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Association for Spina Bifida and Hydrocephalus/ASBAH 10p July/Aug 79

The Great Children's Party

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Association for Spina Bifida and Hydrocephalus/ASBAH

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Tavistock Square,
London WC1H 9HJ.
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ASBAH has an experienced staff ready to help with any problems relating to those with spina bifida and hydrocephalus.

Chief Executive Officer:
Miss M P Gilbertson, MCSP

Finance Officer:
Mr F G Armour, FCA

Director of Appeals:
Miss Judy Kay, MIPR

Liaison Officer:
Mr H D Macfarlane

Education, Training & Employment Officer: Mrs B Newman

Head of Social Work:
Mr Rod Harper, MBASW

Aids & Appliances Officer:
Miss J Vernon, BSc.

Young ASBAH Officer:
Miss Jan Tomlinson

Information Officer:
Miss B Holland

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Mrs S I Gearing

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ASBAH and LINK were at the biggest children's party in the world—The Great Children's Party in Hyde Park in May to celebrate International Year of the Child. And certainly no child has ever been treated to such a feast.

And there were a number of very special guests, too. The Queen and Princess Anne both had walkabouts, meeting many children, and Mrs Thatcher, the Prime Minister, came too, escorted by about 30 policemen.

There was not only lots of free food, including a two-mile sausage, yoghurt, and crisps, but also the chance to paint a London bus, dress up, see yourself on TV, have a go at It's a Knockout, watch fighting dinosaurs, a circus and military bands.

There were also a wild west show and hot air balloons, adventure playgrounds and a fascinating variety of displays to watch.

It was all there in enormous quantity, but perhaps there was just a little too much. Children often seem to prefer simple things, and it seemed to LINK and ASBAH staff that it was a bit too ambitious. There were too many people—the party area was only half a mile wide by three-quarters of a mile long—and most children had to spend a lot of time queueing, whether for free sausage, a ride at the fun fair, a circus seat, or the lavatories. All too soon, the ground became muddy and slippery and more and more lost children sought shelter in the Lost Children's Tent.

ASBAH and about 65 other voluntary organisations contributed a great deal to the Party with different tents, amusements and competitions.

Felicity Phipps (née Birkett, formerly Aids and Appliances Officer) made a brief and very welcome return to ASBAH before going to live abroad, and was a very great help to Judy Kay and Beverley Holland in organizing ASBAH's events.

In the shelter of a large white tent and side by side with the fun fair, ASBAH organised a Giant Game of Monopoly, involving children in wheelchairs who acted as 'the counters'. It took some time to persuade enough children to take part, but three full games were enjoyed.

Much of the credit for the success of these games must go to Bryn Williams and Roy Reader-Smith who acted as toastmasters. Tim Brooke-Taylor spent a large part of the second morning at ASBAH's tent adding his own particular humour to the game. The children loved him and for many of them getting his autograph was the highlight of the day.

Felicity personally supervised obstacle races for children in wheelchairs, and these proved popular.

Mrs Thatcher, and Patrick Jenkin, the new Secretary of State for Health and Social Services, both visited ASBAH's tent, and the children were delighted that Mrs Thatcher was able to spend some time talking to them.

None of ASBAH's activities at the party would have been possible without the sponsors—Waddingtons Games, the Wig and Pen Club, Barretts Development Ltd., Thames Water Board, Greenwood Homes, Wimpey, and the Churchill, Park Lane, Ritz, Heathrow and Cumberland Hotels.

Thanks go also to Cannon Hygiene who supplied and serviced 12 chemical sanitary containers, and to Camden Council's Environmental Department, who supplied the two chemical toilets. This enabled ASBAH to have its own bathroom and toilet tent—the only facility of its kind within the party area.

The Party was undoubtedly an amazing feat of organisation. A great deal of time and money went into it, and a large number of the 160,000 children who attended certainly did have the time of their lives and should long remember the Greatest Children's Party ever.

COVER STORY: The fun and excitement of the Party are captured in these pictures of the children and celebrities who visited ASBAH's tent and joined in. They included Mrs Thatcher (right) and Tim Brooke-Taylor (bottom left). Photos: Larry E. Ware.

