vitamin B ingredients of the multi-vitamin tablets without folic acid. If, therefore, folic acid is the one active ingredient or it is necessary to have folic acid as part of the beneficial substances, then the group without folic acid will also be unprotected; that now comes to 50% of them unprotected.

The third group will receive folic acid alone. Consequently, if one or more of the other vitamin B complex are necessary for protection, then this group will be unprotected. It is evident, therefore, that it could be 75% of women who will be unprotected if they are willing to enter into the trial.

I think it is essential that women at risk should realise this before agreeing to take part in the trial. I find it very difficult to believe that one single woman, would be willing to do this if the full facts are explained to her, knowing that the multi-vitamin preparation with folic acid is available, freely prescribable and will give a seven-fold reduced risk of having a dead or handicapped baby.

Prof John Lorber MD, FRCP, Sheffield

Comments on Prof. Lorber's Letter

PROF. LORBER rightly states that there are excellent reasons for the MRC Trial, but his analysis of the facts leads him to conclude later that the case for Pregnavite Forte F is proved. In fact, Professor Smithells in all his writings is careful not to claim proof. His recent publication of results with larger numbers does not make for any more certainty since the method used was the same and open to the same serious pitfalls of interpretation. Therefore, the world's statisticians are not convinced, and that is a major weakness. Further, there is as yet no clear indication as to whether it is the folate, the other vitamins or a combination that is effective. Probably different combinations offer some benefit, so it is futile to predict what percentage of women in the trial will be protected.

Little has been said about possible dangers. It may be thought that there could be no risk in taking any of these vitamins, but there are known side effects which must be measured. 5% of mothers taking part in the trial have a risk of bearing a NTD child, but 100% are exposed to any possible complications, so benefits need to be at least 20 times as great as the dangers. If we were to give the pills to all pregnant women (who run a risk of 1:2000 of a NTD birth) then the benefits would have to be more than 2000 times more than the risks.

It may be that we have now reached the point where a mother at risk could be advised to take Pregnavite Forte F, but we are a long way from knowing what is best for the population as a whole. In other words, we may now have a chance of preventing 1% of NTD infants (those born to mothers at risk); we still cannot control the 99% who are born to unsuspecting mothers. Trials such as those done by Professor Smithells will get us no further however long they are continued. The *only* way to determine the benefits and drawbacks of different combinations is to conduct a properly designed randomised trial. The MRC have organised dozens of these in different branches of medicine and know exactly what is needed. I have no doubt that the trial is necessary if we are ever to have a national programme of prevention.

The ethical problem is a different matter. It is unfortunate that, whereas it is the national welfare that is aimed at, it is the mothers at risk who are needed to furnish the proof. When a doctor advises a course of treatment, it must be for the benefit of the individual patient, or in this case, the unborn child. The only way this can apply in the proposed trial is if knowledge were to be gained which would help the child of a future pregnancy. Any would-be parents entering the trial need an element of altruism, a willingness to take a step in the dark to benefit future generations. Unlike Professor Lorber, I believe that such people do exist, but the main threat to the trial is that their numbers may be insufficient. ASBAH's role is to make certain that all volunteers are fully aware of all the implications and that consent is obtained honestly and openly. We have undertaken to counsel all applicants and will not hesitate to discourage them if they seem unsuitable.

Duncan Forrest, Chairman, ASBAH Medical Committee

Public
health
Future
civ-soc.


stretch it to fit !
roll it mould it ..

Barnardo's puts variety into holidays

BARNARDO'S Yorkshire Division has recently launched a new holiday scheme providing a variety of different holidays for disabled young people and able-bodied escorts.

There are several projects planned throughout the Summer and Autumn months, chosen to cater for as many tastes as possible.

There's a course on using video equipment together with a theatre and music workshop at Ripon College in September. For five days the group will take over the college, complete with swimming pool and games facilities.

For the more active there's a chance to try rock-climbing, abseiling and canoeing with experts at Carlton Lodge near Thirsk at the end of August.

A caravan holiday at Bridlington, and a week at a bungalow on the Norfolk Broads are planned, as well as a barge cruise on the Grand Union Canal in October.

All the holidays have the benefit of qualified assistance. Staff and volunteers will provide support on a one-to-one basis. No handicap is too severe, and Barnardo's welcomes enquiries and suggestions about the scheme.

If you 'buy' one of these holidays you can also get your own friend to go as a helper with you. Their expenses will be paid fully by Barnardo's. You only pay for yourself.

Further details and prices from:
Mrs Iris Linford, Volunteer Activity Organiser, Barnardo's, Roberts House, 14 Wetherby Road, Harrogate, Yorks. HG2 7SD.

Facilities for the Disabled — Peak National Park.
Available from Information Centres in the area or from the Peak National Park Office, Aldern House, Baslow Road, Bakewell, Derbyshire DE4 1AE.
Please send s.a.e.
THIS 1983 edition gives information on attractions both in the Park and surrounding area.

Cruising along in 'Doubloon' — a canal narrowboat for family holidays. It is for those who want to take a normal holiday but need the assistance of special facilities for a disabled member of the family. 'Doubloon' will take up to six people.

'Doubloon', run by The Potteries Canal Cruising Company, is a sturdily-built boat that is easily handled and gives families the pleasure of exploring the Trent & Mersey Canal, the famous 4-Counties Ring, and the beautiful Caldon, and Macclesfield canals. See foot of col. 3 for booking details.

New youth camp

FOR THOSE who like the 'great outdoors', news of the new Frontier Activities Camp in the Nene Valley, Northampton, will prove of interest.

This new Camp available to all kinds of youth groups — including groups of handicapped young people — is run by the Northamptonshire Association of Youth Clubs.

It provides individual and private camping grounds with plenty of space for all, a Field Studies Centre with log cabin accommodation, a club room, and in addition an all-weather sports area, an assault course, barbeque area, and a private riverside dock.

The Centre and camp are available and suitable for all kinds of handicapped young people.

Complete freedom will be given to recognised groups to run their own camping activities and programmes assuming they come up to basic safety standards.

All kinds of activities are possible from this beautiful site:— camp craft, adventure training, canoeing and boating, rafting, sketching and painting, angling, map reading, orienteering, field studies, archery, botany and ornithology.

Enquiries to: NAYC Frontier Activities Camp Office, Hereward Wake House, Gladstone Road, Northampton NN5 7EG.

Flamingo proves popular

SINCE its conversion in 1981, (IYDP), the passenger boat 'Flamingo' has proved popular with disabled people and groups who have enjoyed the pleasure of short canal cruises from Trentham, Stoke-on-Trent.

'Flamingo', an ex-working boat, has been providing cruises in the Potteries area since 1970, and following adaptations it is capable of carrying up to 20 wheelchairs.

The boat still retains all the facilities required by able-bodied passengers, such as the bar and galley, but now has the flexibility to make cruising comfortable and enjoyable for the disabled as well.

A new feature of the cruises is that Potteries Canal Cruising Co. will gladly arrange, without additional charge, for passengers to visit other attractions in the area, such as the Wedgwood Visitor Centre, thus making up a full day's programme of activity whilst visitors are in the Potteries.

Both 'Doubloon' and 'Flamingo' can be booked from:

Potteries Canal Cruising Co., 32 The Lea, Trentham, Stoke-on-Trent, ST4 8DY; or ring David Dumbleton on Stoke-on-Trent 657507.

Nina and the Manager of Lancaster Training Services, Mr Kay. See story on facing page.

