Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p

May/June 84

TUESDAY, JUNE 6, 1944 *Closing Prices*

BLACK OUT 10.57 to 5.0 — Moon Rises 9.50 p.m. Full Moon, Tonight — Sets 6.29 a.m. Radio Page 7

LATE NIGHT

THE STAR

No. 17,459 • ONE PENNY

TWO BEACH HEADS

Churchill's D-Day Smile

'Going To Plan'

Paratroops In Channel Isles

This first D-Day picture, showing part of the greatest armada the world has ever known on the way to invasion.

THE ALLIED INVASION ARMIES HAVE SECURED AT LEAST TWO BEACH-HEADS IN NORTHERN FRANCE, AND HAVE DUG IN. ACCORDING TO THE GERMANS, ALLIED TANKS HAVE PENETRATED SEVERAL MILES TO THE SOUTH BETWEEN CAEN AND ISIGNY, AND PARATROOPS HAVE LANDED ON GUERNSEY AND JERSEY.

Churchill Says We Are Using

4,000 SHIPS AND 11,000 PLANES

Mr. Churchill said in Parliament today:

"I have to announce to the House that, during the night and the early hours of this morning, the first of the series of landings in force, upon the European Continent, has taken place.

"In this case, the liberating assault fell upon the coast of France. An immense armada of upwards of 4,000 ships, together with several thousand smaller craft, crossed the Channel. Mass airborne landings have been successfully effected behind the enemy's lines.

"Landings on the beaches are proceeding at various points at the present time. The fire of the shore batteries has been largely quelled.

"The obstacles which were constructed in the sea have not proved so difficult as was apprehended. The Anglo-American Allies are sustained by about 11,000 first-line aircraft, which can be drawn upon as may be needed for the purposes of the battle.

"I cannot, of course, commit myself to any particular details, as reports are coming in in rapid succession. So far the commanders who are engaged report that everything is proceeding according to plan—and what a plan!

"This vast operation is undoubtedly the most complicated and difficult that has ever occurred. It involves tides, wind, waves, and visibility, both from the air and sea standpoints, and the combined employment of land, air and sea forces in the highest degree of intimacy.

"There are already hopes that actual tactical surprise has been attained, and we hope to furnish the enemy with a succession of surprises during the course of the fighting.

"The battle, which has now begun, will grow constantly in scale and intensity for many weeks to come, and I shall not attempt to speculate on its course. But this I will say, that complete unity prevails.

"Throughout the Allied armies there is a brotherhood in arms between us and our friends of the United States. There is complete confidence in the supreme commander, General Eisenhower, and in his lieutenants, and also in the commander of the expeditionary force, General Montgomery.

"The ardour and spirit of the troops, as I saw for myself when they were embarking in the last few days, was splendid to witness.

Nothing which equipment, science, or forethought can do has been neglected, and the whole process of opening this great new front will be pursued with the utmost resolution both by the commanders and by the U.S. and British Governments whom they serve."

Pursuit In Italy Now, Says Premier: See Page 5.

The King On Radio Tonight

THE KING is broadcasting at 9 o'clock tonight, it is announced from Buckingham Palace.

Mr. Churchill was received by the King at Buckingham Palace today, and stayed to lunch.

The King today held an investiture at the Palace. In the uniform of Admiral of the Fleet, he gave medals to nearly 300 soldiers, sailors, airmen, men of the Merchant Navy and civilians.

The news about the beach-heads was learned this afternoon at Allied Supreme Headquarters, where it was added that the fleet of planes which carried our airborne troops had not suffered heavy losses, and that more than 640 naval guns, from 16-inch to 4-inch, were bombarding the beaches and enemy strong points in support of the armies.

Earlier, in Parliament, Mr. Churchill had said: "So far the commanders who are engaged report that everything is proceeding according to plan—and what a plan."

German radio followed the Premier's announcement with the report that new landings had been made at Arromanches and Marcouf, in Normandy. Tanks were landed at Arromanches, said the announcer.

First news from Allied sources that the invasion had begun was given in this communique issued at 9.35 a.m. by the Supreme Headquarters of the Allied Expeditionary Forces: "Under the command of Gen. Eisenhower, Allied naval forces, supported by strong air forces, began landing Allied armies this morning on the northern coast of France."

Following the issue of this Invasion Communique No. 1, it was officially learned in London that the landings were in Normandy. Minesweepers swept a way into the coast and the bombarding ships got into position to engage the coastal batteries. The landings took place between 6 a.m. and 8.15 a.m. The naval bombardment went "in the manner planned." It was also learned that first reports were good and that General Montgomery was in command of the British, Canadian and U.S. forces forming the army group carrying out the assault.

The first report that the invasion had begun was given in a German

CONTINUED ON BACK PAGE, Col. TWO

STOP PRESS

STAGE DOOR CANTEEN

will open

SUNDAY
3 June 1984

at the

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Canteen Opens
6.00pm

Closes
12.30am

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1940's Style or
Uniforms Optional

Ticket £10
including 'RATIONS'

0024

1966 - 1984 · asbah comes of age

LIFT runs successful weekend:

Keeping a marriage together:

Sussex wins new clinic:

Fashion fit for all:

Summer project in Ireland:

◀ This LINK cover features the stylish ticket for ASBAH's fund-raising super event — Stage Door Canteen — in June on the 40th Anniversary of the D-Day landings.

See page 16 for more details.

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Association for Spina Bifida and Hydrocephalus/ASBAH

Correspondence to ASBAH at the National Office:
22 Upper Woburn Place,
London WC1H 0EP
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.

Excutive Director:
Miss M P Gilbertson, MCSP

Finance Director:
Mr Derek Knightbridge, FCCA

Appeals Director:
Miss Judy Kay, MIPR

Services Director:
Mrs B Newman

Administrative Assistant:
Paul Dobson, BA (Hons)

Disabled Living Advisers:
Miss Mary Barton, MCSP
Miss Andrea Robinson, RGN, SCM, HV
Miss Mary Small, Dip OT, SROT

Fieldwork Co-ordinator:
Mrs T Cole, MICA

Accommodation & Development Officer:
Ms Siobhan Rowe, BA, Dip HA

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

Information Officer:
Miss B Holland

Link Editor:
Mrs Susan Gearing

LIFT (Young ASBAH) Organisers:
Paul Cooper, BA
Vivian Harper, BSc

The LIFT Weekend

FOLLOWING months of preparation, the first ever LIFT Weekend Conference eventually arrived. I arrived in the early afternoon when everyone was at the stage of doing a thousand words a minute and getting nowhere!!

After a meal I opened the first session and then we went straight into a discussion about the role of ASBAH, LIFT and Local Associations. This discussion went very well and lasted just over an hour. A number of people made contributions during the evening including one person who had flown over from Norway with a companion and he told us about the Spina Bifida Association in Norway. Friday evening ended with a disco run by Paul and a general get together near the bar!

Saturday morning was devoted to the medical aspects of spina bifida. First to speak was Dr John Keen who spoke about spina bifida using a few human/audio/visual aids. Many people asked him questions following his talk. Second to speak was Dian Donai who is a Consultant Geneticist and she spoke generally about spina bifida and genetics. We all found her talk both informative and very humorous. Following the talk on genetics, Margaret and Alan Twyford, a spina bifida couple, spoke of their experiences which included the decision not to have children. Finally Susan Seager who has spina bifida spoke of her experiences following her decision to start a family.

Saturday afternoon consisted of a whole range of workshops varying from CB to Incontinence! In the evening we had a disco (fancy dress). This party began at 8pm and ended around 3.30am!!

Sunday morning proved to be a very quiet session! The first part of the morning began with a discussion on employment, education and meaningful unemployment. The final session of the weekend was chaired by Lady Jean Mackenzie. This session was for the purpose of discussing the weekend and this lasted for about an hour.

After lunch, we all finished packing and said our goodbyes and went home.

In retrospect I feel that the weekend went very well. A unique opportunity was provided when everyone was invited to put any questions to the speakers. In return, we were treated to honest and frank answers with no hidden bits. Also on the social scene many new friends were made. Such questions as "will there be another weekend?" became frequent.

Finally, I would just like to say thanks to all the staff from ASBAH and LIFT for all their work in making the weekend a great success. A special thankyou is also due to the LIFT group which made all the arrangements. It was also great for me to be able to meet so many LIFT members. I really enjoyed the experience of chairing the weekend.

CHRIS HOPKINS
Member of LIFT Working Party

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Stephen earns 'Scout's VC'

STEPHEN COLLETT, 16, of Leeds has been awarded a top Scouting honour — the Cornwell Scout Badge — known as the 'Scout's VC'.

The citation states that Stephen, now a Venture Scout and a pupil at Ralph Thoresby High School, Leeds, was added to the Cornwell Roll of Honour "in recognition of his high standard of character and devotion to duty under great suffering".