About ASBAH

FOLLOWING several recent requests, the May meeting of Council was devoted to discussing reports from Sub Committees and generally updating members with the work of National ASBAH. Fifty-two delegates attended but unfortunately, this apparently good attendance represented only 30 Local Associations. The meeting was generally acclaimed a success. I am sure that anyone who was with us in London that day would say, "Do come next time".

LIFT's work

A MAJOR item on the agenda was the report from Miss Jan Tomlinson describing the work of LIFT and, in particular, the social rehabilitation training weeks, which have been held. In addition to this being one of the most important expansions of National ASBAH's work, it is encouraging to know that the DHSS is watching our progress with interest and has asked to receive a copy of the analysis we are preparing on each training week.

Mobility

THE MEETING was told of the proposed wheelchair proficiency scheme. This is still in planning stage, but we hope something will be mounted nationally, which will be comparable to the existing bicycle proficiency scheme. ASBAH is represented on the Committee of RSVP, the Replacement Specialised Vehicle Project, which is a pressure group endeavouring to establish provision for those who have been deprived by the withdrawal of the invalid trike.

Appeals

MR MUMFORD, member of Executive and Chairman of the Appeals Committee explained the thinking behind the establishment of a small team of professional appeals organisers. His plea for improved communication between Local Associations—"the families which make up ASBAH"—and the national office, and his emphasis on the need to establish, throughout the country, one face of ASBAH was warmly received by Mr Brian Henley, Worcestershire (member of the Appeals Committee).

Inflation

MONEY, or rather the lack of it, looms large in all our minds. Miss Judy Kay reported that our income was up by 15%, but, as the rate of inflation also increases, we are still in grave financial straits. It will, therefore, come as no surprise to you to hear that the discussion of the Association's general financial position occupied a large part of the meeting. Mr Frank Armour spoke to the circulated summary of the Budget, and in the discussion which followed, Mr Michael Booth (Leeds and Bradford) hoped that all Council members would take this problem back to their Associations in the hope that the activities of ASBAH will receive greater financial support.

Training

THE REPORT of the Education, Training and Employment Committee was presented by the Vice Chairman, Miss Faith Seward. One Research Project at Banstead Place, looking into the vocational training possibilities for young people with hydrocephalus, is now under way and we are all very pleased that proposals submitted by Professor Gulliford of Birmingham University for a further project at Derwen College have been approved. We hope that a worker will be appointed in time to start the project at the beginning of the next academic year. The Committee has been very concerned with the production of booklets recently. "Sex and Spina Bifida" has been well received and a new booklet written by Dr Elizabeth Anderson, a Committee member, and Mrs Joan Cambridge on "Handwriting of Spina Bifida Children" is currently at the printers. Although this is, perhaps, a very specialised booklet we think it will be an important addition to our publication list.

Staff

WITH THE very rapid growth of the Association, about 50 people are now employed. Among its many responsibilities, the Management Committee looks after their interests and ensures that the terms and conditions under which the staff are employed are in line with current legislation and good practice. In giving his report, Mr Dennis Bryant, Chairman of Management and Vice Chairman of the Association, paid tribute to the work of ASBAH's staff. He also told the meeting of the proposed plans for an International Federation of Associations for Spina Bifida and Hydrocephalus and the hope that I will be able to represent ASBAH at the inaugural meeting in Stockholm later this year. It is also hoped that ASBAH will host the 1982 Annual Meeting of the Society for Research into Hydrocephalus and Spina Bifida.

Symbol

I AM SURE readers will like to know that, although Mr Richard Stubbs retired as Vice Chairman of the Association, member of the Executive Committee and Council, he has consented to retain the Chair of the very active Publications Committee. In his absence, Mr Ron Tallamy brought members up to date and showed some of the material using the new Appeals symbol. The response to this will be carefully monitored and consideration given to using it as a general ASBAH symbol. For some years now it has been thought that a change of design would be appropriate, but, in spite of considerable effort, nothing suitable has yet been found. The Committee think that it is so important that any change should be exactly right that they are prepared to take time to reach a decision.