SIGS — One way of 'smoking out' jobs

ASBAH, both nationally and locally has gone into partnership with the Manpower Services Commission (MSC) to help secure jobs for individual disabled people through a scheme called SIGs — Sheltered Industrial Groups. SIGS are one of a number of schemes available through the local Disablement Resettlement Officer. Others include Special Aids for Employment and Fares to Work, etc.

What are Sheltered Industrial Groups?
The aim of the scheme is to give severely disabled people the opportunity to work for normal wages under sheltered conditions in a normal industrial or commercial setting. The number of people employed may vary from one person to five or six. In the scheme ASBAH has sponsored, one person only was placed with a host firm.

How does Sponsorship work?
A three-way agreement is involved between:

- The Sponsor — in this case ASBAH — responsible for employing the individual, paying wages and Employers' National Health Insurance Contributions (ERNIC). These costs are offset by payment from the host firm for work done, plus a revenue grant from the MSC.
- The Host Firm — which provides the job, tools, working environment and pays the sponsor for the amount of work done and a proportion of the additional costs.
- The Manpower Services Commission — who share the cost (i.e. the difference between the wages and the payment from the host firm for work done) with the sponsor. This share is 90%* in the case of voluntary bodies such as ASBAH, up to a ceiling of £2,025 per year.

What Role can ASBAH Local Association play?
THERE are two ways Local Associations can take part in the sponsorship arrangements. Agreement on the most appropriae scheme may be reached by discussion between National staff and the local committee.
Scheme A. Local Associations act as the main sponsor. This involves all the responsibilities of an employer, i.e. issuing a contract of employment; payment of wages, PAYE and ERNIC (or refunding the host firm who may act as agent in paying wages); supervising the scheme — usually involving a visit every two months; reclaiming grant from the MSC; accepting financial responsibility for the shortfall. This method may only be suitable for Local Associations who already employ paid staff.
Scheme B. National ASBAH takes on the sponsorship and, therefore, becomes the individual's employer with all the responsibilities outlined in Scheme A. Local Associations agree to find the funds annually to refund the shortfall to National (i.e. 10% of the agreed difference between the individual's work output and the 'norm'.) Secretaries can help to publicise the scheme by contacting local DRO's.

Who would benefit from a job under the SIG Scheme?
Individual disabled people whose handicap makes it unlikely that they would be able to obtain or retain work in open employment under present conditions. ASBAH's Education Training & Employment Committee has agreed to sponsor individuals, provided they have received some assessment to support sheltered employment in the area proposed. This might include a college report, work experience, TOPs or Youth Training Scheme, or assessments at an Employment Rehabilitation Centre.

How can an individual disabled person apply!
You should contact your local Disablement Resettlement Officer (DRO) at the Job Centre in your nearest town, and ask for an appointment to discuss the scheme. Take this article with you to show that ASBAH is willing to act as sponsor. DRO's should be advised to contact the Secretary of the Local ASBAH Association or National ASBAH.

This scheme offers a very attractive way for ASBAH groups to use their funds to support local disabled people in local jobs. It is more cost effective than sheltered workshops. There is little or no capital expenditure and revenue losses are much lower. The scheme also offers a much wider range of employment opportunities.

Barbara Newman
Services Director

**Provisional plans have been put forward by the MSC to increase the revenue grant to 100%.*

What is the Sponsor's Financial Commitment likely to be in a year?
Here is an example

Assuming an individual's wages to be £65 a week, (£3,380 per year), and the working capacity 50%

Sponsor pays out		*Sponsor receives.*	
Wages:	£3,380 p.a.	50% Wages & ERNIC	£1,896 p.a.
ERNIC	412	90%* from MSC	£1,796
Admin.	100 approx.	Total received	£3,692
		Sponsor left to pay	200
Total	£3,892 p.a.	Total	£3,892 p.a.

Pam Dickinson, ASBAH Fieldworker in Lancashire describes the SIG scheme that ASBAH is sponsoring.

Nina's story of success

NINA Unsworth, who lives in Heysham, Lancashire, is our first sponsored employee under the SIG scheme. She has spina bifida, but is able to walk with the aid of a single caliper.

When she left school she attended Portland Training College in Nottinghamshire for two years, where she trained in typing, telephony and general office work. After returning home, she worked occasionally as a "temp" in local offices, and she also took a refresher course at a local college, but for some time prior to her present job she was unemployed.

Lancaster Training Services, where Nina now works, is a training centre for drivers of HGVs and various industrial vehicles. Her duties are divided between general clerical work (typing letters, filing, answering the telephone) and tachograph chart analysis (analysis of mileage log discs from the cabs of lorries).

She joined the firm in July 1982 and after a training period of six weeks paid for by the Manpower Services Commission, she officially began work on August 16th.

In line with the scheme there have been various alterations to the building to make it more accessible. A connecting door was installed between two offices, low filing cabinets and adjustable chairs purchased, an extra step constructed at the entrance to make the step up to the main door easier, a hand rail and hand grip installed outside and a hand rail fitted against the wall of the staircase inside. A hailer to signal for help will be installed shortly.

It is expected that all the above will be paid for by the Manpower Services, but their slowness to respond to applications and estimates has been a drawback and in an effort to speed things up, the firm have so far footed the bill.

Both Nina and the firm's manager, Mr. Kay, seem to be satisfied with the employment arrangements. Mr. Kay finds Nina a conscientious employee who always tries to please.

Nina, herself, was delighted to have this opportunity, and she thinks the work is interesting and enjoyable. It took a little time to settle in, but she has grown used to things now, and recently she has had more responsibility since Mr. Kay is often out of the office.

The entrance to the offices where Nina works. Note the hand rail and hand grip installed outside, and the hand rail against the wall inside.

Round up . . . Round up . . . Round up . . . Round up . . . Round up . . . Round up

Going Danish proves a success

ALAN CHAPMAN of the North East Association describes a mini holiday in Denmark:

"Sailing from North Shields, 31 members of our Association headed for Esbjerg, Denmark. This was our most adventurous group trip to date, having in previous years sampled Blackpool Illuminations, Edinburgh Tattoo, a Mini Weekend in London and plenty of day trips.

"The North Sea crossing was enjoyed by everyone. Facilities for the disabled on the ship were excellent and the passenger lifts to all decks allowed the children to explore.

"After a coach trip to the picturesque town of Ribe on our first day in Denmark the highlight of the trip came on day two with a visit to the fantastic Legoland.

"The thing that really impressed everyone about Denmark apart from the friendly people, and the lack of litter and graffiti was the excellent facilities for the disabled.

Welsh run raises £3,000

LLANELLI was the setting recently for a seven mile Fun Run/Road Race to raise money for ASBAH in Llanelli. It was organised by a local charity group Sospan 7, and two young members of Llanelli Local Association took part — Gillian Slade, and Lise Pudner. Lisa on her trike took 54 minutes round the course, and Gillian using her electric wheelchair and accompanied by her uncle took longer but thoroughly enjoyed herself as the picture (left) shows.

Lawsons Frozen Food Centre, Nike — sports equipment dealers, and Gateway Building Society supported the event, and 1,200 people took part, and raised about £3,000 for the local ASBAH. (Counting was still going on when LINK went to press.)

Australians seek 'pen family'

AN AUSTRALIAN family with two children with spina bifida is interested in corresponding with a family in this country.

The Sutherlands live in Ashwood, Victoria. They have two spina bifida daughters — Robyn aged 2, who is not seriously affected, and 4-year-old Jennifer who at present is coping with the problems of double incontinence.