Although in a wheelchair through spina bifida and hydrocephalus, Stephen joined the Cub Scouts when he was eight and gained all his badges and some proficiency badges before becoming a Scout of equal distinction. He has always managed to keep cheerful, and through determination and courage he has learned to play the violin, and has achieved considerable success in swimming and horse riding.

His mother, Mrs Valerie Collett, told LINK: "The hall was packed for the presentation to Stephen and the speeches were super. They made him feel very proud and special. We have the ceremony on video tape, which is marvellous to look back on, and he will treasure the memory, I know.

"Naturally we feel extremely proud of our son who, we were told, 16 years ago when he was born, would be better dead, because he'd only be a burden to everyone. Well, he proved 'the experts' wrong didn't he, bless him. He's a remarkable boy."

Very few Cornwell badges are awarded nationally in any one year. They are in memory of Jack Cornwell who was the lad who, in the great sea fight off Jutland in 1916, stuck to his gun aboard HMS Chester despite being badly wounded. He died of his injuries a few days later and was awarded the VC posthumously.

Faith Seward

FAITH SEWARD who wrote an article in the last issue of LINK about her view of the Education Act 1981 is headmistress of an **ordinary** primary school in York, and **not** of a special school as stated in LINK. We apologise for the error.

THE PHOTOGRAPHER photographed! Ann Wild, the Kodak young girl photographer of the year, who had her first solo exhibition at South Woodford Library in London in March. Ann, who has spina bifida, is photographed here by John Clark.

Four proud young winners and their awards

FOUR young members of Gloucestershire Local Association with the achievement awards they received from the Association.

The winner of the main award is 15-year-old Emma Cormack (right). For the past three years Emma, who lives in Cheltenham, has won cups for academic achievement at St. Rose's Special School, Stroud.

Her mother, Mrs Mary Cormack said, "She has worked so very hard, even over Christmas. She got a Grade 1 pass in CSE English a year early, and is now going on for O levels. Her hope is that she will get a job in a hospital and give back something to the hospitals that have helped her during her life".

The runners up are Joanne Hall, of Stroud (left) who won three gold medals for swimming at the Olympics at Stoke Mandeville Hospital and Jackie Childs (centre) of Gloucester who completed a 26 mile wheelchair marathon for charity. Sarah Hemmings, 9, (back right) won her award for swimming two lengths of the swimming pool after learning to swim only last year.

Photo: Gloucestershire Newspapers

Small change adds up to helpers holidays

HOLIDAY small change — the few francs, marks, dollars that cannot easily be converted back into sterling after a trip abroad — has formed the basis of a Fund that provides holidays for very severely disabled people.

The Small Change Scheme was started by the International Association of Tour Managers following the discussions of the IYDP Working Group on Leisure in 1981. One of the problems highlighted at these meetings was the great difficulty and expense for severely disabled people wishing to take holidays abroad. They usually had to pay not only for their own holidays but also for that of an essential escort.

The main thought behind the scheme was that tour managers, leading coach parties through Europe, should collect any small change in foreign currency from those who wished to donate as they passed from one country to another. Special arrangements were made to convert all the money collected into sterling.

The scheme really got off the ground when Thomson Holidays stepped in with a generous donation — as well as a number of free holidays for escorts of disabled people. The scheme was then renamed The IYDP Holiday Fund in an attempt to perpetuate the year in which it was established.

The Fund now receives donations from all over the country as it becomes more widely known. BBC Radio 4's programme 'Does He Take Sugar?' in September 1982 resulted in several very generous donations and some organisations around Britain have set up their own collecting points for foreign coins.

The Fund is also trying now to raise money in sterling which is more immediately usable.

Since the Holiday Fund began giving out grants in the Spring of 1982 over £17,000 has been spent to enable a growing number of disabled people to take the kind of holiday abroad which would otherwise have been impossible. Holidays have included group trips and individual holidays all over the world.

Any severely disabled person who needs an escort in order to take a holiday abroad is eligible to apply for assistance from the Fund towards the holiday expenses of their escort, when these cannot be met from any other source.

Funds are limited and applications can only be received from individual disabled people, or from groups who plan to travel abroad but cannot afford to pay helpers' expenses. There are separate application forms for individuals and groups.

Individual applications must be supported by a bona fide organisation or a doctor verifying that the person meets the scheme's requirements. The minimum age for applicants is 17 years.

Applications are considered at meetings held by the Fund Trustees twice a year and there are two closing dates: January 1 for Spring and Summer holidays, and July 1 for Autumn and Winter trips (between Oct 1 and March 31).

Further information and application forms from: Miss D. J. Wright, The Hon. Sec., IYDP Holiday Fund, 'Cottleston', 39 Cranbrook Rd, Thornton Heath, Surrey CR4 8PQ.

ASBAH's new Finance Director

DEREK KNIGHTBRIDGE has recently joined ASBAH as Finance Director.

Mr Knightbridge, a Certified Accountant, was in the money market in the City for 25 years. He was Director of a Discount House and Secretary of a Merchant Bank, and he also launched his own company selling micro-computers.

Among other interests he is actively involved in community affairs.

Mr Knightbridge, who is married with two grown up sons, lives in Hertfordshire.

He takes over from Frank Armour who has been involved with ASBAH since its foundation, firstly in a voluntary capacity, and then later as Finance Officer and Finance Director. Frank is not retiring, but only 'slowing down', and is working as Accountant for ASBAH's successful telesales.

Sport and computer courses on offer

RECENTLY two organisations, Centaur Sports, experts in arranging activity holidays, and Out and About, specialists in holidays for the physically disabled, have come together in a new venture — the setting up of general sports and computer courses for the young physically disabled AND their able-bodied contemporaries.

In 1984 there will be three weeks:
29 July to 4 August
5 to 11 August
12 to 18 August

The courses will be held at Newland Park (a college of Higher Education) in Chalfont St. Giles, Buckinghamshire. Accommodation will be in ground-floor study-bedrooms which are fully accessible for wheelchair users.

There are non-residential and residential terms — £72.90 and £146 respectively

Further details and booking forms (SEA please) from: OUT and ABOUT, 112 Eskdale Avenue, Chesham, Buckinghamshire HP5 3BD (tel. 0494 775377).

Country Wings opens up countryside

GROUPS planning visits to the countryside can make use of the Country Wings Information Service established by Inter-Action.

The service has information on 800 venues in the country providing accommodation, from self-catering hostels to multi-activity centres.

A computer is used to match up the requirements of visitors with venues. Limited information on facilities for disabled people is available.

Country Wings, Inter-Action Centre, 15 Wilkin Street, London NW5. The Information Service is open weekday afternoons, tel. 01-485 0881.

Ten-point plan for keeping a marriage together

MAKING marriage work, under the best of circumstances, can be difficult. Making it work when there's a handicapped child to love and care for can be a hundred times more difficult.

Recently I talked with parents of special children, with social workers, and with a psychiatrist. Out of our talks came ten points you may find helpful if you're in a special-child marriage.

1. Expect your marriage to continue moving in the direction it was heading before you became the parents of a handicapped child. Was it on shaky ground? It will probably grow shakier. Was it on solid ground? It will survive the stress and become, perhaps, an even closer, more intimate marriage.

Which marriages crumble? Marriages involving very young couples. Marriages involving couples who haven't been married long. Marriages with a handicapped first-born.

In general, the older you are the longer you've been married, the more likely your marriage will stay intact.

2. Know that the husband in a special-child marriage is secretly fretting about financial worries. What will the future bring? Will he be able to provide all the care his child requires? Will there be hospitalization? Special schools? Special equipment?

Financial problems tend to undermine any marriage. When you're in a special-child marriage, your money worries begin in earnest.

3. Refuse to let fatigue undermine your marriage. When I talked with groups of mothers, one theme kept rising to the top — fatigue. Nobody, except the parents of a handicapped child, knows how much time and work goes into caring for that special child.

''You're so tired by the end of the day — a mental and physical tiredness — that all you want to do is flop into bed and fall asleep. You've given all you can give. You're empty. There just isn't anything left for your husband'', one mother told me.

How do you fight fatigue? First, recognize that it can destroy your marriage. Second, accept help when it's offered by friends and relatives. Change your routine — hire a sitter and get out! To get away on a badly needed husband-wife vacation, seek out respite care service.

4. Put your marriage first. ''I've lost my wife to our handicapped child!'' This bitter refrain is heard all too often by counsellors. There's a tendency, especially in the beginning, for the mother to throw her whole life into her handicapped child. Nothing, no one else is important — not even her husband.

One mother analyzed why this happens. ''I think it's tied in with the guilt thing. A mother feels guilty, so responsible for her child's condition.