Social work

THERE ARE 17 part-time Social Workers employed throughout England and South Wales. The Welfare Committee is acutely aware of the changing needs of families and has discussed with the

Continued page 16

SALTS

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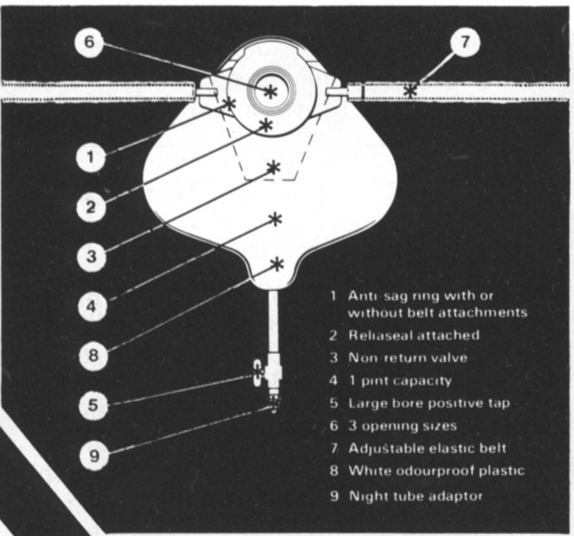

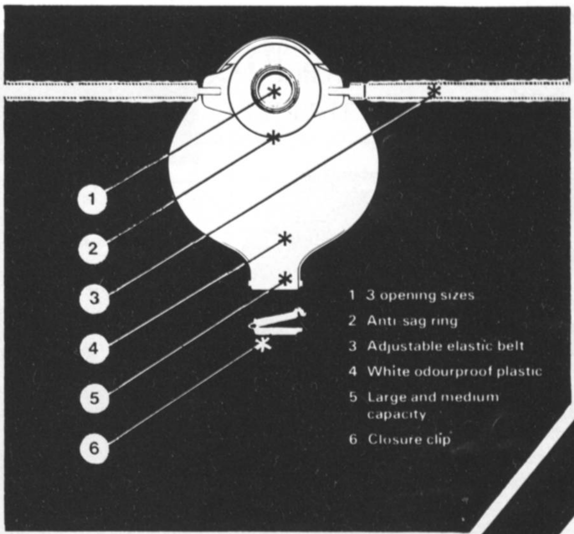

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Caroline's off on the right road!

AT THE age of 17, Caroline Peters, who has spina bifida, is well on the way to passing her driving test—thanks to Camden Council and its specially adapted driving simulator.

Caroline (pictured right) with her driving training instructor, has passed the simulator test which should make the road test that much easier.

She said: "The idea is that we get some road sense and see how to co-ordinate acceleration and steering. We get an idea of how the traffic works first. It's to get us used to driving without being on the road."

Four other boroughs in Britain use similar driving simulators and Camden has gone a step further by persuading schools to include such instruction in the curriculum. One of the machines is adapted for the handicapped.

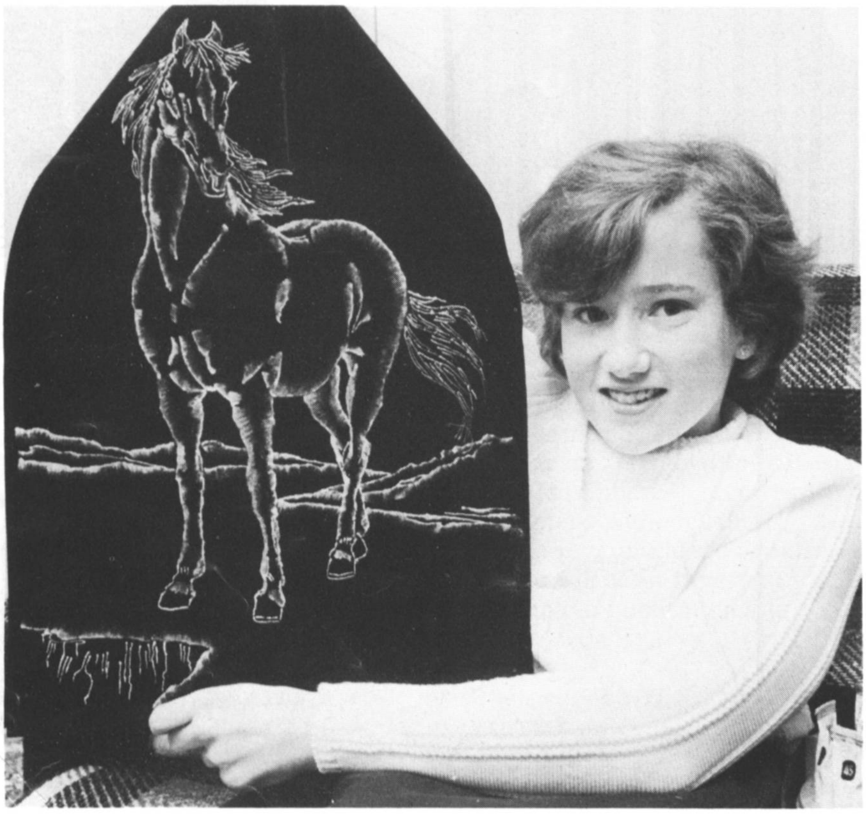
ASBAH has been actively involved with organising this, and there will be a further report in a later LINK.