The address is: Mrs B Donnelly,
21 Jordan St, Ashwood 3147,
Victoria, Australia.

Shared
experience
/ support

1983 SPRING CONFERENCE 1983

As promised, LINK continues the reports from ASBAH's recent successful Spring Conference. Other reports from the Conference appeared in LINK (May/June).

Time to get together with housing associations

THERE IS 'a golden opportunity' at the present time for local groups to tap the resources of housing associations and form a partnership to build special housing for the disabled, said Mr Roger Hoad at the Spring Conference.

"Special projects of this kind are the current trend" said Mr Hoad, Director of the Family Care Housing Association based in South Wales.

The money provided by the housing association combined with the personal knowledge and expertise of a local voluntary organisation — like a local ASBAH group — could result in a very successful housing scheme.

Mr Hoad pointed out that some housing associations would be more suitable and more amenable than others, and the process from the time of approaching an association to the completion of building would not be quick.

He suggested the best approach was to contact the regional office of the Housing Corporation to find out the most suitable association, that would suit the particular needs of the voluntary group.

The housing association would be responsible for 100% of the capital cost, and where necessary might also be able to meet the cost of a warden. Only in cases where special care was needed might the capital sum fall short of the total cost. In such cases it might be possible to get 'topping up' from other sources — perhaps from the social services.

Mr Hoad said that the housing association would be responsible for the housing management, rent collection and maintenance of the property, because of their knowledge in these fields.

"When setting up such a scheme, however, make sure that you are an equal partner with the housing association, and the architect is really designing what you want."

Mr Hoad spoke about the partnership between his Housing Association and ASBAH in the building of eight flats in Newport for people with spina bifida and hydrocephalus.

He said it was important for a local group to 'get in on the scene', and suggested applying initially for share membership of a housing association.

He told the conference of the rapid growth of the housing association movement since 1964 when the Housing Corporation was set up, and the consequent decline in council building. "There is, in fact, a crude housing surplus, but the houses are in the wrong places, in the wrong condition and the wrong sizes.

"Housing associations are independent bodies registered as charities or as friendly societies. They supplement and complement the work of local authorities. Some own just three houses, others as many as 20,000. The beauty of the scheme is that no two associations are the same."

For some disabled people, housing associations could provide the chance to buy their own home — or part of it — through a Shared Ownership Scheme.

"Basically we tell the person to go out and find the house he wants (up to £30,000), and we will buy it for him. He then starts to pay us back at the rate of no more than twice times his income. He buys the house in steps of 25%. If he is buying 25% we then rent the remaining 75% portion to him. He can buy more of the house as his income improves."

Mr Hoad pointed out, however, that rental would be on a full repairing lease which meant the owner would be responsible for maintenance. It would obviously not be a suitable arrangement for some disabled people unless they could afford to pay for the maintenance.

Adaptation of the property, said Mr Hoad, could either be carried out after purchase — with a local authority grant — or possibly by buying an unimproved property and asking the local authority to renovate it incorporating the adaptations needed.

DIAL is primarily a telephone advice service which has been developed by disabled people for disabled people. It aims to provide on-the-spot information about local services and facilities and about local decision-makers.

James Woodward, Development Officer of DIAL UK (National Association of Disablement Information Advice Services) said at the Conference:

"Our volunteers go through an intensive training programme rather like that run by the Citizens Advice Bureau. They are disabled people, and by building up contacts locally in the places that matter they are able to pass on the information that you need.

"For instance it's a waste of time going to the council if you don't know the name of the right person to see. Without the right information you cannot think, act or do. By providing information we are providing the tools for learning."

From small beginnings in the Derby area eight years ago DIAL has now become national, with 65 offices all over the country, all manned.

"It is no longer just a telephone advice service. You can pop in for information or just for a cup of tea" said Mr Woodward.

The DIAL volunteers are able to lead the enquirer through the maze of benefits and services, and try to explain clearly how the information should be used. If requested, they will do it for the enquirer.

DIAL is using micro-computers now to keep up with technology in the field, and hopes that these might make it possible to recruit more severely disabled volunteers.

If you want a list of DIAL numbers, or more information, contact: Mr James Woodward, DIAL House, 117 High Street, Clay Cross, Derbyshire. Tel: 0246 864498.

'A doorbell — it's my proudest possession'

JULIA Davenport from Cheltenham — a member of LIFT national committee — talked about her fight to live the life she wants, and spoke in particular to young people of about her own age:

"Right from the beginning it's been a fight. Social workers had everything planned. They wanted me to go to college; then they were going to stick me in an old people's home. After I finished college, I rebelled. I said 'I'm not going there. I'm 18 now. You can't make me'. However, when I left college I did spend three months in an old people's home while looking for a flat and to give me time to think.

"I found somewhere to live. This was with friends, but it wasn't quite ready, so I moved from hotel to hotel. I quite enjoyed it really and I wasn't paying the bills. Social services were.

"A couple of months ago I moved house, nearer town. It has more room and central heating. My loyalties to my friends nearly stopped me from taking this opportunity but I'm glad I did. It's paradise. I have a front door with a doorbell, and it is my proudest possession. When anyone rings I can say 'Come in' or 'Don't come in'.

"I have more than one room so I can put my friends up. I get a home help two days a week. My District Nurse comes every day. I don't know what I would do without her.

"There are problems. I can't get in and out of my bath. But I go to a day centre once a week and get a bath there. Eventually social services are going to take the bath out and put a lovely shower in.

"My telephone is my greatest asset, and I am fortunate that I have friends to help when necessary.

"I can manage on my own for about six months before I need a rest. I have a very good consultant who believes in preventative medicine and lets me into hospital every six months for a two week rest before I have a collapse and need months of care.

"My furniture I got from all over the place. I bought my own cooker with money given to my by the DHSS. I had a washing machine from the Prince of Wales Trust, bits and bobs from friends, and a bed from social services. My parents, who live in America, help with money.

"I manage to work my life into a routine. I love children and take Sunday school. On Monday, Tuesday and Friday mornings I do voluntary work in a playgroup.

"I do my shopping by getting a taxi there and back. I know that I am not a suitable person to learn to drive and eventually I managed to find a helpful taxi firm. I am friendly with the drivers and they will go in for me and pick up my money. When shopping if I can't reach anything on the shelves I wait for a tall, dark handsome man and ask him to help! When it comes to roads, I normally ask a man to help me, because I'm quite heavy and you need someone strong.

"Some afternoons I lay on my bed — often to keep warm, but also because I'm prone to pressure sores.

"I am very, very happy where I am and when I'm really settled I would like to start a business as a child-minder. It would be a business that would never pay for itself, but would give immense amount of pleasure."

NELLIE BROWN

Living in East Anglia, within a few miles of each other, are two ladies in their seventies. They must be two of the oldest people in the country with spina bifida. Recently they spoke to LINK about their lives and how they and their parents managed to cope in an age when spina bifida was unheard of, and when there was virtually no help available.

Remembering how it used to be

"WHEN I was in plaster after an operation, my mother used to hire a wheelchair for me for 2s. 6d. a week and push me to and from work every day. We never had any help in those days. Life was a struggle".

Mrs Nellie Brown, now 73, remembers the not-so-good old days when she was growing up with spina bifida. She was the second of six children. They lived in Hampshire at the time and life was hard.