''She is two now. Her brain stopped growing at age three months. Doctors tell us that something — they don't know what — happened during the first three months of pregnancy. That hit me like a ton of bricks. I did it. It's all my fault, I kept telling myself. I thought I had to make it up to her by wiping myself out as a person and by living for her.''

Most husbands experience a bit of jealousy toward their handicapped child. But, they're ashamed of these feelings and try not to express these feelings to their wives. They suffer in silence and the marriage becomes what one counsellor calls, ''A marriage that's not a marriage.''

5. Save time and energy for marital intimacy. While everyone knows that sex is a key ingredient in every happy, joyful marriage, some couples with a handicapped offspring let that area slide.

Shirley Masat, a counsellor to parents of handicapped kids in Fairfax, Virginia, told me, ''Often, sex is diminished. There's no time. There's the fatigue. But, there's the unexpressed, underlying fear of having another handicapped child.''

Many couples no longer sleep together using the special-child's night time needs as an excuse. For a few, withdrawing from sex may be a form of self-punishment: I have conceived a defective child during sex, therefore, I cannot allow myself to enjoy further sex.

6. Don't let blame and suspicion destroy the trust you have in one another. One of the first things a couple wants to know when a handicapped child comes along is why. Why did it happen? What is the cause?

One physician told me, ''Often the cause is unknown. The less you know about the cause, the more you hunt for an irrational cause.'' Husbands may secretly blame and suspect their wives. She ate something harmful during pregnancy. Or, her relatives are a strange lot! I wouldn't be surprised if there are some retarded ones she's not telling me about!

A wife thinks: That strange cousin of his — I think the handicap is carried in the family line! Blame and suspicion can drive a wedge into the marriage. Trust decays. Without trust, there can be no real marriage.

7. Talk about the question of another child. Seek genetic counselling from a qualified doctor. When I asked a group of young mothers to identify what they saw as the biggest threat to their marriages, they zeroed in on the point about having another child.

''Could I make it through the shock of another Downs Syndrome baby? NO WAY!''

''I want to try again, but my husband is dead set against it. He says he's not going to take a chance on having his heart broken a second time.

Shirley Masat, counsellor to parents, told me that often, one or the other spouse will feel a strong need to prove that he or she is okay, to prove that he or she can produce a normal child. When that person pushes for another child, marriage can become a battle-ground!

8. Work on keeping the communication lines open in your marriage. Take time to talk honestly about your feelings. In special-child marriages, communication can break down when one parent is either unrealistically positive or unrealistically negative about the handicapped child.

One mother said, ''Our baby's condition is a taboo subject in our

DIVORCE

This article by JO ANN WENDT is reprinted with kind permission of the Spina Bifida and Hydrocephalus Association of Massachusetts.

It also appeared in the Ontario Association's newsletter and was obviously written for American families, but nevertheless LINK feels that the general message is appropriate for readers in this country.

house. We can't discuss it without fighting. Despite what the specialists say, my husband won't accept the fact that Jenny's retarded. He insists she's fine. It makes me so mad I could scream!"

Communication can break down when husband and wife slip into the protective games. "I can't tell my husband how tired and worn out I am, because he'll feel upset and guilty."

"I can't tell my husband that his mother blames my side of the family for the handicap. He'd be too upset with his mother."

Communication breaks down, too, when you play mind reading games. "I used to think my husband should be able to read my mind," Irene said. "He should know when I'm tired, when I want to go out, when I need help. When he didn't react to what I was thinking — not saying! I'd go into a slow burn. Now I know I have to tell him what my needs and feelings are. If I need help, I ask for it and then he's more than willing to help."

9. Don't shut your marriage partner out of the problem. "My wife, my handicapped child, and my child's doctor are in the inner circle, I'm in the outer circle. I'm the outsider."

This is a common complaint of fathers. Sometimes the shutting out is deliberate. The wife feels the need to make up for the delivering of an imperfect child; she insists on shouldering total responsibility. Sometimes the shutting out is more subtle. A wife will say, "Oh, Honey, you just can't diaper her right!" or, "She doesn't eat well when you feed her."

Husbands get the shut-out feeling when they must get all news of their child second-hand. "The doctor said her co-ordination seems better this week." "The therapist and I think she's making good progress."

Don't shut out! Share the care of the child. Most important, go together when your child must be taken to consult a doctor or therapist.

10. Don't assume your partner isn't hurting just because the hurt doesn't show. Irene told me, "I used to think my husband had no feelings about the baby's condition. He never cried or carried on like I did. I used to accuse him — you don't feel anything! One day I found out different.

"In our neighbourhood, every tot celebrates his birthday with a party. How those birthday parties hurt me! It's on the birthdays that you compare kids. How it hurts to see Jeffie not doing what other two-year-olds could do!"

One day I had an appointment and couldn't take Jeffie to a neighbour's party. I asked my husband to do it. He said, "Oh, let's just skip it this time."

I agreed. Later I got to thinking. I went back to my husband and asked him, "Hon, does it hurt too much to see Jeffie not keeping up with the other kids?"

"Yes," he said. There were tears in his eyes.

Marriage, under the best of circumstances, is difficult. Marriage, when you have a special-child, is even more difficult. Hank, a father of a Downs Syndrome baby, feels the key to having a happy, though special-child marriage, lies in mutual support.

"When she is down, you have to lift. When you're down, she has to lift. If the two of you can't do this, you might as well hang it up. You're not going to make it!"

GARY BRAYNE, a member of LIFT's Working Party, has responded to LINK's request (Jan/Feb issue) for articles about interesting holidays. Here he tells about a PHAB holiday in Iceland last year.

Getting away from it all — in Iceland

WE FLEW from Heathrow to Keflavik in Iceland — the flight taking just over three hours and when we landed we were surprised to see that the Airport is used by both civilian and military aircraft. However, as we were to discover, Iceland is a country full of surprises.

"Our base was in a Youth House in the capital, Rekjavik. It had been specially designed with the needs of the disabled in mind."

After a day discovering the local area with their Icelandic guide, Sjorn, the group attended an evening reception at the British Ambassador's Residence. Next day was spent on a trip to Grindavik, a fishing village in the South West.

"The journey was interesting as we drove through a variety of landscapes, including lava fields which we were told were 7,000 years old"

The group also met the President of Iceland, Vigdis Finnbogadottir, the first women to hold this office.

The Residence is an 18th century farmhouse on the Rekjanes peninsula. The view across the bay was really beautiful.

"In the evening some of us went to the theatre where we saw a production of the 'Light Nights' which tells the history of Iceland through folk songs, stories and extracts from the sagas."

Continued on page 11

Employing Disabled People — new booklet

THIS BOOKLET gives advice and information about the policy companies should adopt on the employment of disabled people. It also makes suggestions about how this policy should be implemented.

As the CBI make clear in this booklet, they believe that the Quota scheme should be abolished. They argue that a voluntary approach, based on the guidelines they outline, can be shown to succeed.

Employing Disabled People is available from CBI Publications, Centre Point, New Oxford Street, London WC1A 1DU, price £1.50, including postage and packing.

How Sussex fought and won the battle for a clinic for young adults

LIKE MOST local associations in ASBAH, the Sussex Association has been increasingly concerned about the medical care of our young adults once they reach the age of 16. They receive excellent medical care until then at one hospital, but we were finding young people in their twenties who hadn't received a check-up for years, or seen a physiotherapist, and were generally concerned about their health. No one person was concerned about their overall care.

CARE

The good news is that we have managed to get a clinic for these young people started at Chailey Heritage this year. The bad news is that it has taken us since 1978 to achieve it!

We started by writing to the two Area Health Authorities involved; then progressed to asking questions at Community Health Council public meetings throughout the county, and writing to the regional health administrators and to the six District Health Authorities involved. We needed a champion, and finally found one in Dr Gillian McCarthy, Consultant Neuropaediatrician at Chailey Heritage, who was as concerned as we were about the deterioration of the young people who were asking for her help.

In May 1982 we sent a questionnaire to all our members born in or before 1966 to assess what use would be made of a clinic, and from this we found it would be welcomed by a considerable number of young adults. Plans were drawn up with Dr. McCarthy, only to be turned down by the District Medical Team.

It was time to involve our MPs—all sixteen of them. We wrote, and our members wrote, and a lot of questions were asked. As a result, two of the six Area Health Authorities involved agreed to support the clinic financially.

Political Involvement

We still had to convince Brighton Health Authority, in whose area Chailey came, and this we eventually succeeded in doing at a meeting in June 1983 with the chairman of the Health Authority.

The District Medical Team finally agreed to a two-year pilot scheme in October last year, and our first clinic was held on February 3 this year. The moral of all this must be that one must never be discouraged and take no for an answer if you are concerned enough about a problem!