Photo: Hampstead and Highgate Express.

Look what they got up to

Silly games, strenuous effort and willpower were just some of the ways in which the landlord and regulars of the Hatfield Arms, Hatfield, raised enough money to buy a batric car for the Herts and South Bedfordshire Association.

It is the second car bought by the pub, and the lucky driver of the latest one is 12 year old Jamie Seabrook. The games included 'blow-football' using a match floating in a tray of water. Customers took part in a 10 mile sponsored run, and the landlord Mr Bowling gave up smoking for three months and asked the regulars to sponsor him.



Lesley's new art wins grant

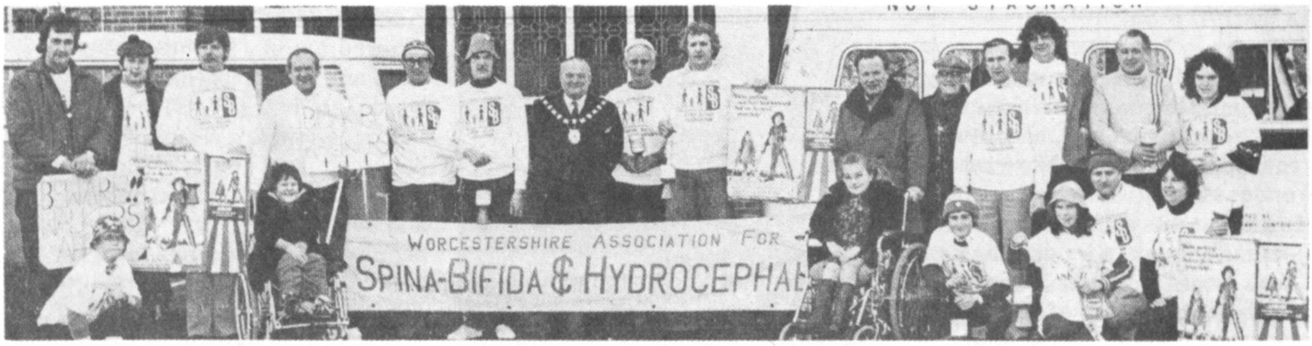
LESLEY Bramham of Sawbridgeworth (left) with one of her Tri-chem paintings. It is a hobby that has won her one of the much coveted 1979 Winston Churchill Memorial Trust grants.

Lesley, who has spina bifida, has chosen a four week trip to America to study Tri-chem art. She will be trained by the main Tri-chem firm and hopes this will benefit her career within the community. She plans to teach this special kind of art in schools for the physically handicapped and in hospitals, after she leaves school this year.

Tri-chem is a special type of oil painting, using biro nibs. It originated in America a few years ago and is just becoming known in this country.

Very best wishes for the future, Lesley.

Photo: West Essex Gazette.



A test of 'wheel power'

LEANDA Vincent (left in the picture below) and Jackie MacKenzie of Salisbury association try out the two powered wheelchairs which were presented to the local association by regulars of the Three Crowns public house at West Harnham. Photo: M. Fatherly.