"When I had to go into hospital we, of course, had to pay, and my parents had to put money regularly into a club for it. "I can remember desperately needing a new pair of boots, and having to walk miles knocking on doors begging for contributions. I must have walked, painfully, about three miles", she said.

Nellie now lives on her own in a comfortable warden flatlet in Colchester. She is as good as a tonic to meet. She has a sunny personality and is full of life despite her handicap and the fact that she has been in a wheelchair for 28 years.

By and large she doesn't recall that life was unhappy, although it was tough.

When she was born, Nellie had an operation to close her back, but Southampton hospital said she wouldn't live. She was sent home and her parents left to do what they could for her. Nellie hung on to life and at the age of two found her feet. Later she went to school like other little girls of her age.

She remembers the determination of her mother in particular. "She insisted that I lived a normal life and always maintained that there was nothing really wrong with me. I took part in all sports, and certainly wasn't one to sit back in a corner.

"My mother worked so hard, and, in fact, in the end she spent several years in bed having worn herself out with overwork.

"When I had to go into hospital, we had to pay"

At the age of 14, Nellie started to have serious problems with her feet which had always turned in badly, and there began a series of operations. It was clear that she could not follow the normal route of girls like herself and go into service, but she managed to get a position, learning tailoring in a clothing factory in Colchester where the family had moved.

"I was very happy there for 21 years. It was a wonderful firm. When I went into hospital they always kept my job open for me," recalls Nellie.

She enjoyed a wonderful social life. To draw attention away from her legs and calipers she made the most of her hair, face and hands and wore eye-catching hats and capes.

In fact, she had several proposals of marriage, and at the age of 29 married a soldier.

It was a happy marriage, but short-lived. Her husband was killed in the war flying back from France. Nellie was then six weeks pregnant.

Although she was told she would have to have the baby by caesarian section, when it came to it she gave birth, naturally, to a perfect little girl.

"Unfortunately I lost her when she was 4½ months old. She died of gastro-enteritis," she said.

Three and a half years later, she again married. "Neither husband knew that I had spina bifida. They didn't ask what was wrong with me and spina bifida wasn't talked about in those days," said Nellie.

She became pregnant again, and her daughter Catherine was born. Nellie found she was well able to cope with Catherine, but doctors advised her against continuing with a third pregnancy. Her feet were proving a real problem, and it was felt that she couldn't cope. Nellie's second marriage wasn't to last, although she still keeps in touch with her former husband.

The strain of coping with housekeeping — by this time she was looking after her parents, a nephew and Catherine — took its toll and Nellie had a nervous breakdown, and after this took to a wheelchair. Catherine was just 7, but in the words of Nellie "she turned into a little mother, and looked after me. She did everything and at the age of 14 was even paper-hanging."

After the breakdown Nellie suffered from agrophobia and didn't leave the small prefab home where they were living for two years.

"Catherine is a really wonderful daughter. I don't know what I would do without her. She is married with two children, lives nearby, and comes to see me every day. Grandchildren, Paul 17 and Mandy, 15, call in regularly, too. "Mandy makes my Sunday dinner for me, washes my hair and tidies by room."

ALICE BURGESS

Life for Nellie in Colchester is very pleasant. She has plenty of friends, enjoying the company of younger people in particular. For years local schoolgirls have visited Nellie to see her and to take her out and she has kept in touch with most of them. She enjoys being taken for long walks, going to the theatre or out for a meal.

She is a member of the Essex branch of ASBAH and through them she has been on holiday for two years to Lulworth Court, run by the Queen Elizabeth Foundation at Westcliff on Sea. "They were wonderful there, and the break really built me up for a long time," she said.

Nellie's health is remarkably good, apart from the occasional balance problems. She has much support from Colchester hospital, and the help of a nurse and a home help.

"One way and another I've been very fortunate", she said with a broad grin.

WHEN ALICE BURGESS was born, it was obvious something was wrong. When she was five days old, her Dad wrapped her up, got on a tram and took her to St Thomas's Hospital in London. She was operated on, christened and put in a cot in front of the open fire to keep as warm as possible.

She was in hospital for a month and Dad travelled to and fro to visit her. Then, although Alice was expected to die, he took her home and he and his wife got on with the business of keeping her alive.

"It wasn't easy. I was a very sick child. Apart from having spina bifida, I had a lot of digestive problems and for a time had to be fed every two hours with special food from Germany," said Alice, who is now 74.

Her parents had no advice on how to cope with their handicapped daughter. They did what came naturally — like massaging her legs — and were rewarded when, aged 2, Alice decided to start walking — another thing the doctors said was impossible.

She walked awkwardly on the outside of her feet, and this meant she needed special shoes, which made a big hole in Dad's wages.

Alice went to the local school and coped quite well, but at the age of 12 she started to get a bad infection in her toes. Fortunately, at the local hospital, one of the consultants started to take an interest in her. He arranged for her to see a specialist at Guy's — "a little old man in a frock coat" — who carried out a tendon transplant operation to try and straighten her legs.

"I remember it was horrible at the hospital — very crowded, and that part of London had an awful smell of tanneries and was very noisy" said Alice.

She was lucky, and clever enough to win a coveted trade scholarship to learn dressmaking at the Borough Polytechnic, but because of the pending operation she had to forfeit the chance. "They wouldn't hold it for me" she said.

"It wasn't easy. I was a very sick child"

At the age of 15, fresh out of hospital, Alice faced the awesome task of finding a job. She was taken on as an office junior at the local laundry, but it proved too hard. "There was so much running about, and often I had to stay on, on Saturday afternoons, and stand for hours sorting laundry."

Then ill-health struck again, in the form of yellow jaundice. But after this her luck took an upward turn and she got a job as a ledger clerk with Harris's in Peckham — where she stayed, with promotion, until she was 57. "The ledgers were great hefty things which I had to heave about, and it was hard, but I managed to stick it and the people were friendly," she said.

One problem was that she had to have a number of operations because of her feet and Harris's wouldn't pay her while she was away. She had to reapply for her job when she came out of hospital.

During the war, Alice survived a bombing of the factory, and the destruction of her home in Bromley by a land mine. One of her four brothers died in the explosion. The rest of the family found themselves homeless and were sent to the local church where they were allowed a pew for their personal belongings. They spent some time split up and billeted in different homes, moving from pillar to post.

Alice's life returned somewhat to normal after the war, although she was extremely ill for some months from thyroid trouble and had to have an operation.

Alice often wondered if there were other people around with spina bifida. She managed to get a letter published in a national magazine asking if other people with spina bifida would contact her. This led to

THROUGH Mrs Meg Garnett, the ASBAH fieldworker in the area, Alice Burgess and Nellie Brown were introduced, and now meet regularly at the Ipswich branch meetings. Last year they went to Lulworth Court for a fortnight's holiday.

Alice realises that today many people, living with spina bifida, are more severely disabled than she was, but she still feels that they are not given the chance to do enough for themselves. "I think Nellie and I are both grateful, in a way, that life was hard for us, and we did learn to be independent and fight, even from an early age" she said.

Continued on p. 14.

(Continued from p. 13)

Remembering how it used to be

a correspondence over several years with a family in Huddersfield who had a child with spina bifida. It was through them that she learned of the setting up of ASBAH and she joined the nearest group, in North London. When a branch started up in Bromley she joined and later became its Secretary.

Three years before retirement age, Alice was made redundant, when her firm — by then taken over by Mothercare — moved to Watford. But she managed to get a job with Royal Exchange Insurance where she worked full-time until she was 60 and then eased herself into retirement by working on a part-time basis for two years.