The clinic is a pilot scheme for two years initially and we have to show in this two years that it is really needed. Finance comes from several different sources. The total estimated cost is £5,000 a year.

The Sussex Association has agreed to contribute £2,000 a year, which shows our commitment to the project. We don't have £2,000 to spare, so we are now setting about raising it. Three District Health Authorities will contribute, and the balance will come from an endowment fund at Chailey itself.

The Clinic takes place on alternate Friday mornings in a group of rooms at Chailey Heritage. A waiting room is provided, with coffe maker (human!), and there are separate rooms for seeing the consultant, Dr McCarthy, and physiotherapist, occupational therapist and our own field worker. The atmosphere is friendly and relaxed.

A maximum of five adults are seen at each session. Each person spends half an hour initially with Dr McCarthy, and progresses to the physiotherapist and occupational therapist, and the field worker. X-rays can be taken immediately, and blood and urine samples, but the patient needs to return on another occasion if IVP's are needed.

[illegible]

The Orthotics Department at Chailey can be called on for occasional requirements such as rehabilitation engineering, special cushions and pressure studies, and our field workers are available for counselling.

The whole idea of the clinic is that it is a preventative centre, looking at the whole person. For any major treatment the patient will be referred to their local specialist hospital. The young people can refer themselves to the clinic direct, or do it through our field workers, but the local GP would be informed by letter after the visit.

The project will be monitored carefully throughout and at the end of the two years the decision will be taken whether or not to continue. We can't foresee what that decision will be, but we have made a start in a small way, and other groups may feel encouraged to do likewise.

MARGARET WHITE
Sussex Association Secretary

Making a splash with adapted 'wellies'

I WAS very interested to read in LINK for Jan/Feb the centre page article "Up Hill and Down Dale".

I was particularly interested in the comment "Oh, for orthopaedic wellies!" No sooner said than done!

My son Gary, now aged 8, has had orthopaedic wellies for 2 years now. I enclose a photo of Gary wearing his wellies from which you will see that he can enjoy himself in the snow — or indeed, puddles — just the same as any other child.

We have found that a time limit has to be enforced to protect Gary from getting pressure sores, but I think that an hour or so (which is his limit) should be enough for any child to play in the snow.

Before Gary obtained his wellies he would get very upset, especially when his younger sister could go out to play in the snow. Now he can join in and it has made winter a much happier time.

Mrs Barbara Coleman
Luton, Beds

GARY Coleman enjoying the snow in his orthopaedic wellies (see letter from his mother).

IF ANY other parents are interested in having their child's ordinary wellingtons adapted like Gary's they should apply through their local hospital physiotheraphy department. The adaptations, under the NHS, are done by John Florence Orthotist at Chailey Heritage Hospital in Sussex.

Studs take the friction out of walking

WE HAVE a 4-year-old spina bifida daughter, Clare who has just started to walk with the help of full length calipers and a walking frame. Her whole body from her chest downwards is held rigid and she walks by pivoting on her feet in turn.

I am sure that many other parents have children in a similar position and that like Clare they have difficulty encouraging their children to walk. We found that the main problem where Clare was concerned was that because her shoes were rubber-soled she could not overcome the friction between her shoes and the carpet or other floor covering.

We overcame this problem quite simply by fixing a domed stud towards the toe on the soles of her shoes. The studs are of the sort fitted to the feet of light items of furniture and can be bought from any DIY store for a small price. It makes walking much more simple as it assists by providing a small point around which to pivot and reduces the friction when turning. When Clare stands still she goes back onto her heels so that she is quite secure when standing. We have not found any problems by reducing the friction in this way, she has never lost her footing as the stud pushes quite deeply into the carpet pile as she transfers her weight from one foot to another. Obviously one must take care that the spikes do not penetrate the soles of the shoes.

This small adaption has made all the difference to Clares life at home and I've no doubt could do the same for other people.

Mr D. J. Lawrence
Walton on the Naze, Essex

Towel aids crawling

I READ with great interest your article on Mobility in your Jan/Feb issue in particular regard to using a towel to assist crawling. It is something I had not thought of and my daughter aged 22 months who was born with hydrocephalus has difficulty in lifting her head whilst crawling. She moves about at great speed now with the help of the towel. I would like to thank Mary Barton for this suggestion.

M. A. Crouch, Hornchurch, Essex

FASHION FIT FOR ANYONE

LINK focuses on Fashion Services for the Disabled which runs design and dressmaking courses for fashion conscious people with a wide range of physical disabilities.

'Just what I've always wanted'

by
Elizabeth Ingram, MA,
Research Assistant,
Fashion Services for the Disabled,
Shipley, Yorkshire.

FOR A LONG TIME Pamela had yearned to wear jeans. She envied her friends their casual, trendy clothes, but thought that confined to a wheelchair with spina bifida such clothes were out of the question for her. Then, on a week's Fashion course, involving daily visits to 'Fashion Services for the Disabled' at Shipley in Yorkshire she was at last able to design and make up her first pair of jeans. With concealed side zips and skilful shaping to avoid any midriff gap they fitted her perfectly and were no more difficult to get on and off than the baggy trousers and skirts she had previously worn.

'Fashion Services for the Disabled' is now reaching the end of its initial three year period. In the training centre various courses are held for dress teachers and for disabled people or their relatives. The dress teachers learn more about disability and work on a one-to-one basis with a disabled person. The disabled people who come on the courses help to design their own garments, make up their individual patterns and toiles and are wearing the completed clothes by the end of the week. For those unable to sew the workshop next door provides reasonably priced made-to-measure garments to order.

Research carried out at the centre includes interviewing disabled people to find out what their clothing problems are and how the centre can best solve those problems. It also involves finding fabrics which solve varying problems of wear, warmth, etc., and looking out for any suitable new fabrics which come on to the market.

Spina bifida presents many clothing problems, mainly concerned with fitting and with difficulties in getting clothes on and off. One young woman who walks with the aid of calipers complains that she 'can't get the young styles to fit' while another, confined to a wheelchair, says: 'You usually find with my figure that you get the older person's clothes and you can't look youthful. If you don't get clothes that are youthful you feel older.' Such people find it invaluable to have their individual patterns which guarantee an exact fit over any figure irregularities and avoid the annoyance of having to cut off several inches of fabric when adapting bought skirts or trousers.

Difficulties in getting clothes on and off can be overcome by the use of stretchy fabrics, suitable styling, (for example, raglan sleeves rather than set-in ones) and strategically placed openings. These not only assist dressing but also help to provide easy access to incontinence aids where necessary, and so make the wearer far more independent.

Maureen Hakes, Fashion Services for the Disabled teacher working with a young student with spina bifida on an ASBAH fashion course.

In the courses at the training centre the emphasis is on self-help, and those taking part are encouraged to do as much for themselves as they can. Most of the ASBAH groups which come are on a residential Independence Course at 'Five Oaks' ASBAH's Centre in Ilkley, where groups of young students are helped to become more self-reliant and where older students come on individual independence training programmes. Those students who come from 'Five Oaks' on the holiday activity Fashion course at Shipley are given talks and demonstrations on make-up and hair care as well as making their own clothes. At the end of the course they are able to celebrate with a night out at an Ilkley restaurant wearing their completed garments.

Their reactions to the course vary from enthusiastic delight to mild surprise that they have been able to complete a garment, especially the ones who have never done much sewing before. One girl who originally insisted that she hated sewing, returns whenever she can and is building up an attractive wardrobe. All seem pleased with their increased independence. One girl says: 'I don't have to wait for pants to be put on me, or pads to be put on me. I can see to myself now.' Another, who has learnt to dress herself, points out: 'I'm not going to have my Mum and Dad always.'

Courses are also held at Shipley for groups of children with varying disabilities from local schools. These are very popular with the children, who are impatient to get to the centre in the mornings and will rush their dinner break in their haste to finish their garments. One spina bifida boy is keen to become a dress designer, and all know exactly what they want in the clothing line.

Other courses at the centre are run for parents of handicapped children and these are popular not just for the advantage of having an individual pattern and expert tuition but also for the chance to meet together to

FASHION FIT FOR ANYONE

Left:

Sharon from Bermerside School, Halifax, wearing an eyecatching and comfortable red and navy tracksuit which she made herself.

Right:

Alan, also a pupil at Bermerside School in fashionable clothes made by himself on a fashion course

discuss school events and compare their children's problems and achievements. Also of great social value are the classes run for older disabled people, who would probably otherwise be on their own at home and who really enjoy the friendly atmosphere of the classes. A newer venture is mother-and-child dressmaking, where work and benefits are shared.

Even the more severely handicapped who come on courses are encouraged to help as much as they can in making their own clothes. One boy with cerebral palsy was unable to do any more than press the pedal of the sewing machine when instructed, but even this gave him a sense of achievement and he was keen to take part, and interested in all stages of the process.