. . . Philip is more traditional

PHILIP Brown of Hull and District Association (below) with some of his more traditional painting. The aeroplane painting was exhibited two years ago at the Winter Exhibition of the Ference Art Gallery in Hull, and "Mary Anne the Donkey" was accepted for this year's show.

Buffaloes go on 20-mile trek

THE MAYOR of Stourport and members of the Wilden Lodge of the Royal Antediluvian Order of Buffaloes (above) before the start of their 20-mile sponsored walk which raised more than £400 for the Worcestershire Association.

The money goes towards fitting out an old library building in Stourport which is to be used as a training centre for 25 handicapped children with special emphasis being given to training for leisure.
Photo: Kidderminster Shuttle.

Leicester's looking for a sunflower

LEICESTER Association is hoping for a lot of sunshine this year in order that its Sponsored Sunflower Competition proves successful.

The purpose of the competition—apart from money-raising—is to find the grower of the tallest sunflower. Each competitor is also expected to find sponsors to pay a small sum for each foot of sunflower by the closing date.

Association bids for £25,000

STAINES, Hounslow and District Association is raising money towards the £25,000 target figure for an Optascop Machine for Queen Mary's Hospital, Carshalton.

This is a specialised form of portable x-ray machine used as an aid to the surgical treatment of hydrocephalus and spina bifida.

Its main use is to help in the accurate placing of the drainage tube in the brain for the treatment of hydrocephalus.

Extracts from the diary of an ASBAH Social Worker

ASBAH social workers are usually people who have trained in social work and have varied experience in other situations, such as medical social work and social services departments.

Though the examples in this article are based on actual events and conversations, only one or two of them are reproduced exactly as they happened, and all the names are ficticious. Where actual events, taken from one family, have been described, permission for these to be included has been given by the families concerned.

JAN 5th. I took a Hurstwood Trike out to John James in an isolated village. He was most enthusiatic but annoyed that, despite the Dycem pad, his bottom kept slipping forward. We tried to work out how to hold him on. However it was difficult to hold him still long enough to try anything.

Mrs James mentioned some doubts about the size of John's wheelchair. Whilst contemplating the chair and discussing whom she should contact, she aired her worries about John being tipped out of the chair during school playtime, and I realised that he had been at the village school for over a year with no strap on at all. We arranged to get that sorted out. I visited the school next. They are pleased with John's progress, especially now that his concentration has improved.

JAN 8th. Phone calls galore.

- A health visitor phones. A new baby is arriving home tomorrow. She has no experience of spina bifida. She has met the parents, who would like to see me. We arrange to go together.
- Two mothers rang, both with good news about their pregnancy test results: another member phoned to say that her sister had been refused the test.
- Mrs Roberts rang. The local playgroup will be glad to have her daughter, Angela. She has told them that I am prepared to visit before Angela starts, to talk to the playleader about spina bifida and discuss any worries they may have about dealing with a handicapped child, and also that I will keep in touch once Angela is at the playgroup. In addition our Association will loan them a Shasbah Trolley which they can keep at the playgroup for Angela.
- I telephoned Area Health about problems with the local incontinence supply.
- Mrs Daub phoned. I haven't seen her for some time, but Tony is due to leave school next year and she is very worried about his employment prospects. I had a few ideas about what he might be able to do and with whom we might talk about this. I promised to take her some leaflets about training centres and F.E. colleges.
- Jane Lang telephoned. She and her husband saw the consultant yesterday. The hospital has given the baby loving care through many crises. Now they are uncertain about going ahead with further surgery. The baby is very poorly. They want the family to decide whether to wait a while. It would be nonsense to pretend that our families are not getting caught up in the "quality of life" debate. Some doctors, as we know, are better at explaining this to the parents. Others say nothing at all. I arrange to visit.

Another evening visit to Mr and Mrs King. Their daughter is doing fine, but the long years of worry have affected their marriage. Many of the mothers I visit talk of marital strains and stresses, but so often they don't want their husbands to know they've told me.