Alice now lives in Ipswich in a comfortable bungalow, near one of her brothers. She is an alert 74-year-old who loves reading and is still able to get about quite well on calipers, and to look after her small garden.

A chance to try independence

SITUATED in the grounds of Seven Springs, Pembury Road, Tunbridge Wells, Kent, is the Arthur Busk Memorial House.

It is a fully furnished bungalow which is divided into two self-contained units. Each comprises a kitchen, a twin-bedded room, shower and toilet. One unit is designed for one or two disabled people wishing to establish that they are capable of looking after themselves.

The other end of the bungalow is for visitors: visiting relatives or friends or visitors from overseas and other Cheshire Homes. Milk, tea coffee, bread and butter will be provided on arrival — thereafter self-catering. Main meals can be taken in the Home for a nominal charge if notice is given.

Applications to stay should be addressed to Head of Care at Seven Springs, Pembury Road, Tunbridge Wells, Kent.

An introduction to the skills of counselling

A WEEKEND course is to be held on Friday, 28th October — Sunday, 30 October, to introduce counselling skills to disabled and able-bodied students.

Disabled students requiring minimal help will 'share' one resident helper: anyone requiring more help is requested to bring their own helper, who will pay residential costs only.

Further details are available from The Senior Tutor, Counselling Courses, South West London College, Abbotswood Road, London SW16 1AN.

Getting Together.

A study of Members of PHAB Clubs by Rosalind Lam, published by JFER-Nelson. Price £4.95.

THIS provides a great deal of background information about PHAB Clubs. It looks at the ratio of able-bodied to disabled members, and the activities which take place within Clubs. There is an analysis, too, of what club leaders believe to be the function of PHAB, and what Club members think about the organisation.

answering service

your questions answered by experts

My son has hydrocephalus and is keen, like any other youngster of his age, to take part in sports of various kinds. Should I discourage this if it is likely to be dangerous for him, with a valve fitted? Are there any sports that should be avoided?

In general, sport should be encouraged to the limit of a child's ability in order to give a sense of achievement and help integration with the able-bodied. Obviously choice of sport must depend on the severity of the hydrocephalus, whether there is a shunt present, whether there is any spasticity or other abnormality of the limbs and if there is tendency to fits.

In severe cases, swimming (well supervised) is especially useful as it releases stiff or awkward limbs or a top-heavy body from gravity. Gymnastics will help co-ordination and hand-eye control.

One must weigh up the dangers against the benefits to be gained. Contact sports carry a risk of direct damage to the valve lying under the scalp, but the chance of a shunt being broken by a direct blow must be very remote. More real is the danger of a head injury causing concussion. This would be more liable to serious complications than in a normal person and should be taken seriously. Many hydrocephalic youngsters play soccer (perhaps avoiding heading the ball), a few play rugby, but boxing is not advised. All sport should be under expert tuition and supervision.

Duncan M Forrest,
Chairman, ASBAH Medical Committee.

My daughter has urinary incontinence and this is managed with pads and pants. Despite regular and careful washing odour still stays on my daughter's skin. Do you have any suggestions how we can eleviate this unpleasantness?

Dr Roger Morgan of the Cambridge Health Authority finds Mycil powder useful in reducing the "ingrained urine" odour which stays on the skin. It works by reducing the growth of bacteria on the skin and is usually used to treat atheletes foot where it has a similar action.

Dr Morgan advices that Mycil should be used like ordinary talcum powder over the entire skin surface affected by urine and a small amount should be shaken into the underclothing. He has not come across any allergic reactions but it is wise to check after a few days that the powder is not causing a rash or irritation.

Mycil can be obtained across the counter from any chemist and costs about £1 per tin.

My daughter has hydrocephalus, and despite her shunt she has an abnormally large head. She enjoys horse riding classes. However, we are finding it very difficult to purchase a riding hat which fits her head securely. Do you know where we can buy an outsize protective hat so that my daughter can continue to participate in this enjoyable sport?

I am very pleased to hear that your daughter likes horse-riding. Most children who have the opportunity to go horse riding enjoy it, and disabled children also benefit physically from this type of exercise.

An address of a firm of saddlers who will be able to help is: RAWLES, Garrett Lane, Earlsfield, London SW18. This firm will be pleased to give advice on riding hats and can produce made to measure riding hats for children and adults with similar problems to that of your daughter.

Mary Small, Disabled Living Adviser.

The fact that you can't see it may be the least of its benefits.

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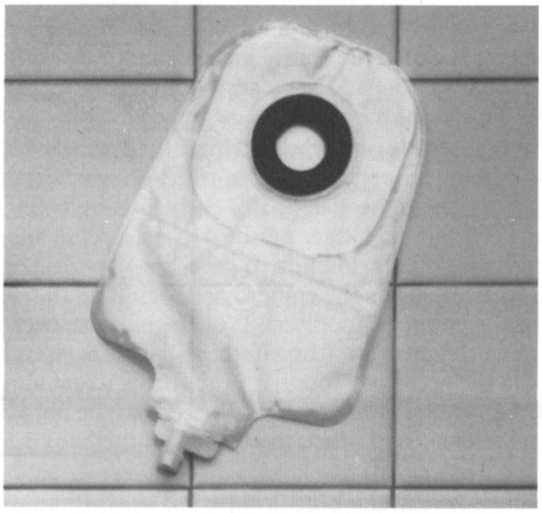

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Embryology of Spina Bifida and Hydrocephalus

The start of the problem

Prof John Emery describes the early development of a baby, and how spina bifida and hydrocephalus occur.

MANY severe 'spina bifidas' when we see them in the newborn child look like big scars on the baby's back — a long or oval red area where the skin is obviously missing. In other children less severely affected, the back presents with a soft swelling (spina bifida cystica), the cysts being full of brain fluid where the swelling is covered by a thin often abnormal skin. In more severely affected babies the tissues behind the spine are apparently missing so that the bones of the spine are exposed and arched (a kyphos). Such babies often have other deformities which cannot be seen from the outside of the body and this particularly applies to the brain, the kidneys and the bladder.

The onset of the deformities occurs very early in the embryo within six weeks of conception, and the changes that take place afterwards are probably the consequences of this. This first six weeks is a time when many women are by no means certain that they are even pregnant. By the time the mother has missed two 'periods', the danger period for the baby developing a significant spina bifida spinal lesion has probably long gone by. Perhaps an explanation of this early stage of development is more helpful than some of the things that occur later.

The egg is shed from the ovaries inside the mother's abdomen and floats into the open ends of the Fallopian tubes (the tubes that are tied to produce sterility), and then is wafted slowly along the tube towards the womb (the uterus).

If the woman has had intercourse with a man, the sperms from his semen will have been deposited at the opposite end of the womb near the cervix, and these sperm swim up through the uterus and enter the uterine end of the Fallopian tubes — the sperms and the ovary often meet in these tubes. The egg is still floating in fluid at the time that the sperm bores its way through the outer surface of the egg. It enters the egg and the nuclear material of the sperm then unites with that of the egg to form the first true cell of the new baby.