Caroline has spina bifida and spends most of her time in a wheelchair. She is also blind. To cope with this problem Caroline's teacher at the centre imagined herself in the blind girl's place and adapted the equipment accordingly. First Caroline made her own pattern by drawing round the edge of a cardboard block. Next the seam allowances had to be marked and here Caroline was able to follow the dots left by a tracing wheel. Once the material was cut out Caroline tacked it together by feeling along a line of pins. Finally, to enable Caroline to use a sewing machine her teacher taped a pencil alongside the needle to act as a guide, and the seams were beautifully straight. Caroline had never seen a sewing machine, but went home at the end of the course determined to buy a machine of her own.

The future for 'Fashion Services' looks exciting. 1984 will see the first International ASBAH Fashion courses, with members coming from several different countries. Within Britain requests come in from all parts of the country for people to come on courses or to have clothes made for them. Ideally we should like to see similar centres set up in different areas to cope with the demand so that eventually anyone with clothing problems can become a satisfied customer and say, like Pamela, 'it's just what I've always wanted'.

Fashion Services for the Disabled,
B270-B320 Saltaire Workshops,
Ashley Lane,
Shipley BD17 7SR

ICELAND: Continued from page 7

Gary and the others also stayed two nights on the North Coast at Akureryi in a Schalfsborg — similar to a day centre in Britain.

Apart from visiting many interesting and unusual sights, including volcanic landscapes, houses made of turf, spectacular waterfalls, and a glacier, the group also had time for shopping, swimming, and encountering the local brew, a visit to the National Museum and Art Gallery and the National Park on the outskirts of Rekjavik.

A particularly memorable evening was one spent with a local family.

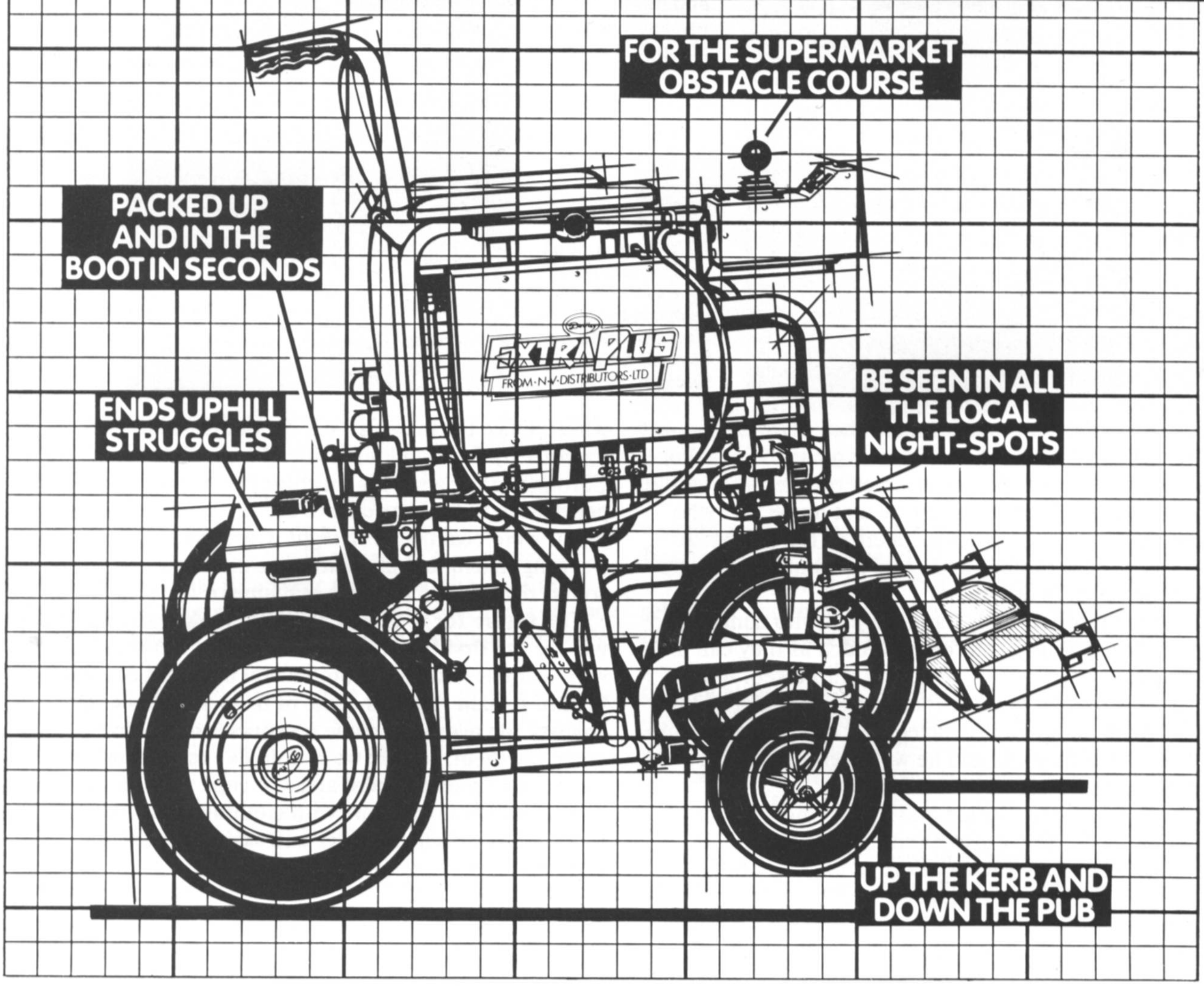
"We were divided into groups of three or four and were taken to meet the families who had agreed to act as our hosts for the evening. The family I visited had prepared a traditional Icelandic meal of smoked pork, vegetables and lava bread followed by Danish pastries. Most of us were a little apprehensive about the visit but we really enjoyed the evening which went all too quickly".

Gary concludes: "It is difficult to summarise the trip . . . the scenery must be among the most memorable in the world. We remember the hospitality of the people and the fact that even when we went to tourist attractions there were no large crowds.

"If you enjoy beautiful scenery and enjoy getting away from the crowds on holiday then Iceland is the place for you".

● *This was Gary's first holiday abroad and he seems to have caught the travel bug because he is going to Sweden this year with the Phoenix Trust!*

Look what happens when we draw on your experience.



A lot of people have very positive ideas about their ideal chair. Listening to them has helped us perfect the Extra Plus – a chair for those who spend a good deal of their time out of doors.

The Extra Plus responds to your every need, whether you're gliding up a 1 in 4 hill or getting a cup of tea indoors. This is because it combines power with manoeuvrability. As well as simple fingertip control and a host of features that make it excellent value for money. A heavy duty frame and orthopaedic seating ensure it's tough on the street but not on you.

Another reassuring plus is that it's got all the proven Dudley technology you expect from NVD, the leaders in mobility products. So if you'd like to know more please contact us. After all, the Extra Plus is the chair you helped us design.

✂

Cut out this coupon for your free brochure and send to:
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Industrial Estate, St. Albans, Herts. AL3 6BR.

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EXTRA PLUS

LINK looks at the work being done by the Irish Association in its SUMMER PROJECT to encourage its young members to be independent.

Summertime — and the living is busy

by Phillippa F. Daly, M.A.O.T.I., Community Occupational Therapist


Ready for anything — a group of 9 - 12 year olds.

THE SUMMER PROJECT has been an annual event now for four years. No two years have been the same as our unique enterprise is maturing and developing in accordance with our children's needs. In 1983 we had forty participants. They came from almost every branch, including our first international participants who came all the way from Spain.

The Project ran over a four-week period with ten participants each week and was held in the Round Tower School, Clondalkin. The weekly groups were divided according to age, i.e. first week, 14 – 16 years, second week 12 – 14 years and third week 9 – 12 years. Our fourth week was very special as, for the first time we had a group of mobile children. All of these children had either very mild spina bifida or hydrocephalus. Their main difficulties were lack of co-ordination leading to clumsiness, difficulties catching a ball and so on. So the week concentrated on gross motor activities through P.E.

Our P.E. teacher, Jass McEvoy, was excellent and full of exciting ideas. Through the week we all became very fit with the activities as there was participation by everyone. At the end of the week on parents day the children gave a show of movement to music. It was their idea that was gently nurtured by Jass. The end result was

Continued over Page

ON SAFARI at Windsor Safari Park and Seaworld

Saturday, 16th June 1984

A great day out — at special concessionary rates — for members of ASBAH, your families and friends, which will also help to raise funds for ASBAH.

- **Drive through 7 Game Reserves (using your own coach or minibus)**
- **Seaworld Show including Dolphins/Killer Whale Show & High Dive Spectacular**
- **Fun Run/Wheelchair Push with Prizes**
- **Safari Park Quiz with Prizes**
- **Extensive Areas for Picnics**
- **Children's Farmyard and Play Area**
- **Parrot Show**

Planned in conjunction with asbah

To make your booking please complete this form and send it with full remittance to:

The Party Booking Office,
Windsor Safari Park,
Winkfield Road, Windsor,
Berks SL4 4AY

Name of Group..............

....

Address....................

....

Tel No.....................

Group Leader...............

Est. Time of Arrival..........

Number in Party.............

No. of Wheelchairs..........

Total amount of cheque/PO enclosed (prices inclusive of VAT)

....

(Payable to Windsor Safari Park)

No refunds will be given

The Park will be open from 10.00 am until 6.30 pm and the special 'fun day' price will be £2.00 per head (adult or child).

superb—I think some of the parents could not really believe that it was their child who was actually producing such smooth and elegant movements to music. The week was an absolute success and will now certainly be part of our Summer Project.

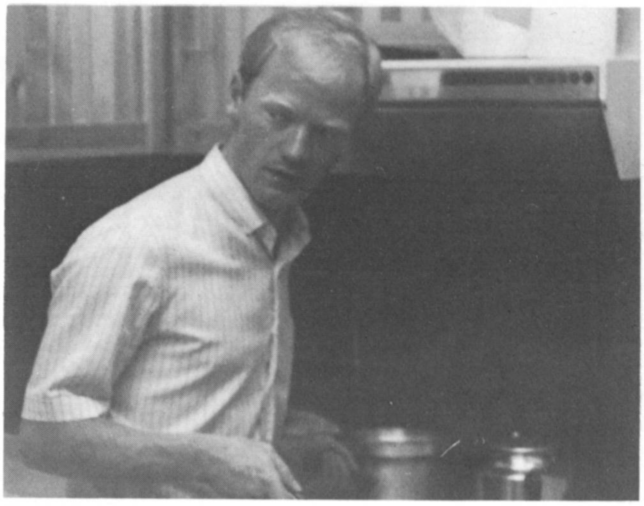
The first three weeks were quite different in their format. We had the help of nurses, house parents, helpers, physio and occupational therapists.

Our aim was, is and always will be independence. But independence does not just mean being able to dress oneself and transfer in and out of wheelchair, etc. It also means being able to stay away from home and family, being able to make a decision on one's own, being able to answer questions and have conversation, being able to carry out a task, being able to plan activities; that is being able to fulfil life as a person in his/her own right.

During the various weeks we do try to cover all the essential elements of independence which do, of course, vary with each group, their needs and their demands.

Each week ended with parents day where staff and parents had the opportunity of confidentially and openly discussing difficulties and how to overcome them. As the weeks were always full of achievements by the participants the day had a very positive air to it. Parents day also gave the parents themselves the opportunity of chatting informally, sharing good times and bad times, airing their views and opinions and advising one another.

The finale was, of course, the disco and the presentation of awards to all our participants. An apt way, indeed, of coming to the end of a week that was so full, to bursting point, of achievements.



Kevin Plunkett at the stove.

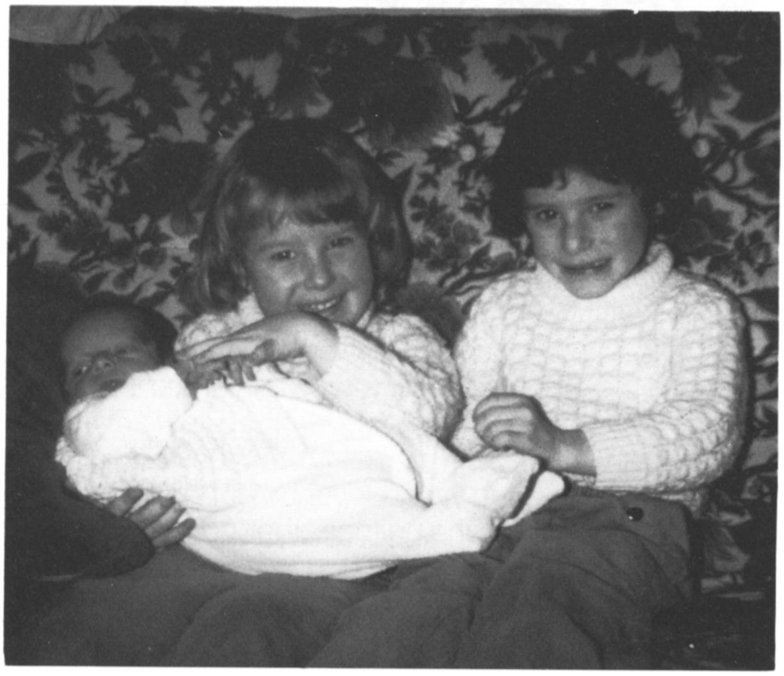
A first taste of being a house parent

by Kevin Plunkett, aged 20, a Psychiatric Student Nurse.

A YEAR ago had someone roared at me, "hey Da", I would have looked over my shoulder, maybe even have

→

'My husband and I were delighted to learn that I was expecting twins'



FOLLOWING the birth of the Parkinson twins, Gemma and Jodie on June 15 last year, LINK asked for news of any other twins born to readers.

Lo and behold we have now heard from a family in Cleveland. Mrs Jenny Sunley, having seen the happy pictures of the thriving Parkinsons, sent a photograph of her three children, including twin daughters, together with a short letter.

Jenny Sunley writes:

"I thought you might be interested in the enclosed photo of our 'happy little family'.

"I have spina bifida, and my husband and I were delighted to learn, after six months of marriage, that I was expecting twins.

"Elizabeth (the blonde twin) and Victoria were born on June 13, 1980. They were delivered by Caesarean section five weeks prematurely as tests showed that Victoria was not growing satisfactorily. She weighed 2lbs 3ozs and Elizabeth weighed 4lbs 5ozs — both perfectly healthy.

"Our little boy was born on February 3 this year. James was a normal delivery and is also perfect in every way."

Party preparations call for a team effort.

A group learns the art of wheelchair maintenance.

been insulted. But now it comes as naturally as "hey handsome" or something in that line that I'm used to.

The Summer Project '83 was my first project, and I was a bit apprehensive about the whole thing in the beginning. I had only briefly met some of the previous year's participants in Ballymun. I knew some of the volunteers I would be working with, and the thought of having to deal with the professional staff scared the hell out of me.

The term "House Parent" sounded a bit alien too. The only parents I ever knew were my own, and there were times when they easily qualified for a Moon Launch!! My job, I was told, was to take a group of participants and volunteers, and to create an atmosphere and situation where we could live together for a week. During this time we were to share ourselves and our abilities so that each one of us would learn something about ourselves, and discover skills and talents which we possessed but did not use. As a group we were to sleep in the same area, eat in the same kitchen and, play the same games.

Often the gap between theory and practice is wide. I suppose with such a mixed bunch of people that gap might have been even wider. Funnily enough there was not so much of a gap as I thought there would be. After the initial polite introductions we got to know each other fairly well. It's hard to be around someone all day long and not let the barriers drop after a while. The dropping of the barriers quickly showed us that there was not a great difference in the things that we did and thought, but only in the way we did them. My legs did something for me, and someone elses arms did more or less the same thing for him or her.

I think the biggest barriers to be overcome by everybody were those which hid what we could and couldn't do. Many of the participants seemed to have pre-conceptions about things such as incontinence, and pressure sores, as things which were unavoidable and even inevitable.

Some of the volunteers saw little that could be done in the circumstances. But talks and demonstrations both as a group and in private, showed many of us that when all is said and done we can have control over these things, and make things a lot more comfortable for ourselves, the participants and their families. I'm a firm believer in "practice makes perfect" and I got plenty of practice.

I found it tough enough being a house parent, and I'm sure others found me difficult at times as a "Daddy". Mind you it was always comforting to know that the other partner, "Mummy" could be blamed for approximately half the problems which arose. I think the hardest role I had was to go between the professional staff, and the volunteers and participants.

A house parent should be all things to all present, and this was sometimes compounded by different disciplines, needing different things done at the same time, or at times when most people simply wanted rest. This is not a critisism as such, but an observation which can be viewed from different angles.

However the most pleasing role was undoubtedly that of being "Daddy". When you are walking through a shopping centre and about six girls and boys are calling you "Daddy", it is interesting to note the consternation and confusion on people's faces. And when a beautiful "Mammy" takes your arm to catcalls and whistles from her children, it really throws things in a heap. The real problem though is when **real** Daddy arrives and **I** end up absolutely confused and worried.

I enjoyed the Summer Project a lot, and so, I am, sure did everybody else. I don't think I would mind being a "Daddy" again, that is of course if "Mammy" and the kids don't have me barred. The volunteers and the participants too showed each other an awful lot, and learned much from each other. It will be nice to meet again sometime to learn more and have a good time.