During this time the egg is still floating and has reached the cavity of the uterus. This egg then comes to rest against the surface of the uterine cavity (the endometrium). The endometrium has many glands which are secreting fluids, and around this time the small ball of cells is receiving food, both oxygen and sugar and other supplies through its surface. This ball of cells then becomes attached to the wall of the uterus and rests a little way inside it rather like a seed in soil. During this stage when the ovum is in-bedding itself in the wall of the uterus, the early ball of cells forms a small cyst and within this cyst, the layers of cells that are going to form the skin (the ectoderm), the general tissues of the body, (the mesoderm) and the lining tissues of the intestine (the endoderm). The tissues of the mesoderm develop some small primitive blood vessels and these small blood vessels begin to grow into the side wall of the cyst that is virtually lying in contact with the mother's blood in the endometrium.

While this is happening the early embryo which is now a somewhat flattened structure is already beginning to form the central nervous system. All the cells of the brain and spinal cord are formed from the surface cells of the body. The first thing that occurs is that a trough forms in the surface cells, the ectoderm, and ridges form either side, which eventually come together to bury the cells completely, to form a tube of cells. The early structure is called the neural groove, and it closes over first in the middle and for a period it consists of a buried tube, the neural tube, that is open at each end. Throughout this time, the nutrition for these developing cells comes through the fluid in which they are bathed — that is, through the wall of this early little cyst. But now as the cells are no longer on the surface a more advanced food structure is beginning to develop: Very fine blood vessels from inside the embryo are beginning to form contacts with the blood vessels of the mother, eventually forming the placenta (the afterbirth). This is essential to enable the necessary foods for the foetus to get almost direct from the mother's blood stream to the baby's blood stream, and hence to all parts of the baby.

This is an extremely critical period — the time when parts of the embryo can become starved of food, and it is just the period when the open neural tube is sealing itself off, at both the head and tail. In research this has proved to be the only period when we can produce spina bifida deformities in animals — almost any damage to the pregnant rat at this period will result in the same deformity.

If at this critical stage something interferes with the head end of the neural tube, then the baby will tend to be formed with what is called anencephaly, or if the tube does not become completely sealed off at the lower end, we get the more familiar spina bifida.

In many of the severe cases, the embryo is so deformed that it dies and becomes a spontaneous abortion. Many studies have been carried out on the small fragments of tissue that come away usually before the mother is twelve weeks pregnant, and it has been shown that there is a very high incidence of gross deformities of the central nervous system and severe spina bifida lesions in such embryos.

Thus is it usually the less severe affected embryos that continue and result in a birth at the normal time. I stress this as it will be easy to see that what we call 'spina bifida' is not a single condition, but a consequence of an altered growth process with abnormalities of greatly varying degrees of severity due to a balance of factors: the rate of closure of the neural groove, the rate of development of the placenta and the 'healthiness' of the lining surface of the uterus. This is important when we consider methods of preventing 'spina bifida'.

Embryology of Spina Bifida and Hydrocephalus

The development of the brain and the problems of hydrocephalus.

Now what is the relationship between hydrocephalus and the spina bifida? This is a topic that has been the subject of much research and there are people who have strong views in one direction or another. Disagreement arises on whether the brain is deformed from the beginning or is due to the consequences of the early lesion — in other words, whether the incomplete closure of the neural tube itself sets in progress changes which eventually produce hydrocephalus or whether there has to be a deformity present in the brain as well as in the tissues surrounding the spinal cord. These theories are not purely academic. If the brain is primarily deformed, then the chance of altering its structure later by means of surgical or medical care is less likely to be effective than if the changes in the brain are due to the consequence of the spina bifida lesion, and which can more easily be treated.

Different parts of the brain grow at different rates and at different times. The central part of the brain, that part that lies nearest to the back of the nose and throat, is formed first, and this is the part that deals with functions of the body that are related to survival such as breathing and swallowing.

The second part of the brain to develop is the cerebellum and this in the fully formed brain lies right at the back, fairly low down near the neck. This part of the brain has a very convoluted structure. Its surface area, if it were extended out, equals the surface area of the whole body. This part of the brain is concerned with non-intellectual activities — those of co-ordinating movements and the complex adjustments that all parts of the body have to make in carrying out extremely complex total body activities such as walking or running. It is very largely fully formed at birth.

The third part of the brain (the cerebral hemispheres) develops last and is the most human part in that it is the most fully developed in man, and concerned essentially with intellectual activities. The cerebral hemispheres are very incompletely developed at birth, and their development mainly takes place in the first few years.

The whole of the brain floats in fluid. This is the remains of that fluid mentioned earlier that was necessary for carrying food from the very primitive egg to the surface cells of the embryo at the time that the neural plate was forming. Indeed, when every cell in the brain divides to form another cell, it moves to this fluid surface area to actually perform the cell division. Very early on, when the spinal cord was formed by the folding of the epithelium, a tube was also formed in the centre of the brain to form the brain cells. The fluid inside this tube circulates throughout the length of the brain and spinal cord and some of it escapes through a series of holes, which are situated at the back of the neck, where it circulates over the whole spinal cord and the cerebral hemispheres.

If the spinal canal has not been formed properly and a spina bifida exists, the fluid comes to the surface where the tissues are incomplete over the back. If the spinal cord is covered with a thin film of tissue it will make that area of the tissue distend to form a big bag or cyst — the condition called spina bifida cystica. While this fluid escapes in this way two things occur — first the pressure inside the brain is not evenly distributed because the pressure lower down in the spinal cord being open on the surface is slightly less than that inside the brain, and for this reason the cerebral spinal fluid flows in that direction. There is also a tendency for the tissues of the brain to grow and flow in that direction.

The second thing is that if the fluid can escape easily through the central canal, then the formation of the space containing fluid around the outside of the brain is delayed because there is no pressure head of cerebral spinal fluid to circulate. This is the reason why a very large number of babies who are born with spina bifida do not have an enlarged head — many do not have any enlargement of the fluid cavity spaces inside the skull and indeed, some may well be smaller than normal. It is only when the outflow of fluid through the back ceases that the problems of hydrocephalus (which simply means water in the head) occur.

In children born with spina bifida this fluid running through the central canal in the spinal cord, and the similar central canal in the brain stem within the head, cannot be allowed to flow freely away through the surface of the body after birth, as infection would just run straight up into the brain from the open lesion. This is why surgeons are concerned with taking this same fluid and diverting it by means of valves into the bloodstream of the heart, or to other places and parts of the body where it is not likely to become infected.

It is thus, after the back has been closed (that is the operation for the closure of the spina bifida) that the need for this second operation occurs. You may say, "why wait for the hydrocephalus before treating it?" The answer is that in the brain of the newborn child with an open spina bifida, the cavities which normally contain one or two spoonfuls of fluid in the centre of the brain are often collapsed, and it is not possible to place the open end of a tube inside a very small slit. The efficiency of draining the cerebral fluid from inside the brain is much better when there is a small amount of distention of the cavities of the brain already existing.

There is another complication: in these babies that have had a reduced pressure in their spinal cords, the cerebellum has not grown in a normal free state in a bag of fluid, but has tended to grow down into the space of the spinal cord through the backend of the skull so that it forms a sort of loose cork around the upper end of the spinal cord. This tends to restrict the movement of fluid from inside to outside the brain. When this fluid is restricted in exit it becomes dammed back into the cerebral hemispheres and these dilate and can press

Continued over page

Embryology of Spina Bifida and Hydrocephalus

down on and around the brain stem, and this can have the effect of pushing the cerebellum further into the neck, and also of pressing on the sides of the brain stem compressing the tube (the Aquaduct of Sylvius) in its centre. We often have a vicious circle of distension causing obstruction and more distension.