Reproduced from the magazine of the Irish Association — AID

Mobility Road Show 1985

THE NEXT Mobility Road Show will be held on 13, 14 and 15 June 1985, run by the Department of Transport.

It will be held once again at the Transport and Road Research Laboratories at Crowthorne in Berkshire and will provide disabled motorists with an opportunity to test drive a number of cars or to be a passenger. By providing almost 18 months' notice it is hoped that many more disabled people will be able to attend it than was possible last year.

Vera Lynn stars at the Stage Door Canteen

DID THE cover of LINK this month make you wonder what was going on? Happily, no time-machine has turned the clock back 40 years, but on the 40th Anniversary of the D-Day Landings Barry Mishon will, once again, be promoting the Stage Door Canteen using the formula which proved so successful last year.

At the time of writing, more than 1,000 advance bookings have been received, so it seems very likely that by Sunday, June 3 our guest celebrities will be playing to a capacity audience of 1,800. As usual, this will be a star-studded event, with stars of stage and screen not only performing on the stage, but also mingling with the audience as taxi-dancers, waiters and waitresses.

As our 'Grand Finale' we are most fortunate to have Miss Vera Lynn who, I am guessing, might be prepared to sing 'There'll Be Bluebirds Over the White Cliffs of Dover''. For many present this will certainly bring memories flooding back.

Last year, almost everybody came dressed in the style of the period, whether in uniform or civvies, which did a great deal to create a superb atmosphere for the evening, truly a night to remember. So, if you would like to join the revellers at the Lyceum on June 3, we would be delighted to welcome you, but would warn you that prompt booking is essential.

BARRY MISHON really does seem to be hitting the headlines, not only in LINK this month, but throughout national media, as I am certain that you will have heard mention of his fabulous ''Night of 100 Stars'' which was held at the Theatre Royal, Drury Lane on February 26.

In fact, 105 'top-liners' took part in a superb performance which demonstrated the ability of our leading actors and actresses to perform as song and dance artistes with equal facility. The show was co-hosted by Ned Sherrin and David Frost, who brought a great deal of wit to the proceedings, as did a host of continuity announcers such as Derek Nimmo and Sheridan Morley.

We were honoured on this occasion by the presence of our Patron, Her Royal Highness The Duchess of Gloucester, who thoroughly enjoyed the show and stayed to meet many of the performers at the reception which followed, making it a memorable evening for them too.

It looks as if we will be running the event again next year, by popular demand on the part of all concerned.

I HOPE that LINK readers saw our recent television appeal, presented on commercial television by Miss Thora Hird on Sunday, March 25. Donations are still arriving at the office and it is hoped that proceeds will exceed £10,000, which will certainly prove to be a much-needed boost to our all too limited funds.

As this is the third television appeal which we have had broadcast on behalf of the Association in the past seven years, I think we may count ourselves very fortunate to have found such favour in the BBC and commercial television co-ordinating committees.

APRIL 14 and 15 marked the occasion of our third annual Chatathon to find the ''Conversationalist of the Year'' 1984. LBC helped promote the event and now that the event is firmly established in our yearly calendar we hope that a similar trend will emerge for planned Chatathons in the Birmingham and East Midland areas.

TO PROVE that ASBAH's Appeals Department is, as ever, as diverse as possible in its fundraising enterprises, I am delighted to report that our Association has been selected by the Meat Promotions Executive to organise and benefit from ''Pork Pie Month'', which runs from May 14 until June 9, with the slogan ''Pie in the Sky''.

The Royal Aero Club have kindly agreed to support us in running the event, and participants in all branches of sporting aviation are being challenged to ''Fly with a Pie'', whilst at the same time raising funds to benefit ASBAH. If you are interested in consuming pork pies whilst your feet have left 'terra firma', do get in touch with me, as I will be delighted to send you details of participation, as well as information about the very substantial cash prizes which the Meat Promotions Executive are making available.

THE ABOVE are just a few of the past, present and future events which the Appeals team at ASBAH have been and are devising with, some might say, our tortured imaginations. As always, you are invited to contact me if you would like a complete run-down of the attractions and challenges which all go to make up our attempts to further the aims of the Association.

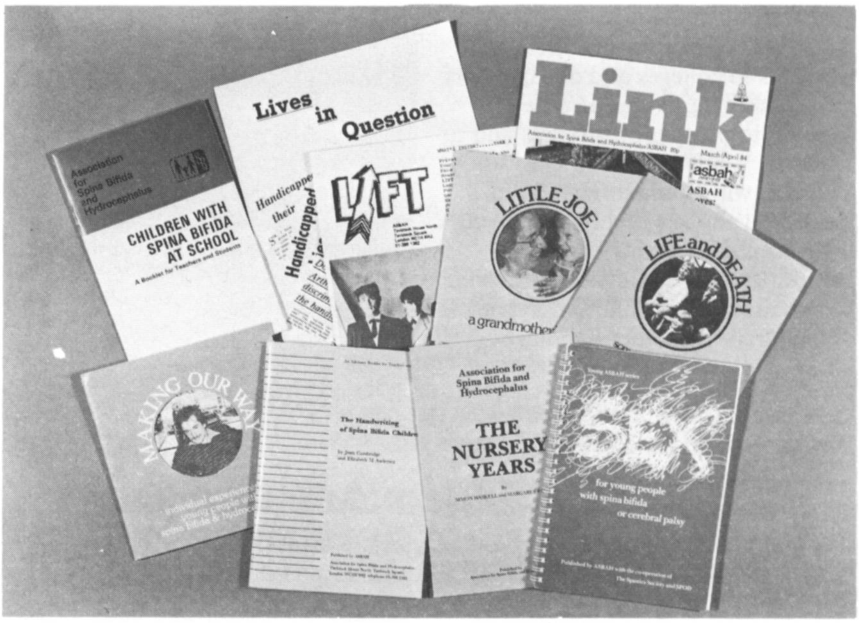
This is our 18th birthday year, so we must endeavour to keep celebrations going as long as possible from the date of our actual birthday on April 28, which was marked by a special lunch party at the London Forum Hotel. The response to our request for people with spina bifida and hydrocephalus born near our birthday has been tremendous, and as a result eighteen 18-year-olds were due at the party, and were to include Wesley Todd who was 18 on the 28th itself and who came over from Northern Ireland. The party was organised by Denise Dunning, Education, Training and Employment Co-ordinator for ASBAH, Jane Hayman, Appeals Organiser, and Vivien Harper, LIFT Organiser.

Our ''Coming of Age'' is certainly a time for congratulating the many thousands of people who have made the occasion possible by supporting us so generously over the years. But, on no account, must it be a time for resting on our laurels, if we are to rise to the challenges which lie ahead.

JUDY KAY

Appeals Director

Reading matter that helps keep you on the right lines



HERE is a reminder about the publications which ASBAH has on offer.

A major new book — *Spina Bifida and You* — a guide for young people, will be published later this year.

All ASBAH publications are constantly under review to ensure that the information remains up-to-date.

In addition to the books listed below ASBAH's information department has a number of very useful *Fact Sheets* which cover a variety of subjects including: Spina Bifida and Hydrocephalus, Spina Bifida Occulta, Neural Tube Defects, Antenatal Screening, Information about ASBAH, Guidelines for Swimming, the Orange Badge Scheme, Mobility Allowance Appeals, Attendance Allowance Reviews, Holidays.

Fact Sheets about spina bifida and hydrocephalus are also available in Bengali, Gujarati, Hindu, Punjabi and Urdu, and in Welsh. Although these are free it is a help if you can send postage of at least 20p.

There are special rates on books for Local Associations. All are available from ASBAH National Office, 22 Upper Woburn Place, London WC1H 0EP.

Continued over Page

Continued from Page 17

The Handwriting of Spina Bifida Children

by Joan Cambridge and Elizabeth M Anderson. £1.25

THIS IS intended primarily as an advisory booklet for teachers and students in colleges and departments of education and may also be of interest to other professionals and to parents. While it is specifically about children with spina bifida and in particular those with accompanying hydrocephalus, many of the suggestions are equally applicable to non-handicapped children, as well as to children with other handicaps.

Sex for Young People with Spina Bifida or Cerebral Palsy

(Young ASBAH series). £1.25

THIS BOOK which has proved very popular and useful is written for young people in a straight forward easy-to-read style, with plenty of illustrations. It gives an outline of sex and sexual relationships, and could prove valuable not only to young people but to their parents, too.

The Nursery Years

by Simon Haskell and Margaret Paull. 35p.

THE EARLY years are vital. It is during this time that children with spina bifida or hydrocephalus need an abundance of normal experiences just like other children. Love, care, stimulation and appropriate training are of special importance in ensuring that your child gets a good start in life.

Parents have an important role to play and this booklet is a guide to some of the ways in which they can help their child to develop physically, emotionally and mentally.

Children with Spina Bifida at School

Price 50p.

WRITTEN by members of ASBAH's Education, Training and Employment Committee, this book looks at the effects of spina bifida and hydrocephalus on children, on their health, personality, behaviour and school progress. It also discusses as what teachers can do to help the children improve their school work. It is a useful handbook for both teachers and students.

REMEMBER BABY . . . REMEMBER ASBAH

AN ASBAH Baby Book makes an attractive souvenir of a baby's first days, with spaces for baby's first photograph, baby's hand and footprint and details of the first holiday.

What's more, if you give the birthdate of the baby you will receive a free horoscope for his or her Star Sign. The horoscopes also include recommendations on how to deal with various quirks of character.

And remember every book sold helps ASBAH. The price is very reasonable — £1 each, including postage, from ASBAH National Office which is now at 22 Woburn Place, London WC1H 0EP.

Little Joe

by Winifred Foster. 50p.

THIS IS the moving story of a child born with spina bifida and hydrocephalus written by his grandmother. The account of his struggle for life and the effect this had on his parents and grandparents who had to adapt to this new member of the family is told clearly and vividly. It is a story that should help many other grandparents of handicapped children.

Life and Death

Price 75p.

SINCE ITS publication last year this booklet which looks at the subject of bereavement has proved to be in demand. It is a compilation of personal stories of bereavement, written by parents of children with spina bifida and hydrocephalus, and the views of 'experts' on bereavement.

It endeavours to bring this taboo subject out into the open, and hopes to ease the way for bereaved parents. It could also prove useful for other members of the family, for friends and neighbours, and for professionals, all of whose attitudes and actions at the time of bereavement, as well as before and after, are so very important.

Making Our Way

by Susan Gearing. £1.

THIS booklet is about the individual experiences of eight young people with spina bifida and hydrocephalus. It shows some of the problems and challenges that they have encountered and how they have met them in their different ways.

Lives in Question

Price 25p.

This Special LINK Supplement was published in the Spring of 1982 and attempts to clarify some of the issues involved in the debate on how far we should go in prolonging the lives of severely disabled new born babies. It is a subject brought to the forefront during the Dr Arthur case. The Supplement carries the views of some of the leading professionals and of parents.

LINK

Bi-monthly

ASBAH's magazine carries a wide range of articles offering advice and information on medical, social and welfare matters, research, aids, benefits, and news, views and local activities. It is circulated through the Local Associations and by direct mail. LINK is read widely in this country, and also abroad. Price: 20p per copy; £2.30 annual subscription (post paid)

LIFT Bulletin

This lively newsletter is free to members of LIFT (young ASBAH) and is published in the Spring, Summer, Autumn and Winter.

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.
Please note that there is a 10% discount if you book six advertisements in advance.**

Adverts for the next LINK (May/June) should be in by April 5. Send to the Editor Mrs. Susan Gearing at home: The Gables, Long Lane, Wrington, Avon. Tel: Wrington 862279.

HOLIDAY ACCOMMODATION

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.

CAISTER ON SEA. Two 6 berth caravans. Mains electricity, gas, shower, TV. Details: Mr L. J. Fletcher, 48 Humes Avenue, Hanwell, London W7 2LP. Tel: 01-579 2623.

CENARTH, W. Wales. Luxury chalet adapted for wheelchair. Sleeps 6. Colour TV. Heated pool, restaurant, shop, launderette. Details: Mr T. Noon, 14 The Chase, Leicester LE3 2WA. Tel: 0533 895691.

CHAPEL-ST-LEONARDS, Lincolnshire. Huddersfield and District Association have vacancies at their luxury holiday Chalet. All amenities, including colour TV. Details from Mrs J. Brook, 11 Standiforth Road, Dalton, Huddersfield (21776).

COLWYN BAY AND PWLLHELI. Two purpose-designed and built luxury 6-berth holiday homes with ramps, sited in Colwyn Bay and Pwllheli areas. Details: Mrs C. Hughes, 66 Sea Rd., Abergele, Clwyd, N. Wales. Tel: Abergele 824673.

EAST SUSSEX. Delightfully converted cottage flatlet situated in grounds of Victorian house. Adapted for the disabled. Sleeps 2 plus 2 in main house. Eastbourne 17 miles. Colour TV. Tel: 04353 2529 after 6 pm.

GREATSTONE, Kent. 3 bedroom bungalow. Lounge, kitchen, well equipped large bathroom with hoist. Large garden. Close to safe, sandy beach and shops (200 yds). NE London association (NELASBAH). Details: Pierson, 18 Kingsley Road, E7 9PP. (S.a.e. please).

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.

PRIMROSE VALLEY. Fully adapted luxury caravan. Sleeps 6. Bath/shower, ramp. Many facilities on site. Details: Mr J. Adams, 105 Blakey Close, Redcar, Cleveland. Tel: Middlesbrough 472920.

WESTWARD HO!, North Devon. Holiday Bungalow, sleeps six. Excellent Club, swimming pool. Shop on site. Near Sandy beach. Details: Mr G. Oakley, 12 Farleigh Road, Perton, Wolverhampton. Tel: 751484. (S.a.e. please).

WINTERTON-ON-SEA, Nr. Gt. Yarmouth. Fully equipped chalet. Sleeps 6. Indoor heated pool, shop, amusements, snacks, club, play areas. Details: Mrs A. May, 20 Ridley Close, Blaby, Leicester.

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.

EXCHANGE & MART

Leisure Wear: White cotton **Tee Shirts** with green family symbol and words 'Support Spina Bifida'. Also **Sweat Shirts** in reverse colours. All sizes. Details from Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

Meyra Brigitte Playmobile Tricycle, hand propelled by cranked pedals/chain driving front wheel. Safety bucket seat. Adjustable height and reach. Suit 6-11 year old. Offers. Tel. 021 445 3542.

ASBAH booklets, etc . . .

Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	50p
The Handwriting of Spina Bifida Children, by Joan Cambridge and Elizabeth M. Anderson	£1.25
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
Making our Way — individual experiences of young people with spina bifida & hydrocephalus	£1
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 at least 30p for postage.

SEE PAGES 17 AND 18 FOR MORE DETAILS ABOUT ASBAH PUBLICATIONS

Scottish Spina Bifida Association Booklets

The Spina Bifida Baby by O. R. Nettles, McSP, ONC	40p
Growing up with Spina Bifida by O. R. Nettles, McSP, ONC	35p
Keeping Fit by Jean M. Temple MCSP	10p
Self Help with Spina Bifida by E. Wilson and E. Taylor	10p

Postage and packing is extra.
Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW.

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Tel: Sunderland 283568.

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Miss F M Seward,
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Pontardulais,
Swansea, SA4 1LL.
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Penmaenmawr,
Gwynedd.
Tel: 0492 622550.

SOUTH WALES
Mrs Brenda Sharp,
38 Redbrick Crescent,
Barry Island, S. Glamorgan.
Tel: Barry 735714.

SCOTTISH ASSOCIATION

Mrs Audrey Smith,
General Secretary,
190 Queensferry Road,
Edinburgh EH4 2BW.
Tel: 031-332 0743.

NORTHERN IRELAND

Mrs E I McDowell,
23 Dalboyne Park,
Lisburn,
Co. Antrim BT28 3BU.
Tel: Lisburn 6023.

Antrim
Mrs R Lynd,
2 Gortgorn Terrace,
Toomebridge, Co. Antrim.

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OTHER LOCAL ASSOCIATIONS

Blackpool & Fylde
Mrs M Brammer,
9 Wolverton Avenue,
Blackpool.
Tel: 0253 591115.

Beeston
Mrs S S Goodfellow,
5 Cyril Avenue, Beeston.

Cambridgeshire
Mr R Wilkie,
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Mrs L A Christie,
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Isle of Wight
Mr D J S Sprake,
Springfield, Town Lane,
Chale Green, Ventnor.
Tel: Chale Green 234.

Lancaster, Morecambe &
District
Mrs M Dyson,
25 Royds Avenue,
Heysham, Lancs.

Rochdale
Mrs Ann Lawton,
20 Spencer Street,
Chadderton, Oldham,
Lancs.
Tel: 061 652487.

Somerset
Miss June Roberts,
1 Ilford Court,
Wiltshire Close,
Taunton.

Teesside
Mr J Gray,
Marchesi Centre, Tollesby Road,
Middlesbrough, Teesside.

Please will all local Secretaries who want their telephone numbers included in this Directory get in touch with LINK Editor: Mrs S. Gearing, at National Office: ASBAH, 22 Upper Woburn Place, London WC1H 0EP.

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