These movements of structures within the skull are complex and are interdependent, but surgical skill has developed to such an extent that with the use of different levels of pressure valves, the pressure within the cerebral hemispheres can frequently be maintained in such a way that the cerebellum is able to grow back upwards away from the neck. Also the pressure on the sides of the brain stem can be reduced so that the central canal of the brain stem can re-open. This is almost certainly why many children that have been successfully treated with a shunt later probably do not need the shunt any more, because the brain has had the opportunity to re-grow back into a more normal form.

To summarise the story — in the life of a baby with hydrocephalus and spina bifida there are really two crisis periods. The first is very early on — before the baby is ten weeks old in utero, i.e. before the mother has missed her third period — and this is the time which determines whether a foetus late presents as a spina bifida or not.

The second crisis period is around the time of birth and during the first few months after birth, and is one with which parents are usually familiar. It is a period when the brain is still very actively developing and where modifications towards normality are sometimes achievable.

Prof Emery is Emeritus Professor of Pathology at Sheffield University.

Net fishing in the River Wharfe near Ilkley, Yorkshire, for young people staying at Five Oaks.

Friends who understand

A QUESTION in Answering Service (March/April LINK) concerned a young mother with a hydrocephalic baby who desperately needed someone to talk to and someone to answer her queries and worries. It prompted this letter from Olga Lavender of Sheffield:

On reading LINK (March/April) it brought back memories of my own experience on being told our daughter had hydrocephalus. It was something I had never heard of. This was in 1956 and treatment wasn't like it is today.

I am not much good at writing letters, but thought you may be able to put a little letter in to let people know that these children can lead normal lives.

My daughter, Diana, is now like any other young lady of 26. She has a nice fiance and is getting married on July 30 this year. They have bought a house and are really happy.

Let the lady who has just been told her baby girl has hydrocephalus know that she has friends in the local associations who understand.

A future for the orthotic service?

THE ORTHOTIC SERVICE in England and Wales needs central direction and funds from the DHSS. The service must be improved, new recruits attracted, and research and development encouraged. These are the findings of a report 'A Future for the Orthotic Service'.*

It states that too often aids and appliances provided by the National Health Service don't fit or are uncomfortable. Small firms supplying appliances are being forced to close, craftsmen are retiring and not being replaced.

"Time is running out if the deterioration of the service is to be reversed and a crisis avoided . . .".

*A summary of the report is available from RADAR, 25 Mortimer Street, London W1N 8AB. Price £1.

Talk about a success!

ASBAH's second Chatathon took place at the Inter-Continental Hotel in April. Assistant Appeals Director and Organiser, Mr Ian Morrison, was delighted that the turnout of participants for the second year had virtually doubled those in the first.

About sixty people arrived at 10.00 a.m., armed with throat sprays and other stimulants to conversation, to commence the gruelling twelve hour programme. At 10.00 that evening, eight quarter finalists were announced and they re-convened the following afternoon to subject themselves to the judgment of Mr Derek Coltman, the 1982 Conversationalist of the Year, Dr L. L. Ware, founder of MENSA, Gyles Brandreth and television personality and wit, Mr Willie Rushton.

Two finalists emerged: Mr Byng Hopwood, Marketing Director of Taxi Media and Dr Tony Deeson, who as LINK readers may know advises ASBAH on public relations. Dr Deeson emerged the winner, which came as no surprise to those of us who know him and have long been aware of his reputation for fluent bursts of conversation. Dr Deeson has subsequently appeared on TV-am and broadcast on BBC Radio 1.

LBC Radio, who covered the entire event, were well satisfied with the weekend and plans are already in hand for next year's contest. Meanwhile Pebble Mill studios in Birmingham have taken up the gauntlet and the Midlands Chatathon is being planned.

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WE HARDLY seemed to have vacated the ballroom at the Inter-Continental when we found ourselves back there on 11 May for our annual showcase event, the Crown Jewel Ball. A team of ASBAH young ladies worked very hard behind the scenes to set up a most successful tombola, £5 raffle and American Auction and remained remarkably undistracted despite the penetrating gaze of ten former SAS men who had been retained to keep a watchful eye on the £200 million worth of gems on display that night.

The audience that night had an unparalleled opportunity to admire the jewels which were paraded by a team of professional models under the witty professional compering of Mr Derek Nimmo. Nearly £2,500 was raised on the evening and profits from the sale of tickets and advertising space brings the overall profit of the Ball to nearly £10,000. A very worthwhile outcome.

* * * *

BY THE TIME that you read this, the second Monopoly Marathon will have taken place in London on 26 June. About 2,000 people were due to take part in this unusual event, which has attracted a great deal of press interest. London Transport has been co-operative in displaying posters around the principal London underground stations and in offering a reduced price ticket for those who wish to participate in the event by means of bus and tube.

Chatting the night away — the two finalists in this year's Chatathon, Byng Hopwood (left) listening to the rhetoric of Tony Deeson. (See lead item on this page.)

Willie Rushton will be on hand as our principal judge for the event. Madeleine Legg, organising the event, has asked me if I will judge the male beauty contest (to justify the Community Chest Card "You have won first prize in a beauty contest"), and with Willie officiating with the ladies. I suppose I will never again have the opportunity to grumble that I don't get any of the best jobs!

As with last year, the participants will have to visit each of the 26 locations on the Monopoly board and be sponsored for each visit achieved. We have reason to be confident that the event will prove an overwhelming success, both financially and socially.

* * * *

THE SECOND BALL of the summer season entitled The Good, The Bad and The Ugly, is being held this month at Madame Tussaud's exhibition. Our guests will 'Boogie with Borg', 'Minuet with Maggie' and 'Jive with JR' as well as bop in the Chamber of Horrors Deathcotheque, generously provided by Peregrine Armstrong-Jones' discotheque — Bentley's. Although dress is optional, we hope that many guests will choose to come dressed as one of the waxworks on display.

* * * *

WHILE THE SOCIAL SET are dancing the night away in London, Mr Fred Jago will be about half way through his non-stop seven day walking record attempt.

Fred will have started on Monday 4 July to stride around Leazes Park in Newcastle upon Tyne, making twice daily sorties to the Eldon Square Shopping Centre in the centre of Newcastle. Tyne Tees television have been most enthusiastic in their support of the event, giving it live coverage on a twice daily basis, as well as inviting their viewers to contribute sponsorship.

Fred assures us that his walk really will be non-stop and as he has already held the world record with a time of 6 days 8 hours, we have every confidence that he will successfully regain the title which he lost a year ago. The event is being monitored by students from a local technical college and it is hoped that useful information may be gained as to the mental and physical reaction to such an extremely gruelling programme, which may assist in the treatment of stress factors.

Continued over page

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Box 4ZB London W1A 4ZB
Telephone 01-741 3332 (24-hour-line)

RICKY LOWE WRITES FOR LINK ABOUT A FRIENDSHIP CLUB FOR DISABLED PEOPLE WHICH SOME OF YOU MAY HAVE HEARD ABOUT, AND WHICH MAY HAVE AROUSED YOUR CURIOSITY. (The address is above.)

An inside view of the Outsiders

THE OUTSIDERS CLUB was formed over five years ago and provides its members with the opportunity to overcome the feeling of isolation that many of us feel due to the lack of understanding of most fortunate, able-bodied people.

Healthy 'ordinary' people often take their abilities for granted: walking, talking, eating, loving (etc.) without ever really thinking how fortunate they are that all the nerves and muscles they need to perform such activities make all the correctly co-ordinated signals and movements.

When 'ordinary' people see disabled people they are often shocked or upset or even a little disgusted at the sight of a disabled person trying to perform what, for them, is the most simple of tasks. This usually results in the disabled person becoming withdrawn and self-conscious, and even afraid of strangers whose lack of compassion and understanding can be hurtful.

The aims of the Outsiders Club are: to provide such isolated, lonely people (disabled *and* able-bodied) with contacts so that they can meet and form relationships with people who will be sympathetic to their needs; and to encourage these people to make the most of their abilities and give them advice and support on how to make the best possible impression on those they meet.

The club is national, and communication is usually by post and telephone. There are club get-togethers every month and all members are encouraged to participate, where possible, as well as organising their own local events and meeting other members on a one to one basis.

Once or twice a year we have a big party to which people come from all over the British Isles. Often these parties last all night.

Emphasis

My disability is congenital hydrocephalus which has caused me to have curvature of the spine and some spasticity (which is effectively controlled by drugs). Within my limitations I am able to do most things unaided.

Of the many clubs I have joined over the years, the Outsiders Club stands out as being the Club for disabled people which puts the **least stress** on disabled, and the **most emphasis** on people.

Because I am unemployed at present and have plenty of time on my hands, I help out with the office work and find it surprising the number of disabled people who are trapped in isolation due to their lac[illegible] of social skills and their lack of self-confidence resulting from this situation.

We seem to spend a lot of time trying to convince members that they themselves can do a great deal to get out of their isolation. Although disabled people are at a disadvantage when it comes to finding a partner they can do a lot to help themselves. On the other hand some members want to marry the first person they meet who seems at all suitable, which can be very unwise.

The females in the club love to hear news of forthcoming marriages and romances. The girls can be very good people with whom to discuss personal problems. They can talk about incontinence, intercourse and intimacy as if they were recipes!

I have gained a lot of self-confidence and made many new friends since I joined the Outsiders Club.

Continued from p. 21.

MOUNTAIN EXPRESS is another physically demanding promotion organised by ASBAH. It will take place in the Brecon Beacons over the weekend of 20 and 21 August. This is the third year in which we have run this event — ably assisted by its originator Mr Gerry Wyndham.

We anticipate a record number of entrants and have felt it necessary to limit the numbers to 300 to ensure adequate safety coverage. Once again we have been fortunate to be loaned a helicopter by the RAF in order that any distress signals may be rapidly responded to. Happily, last year only two of our participants needed minor medical attention, but the helicopter came in useful in rescuing three members of the Hon. Artillery Company who collapsed with hypothermia and were rushed down to our base camp for treatment by our team of volunteer doctors.

This year the Mountain Express is going more commercial with specially designed T-shirts and embroidered patches, which are, of course, available to LINK readers at popular prices, as indeed is participation in the event itself, providing the experience qualifications are fulfilled and places still available.

ALTOGETHER I hope you will agree that the ASBAH fund raising programme continues to be as varied as ever and I am in the happy position of having too little space to report on the many other events which are taking place up and down the country, as we struggle to bring ASBAH's income a little nearer to the ever growing expenditure of the Association.

JUDY KAY
Appeals Director

CLASSIFIED 'ADS'

The advertisement rate is:
£2.25 for up to 30 words. £3.30 for 30-45 words.
£4.50 for 45-60 words.
Please send remittance with your advert.
Adverts for the next LINK (Sept./Oct.) should be in by Aug. 5. Send to the Editor Mrs Susan Gearing at National Office.

HOLIDAY ACCOMMODATION

HEYSHAM, Nr. Morecambe. Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 5 Roman Way, Whitchurch, Shropshire. Tel: Whitchurch 3691.

MABLETHORPE. 2 fully equipped cedar chalets on Links estate. Sleep 6. Further details: Mr B. Guest, 57 Bloxwich Lane, Walsall. Tel: Walsall 31725.

WITHERNSEA: Well-equipped 6-berth chalet at Golden Sands Chalet Park. Shop, licensed club, play areas, amusements on site. Details (sae please): Mrs P. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel: 0422 56402.

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

WINTERTON-ON-SEA, Nr Gt Yarmouth. Fully equipped chalet. Sleeps 6. Indoor heated pool, shop, amusements, take-away snacks, club room, play areas. Details: Mr R. Morris (0494) 32184.

WESTGATE ON SEA, Near Margate, Kent. Semi-detached bungalow, 3 double bedrooms, Sleeps 8/9. Bath hoist, garden. 10 mins walk quiet sandy beaches with slopes accessible for wheelchairs. Details: Jean Jones, Tel: 01-467 8148. **Greenwich Association.**

PRESTATYN, North Wales. Bourne Leisure Camp. 6 berth caravan. Near Prestatyn railway station. Fully fitted, running water, flush toilet, electricity, TV, Ramp, Ascot water heater. Details: Mr W. Gilcrest, 41 Folkestone Road, West Clayton, Manchester. Tel: 061-223 8557.

LOCAL ASSOCIATION SECRETARIES

The following changes in the names and addresses of the Secretaries of local ASBAH's have taken place since the last issue. A full Directory will appear in the next LINK.

BOLTON & BURY
Mrs Beth Day,
26 Catterall Crescent,
Bradshaw, Bolton,
Lancs BL2 4AD.
Tel: Bolton 53389.

BRISTOL
Mr S Egar,
64 Rookery Road,
Knowle, Bristol 4.
Tel: Bristol 777942.

ESSEX
Mrs Leslie Anderson,
25 Acacia Drive,
Upminster, Essex.
Tel: Up. 50449.

ASBAH booklets, etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	35p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	35p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	50p
Sex for young people with spina bifida or cerebral palsy	£1.25
The Nursery Years by Simon Haskell & Margaret Paull	35p
Little Joe (A Grandmother's story) by W. Foster	50p
Life & Death—thoughts on bereavement	75p
Information leaflets	100 for £4.00

Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free from national office. Translations into Bengali, Gujarati, Hindu, Punjabi and Urdu. Welsh language sheets are now ready too. All available from ASBAH. (Special rates available to Local Associations.) Please allow 20p per booklet postage.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida	35p
The Spina Bifida Baby	35p

both by O. R. Nettles, McSP, ONC.
Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

FUND RAISING AND PUBLICITY MATERIAL
Posters

Best Foot Forward 20 x 30 in	**10p each**
Best Foot Forward 15 x 30 in	**10 for 40p**
For local publicity 15 x 10 in	**10 for 40p**
Car Stickers	**13p each**
Plastic Lapel Badges	**8p each**

All available from Appeals Dept.—postage extra.

Film 'Appeal for ASBAH' 10 mins 16 mm Colour/Sound	**£4 Hire**

The Appeals Dept. carries a range of fund-raising and publicity items, i.e. posters, pens, key rings, games. Send for list and order form.

Flag Day equipment can be obtained direct from: Angal, 48a Holmbush Road, London SW15 3LE (01-788 5464).

EXCHANGE & MART

ESCORT. 1980. V registration. 1300. Automatic with hand controls. Stereo/radio cassette. Servo brakes. Good condition. 3,000 miles. £2,100. Tel: Portsmouth (0705) 690848.

Leisure Wear: White cotton **Tee Shirts** with green family symbol and words 'Support Spina Bifida'. Adult sizes, small, medium, large: £3.75 each. **Sweat Shirts** in reverse colours. Adult sizes, small, medium, large, XL: £7.50 each, postage included. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

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