Social workers are often accused of not giving enough time to fathers.I think this is true, but I suspect that we are often blocked off by mothers from talking to fathers about the things that really concern *them,* like their wives' preoccupation with the handicapped child and the effect this has on the whole family.

It is of course a *very* narrow line between discussing, with families, the problems that concern them and being felt to "pry" into people's private lives.

JAN 9th. A meeting with the Social Services Advisor to the Physically Handicapped to discuss what is happening to the new babies and why parents are not getting more help. Obviously the referral system is not working properly. Discussions may need to take place with hospital staff to emphasise the need for families to discuss their situation, if they want to, as soon as the baby is born and not be discharged, from the protective cocoon of the hospital, into a community which, on the whole, will not be geared to give them early support and may well not even be aware that they are there.

The question then arises as to the possibility of a need for a specialist social worker to cope with early referrals of all *handicaps, not just spina bifida. Some departments have appointed workers for the mentally handicapped because of national pressures about their neglect in this field. I take the opportunity to ask why children with physical handicaps are any less of a priority.*

Straight on to talk to students on a further education course on the needs of handicapped children.

Called at the Gardner's. Jim is still very angry at having to go away to school. He feels it just isn't fair. Unfortunately he lives too far away to attend as a day pupil and he can't manage the stairs at the local school.

The special school feel that he has settled down well, but he is very bad-tempered at home at weekends, and especially on Sunday nights when he knows he has to go back to school the next morning.

Unfortunately there is often little that can be done in a situation like this, except to make sure the school is aware of how the child is behaving at home and to offer some support and sympathy to the child and the family whilst they cope with such a *strained situation. The harsh reality is that life* is *often unfair to handicapped children, and no amount of sympathy or understanding will change that.*

JAN 10th. Mrs Tate telephoned at 8 p.m. I had been at a meeting out of town all day. John had died that morning. I went straight round—I have known them for so long and I wanted to share their grief a little. They didn't much want to talk but they seemed to welcome the fact that I had come.

Later on, long after other people feel that it is tactful not to mention John's name, the family may be glad to talk at length about him and about the feelings of loss which they still have, and how they have to carry on their lives as if nothing had happened. After the funeral there will also be some practical jobs to be done, like taking away John's wheelchair and walking frame.

JAN 11th. Spent the morning at my desk as a pile of letters has built up. Two children, for instance, have had their Attendance Allowance reduced without explanation. One family is uncertain about applying for Mobility Allowance. Another father has been put off by a first refusal.

One family has come to a standstill over their child's treatment. He is now ten, but has not been under a paediatrician since he was two years old. Over the years various problems have developed which have not been adequately sorted out. I suspect that he might need to be seen by both the neuro-surgeon and the urologist, though obviously as a non-medical person that is not my decision.

I know that the community physician will be very helpful and since, apart from the parents, I am the only person who is aware of all the events over the last few years, the parents agree that I write him a long letter describing their predicament and asking him to look into it.

I also write three letters to the Family Fund—one asking for a tumble drier, one suggesting a holiday grant and one describing a family's transport difficulties. Of course many families make their own applications, but often people are not happy with letter writing or application forms and are grateful for a lengthier explanation of their situation to come from me.

I also write to two different housing departments: one family is carrying a severely handicapped child up three flights of stairs to a flat; other parents feel that the dampness and condensation in their house are causing their child to have constant colds and bronchial problems, and they want to know if the council will consider installing central heating.

A second meeeting, in the afternoon, with Mr and Mrs Raye. Their baby came home from hospital before Christmas and they are delighted with him. His back has healed well and he is kicking his legs vigorously. They still haven't seen the consultant, except when he came out of the operating theatre and told them the baby had a 50-50 chance of surviving the closure of the lesion, and to tell them briefly of what effects the spina bifida *might* have.

I had advised them to ask to see the consultant before the baby was discharged, but as it was taking them 1½ hours on the bus each day to travel to the hospital with their three other small children, they had been unable to be there when he did his rounds.

They were eventually told by the ward sister that they could take the baby home. They sensed that the nurses were unable to give them any specific details about their baby except that he was "doing fine". Mr Raye had obtained a medical book which was a bit alarming. Also there is a spina bifida child in the village who is confined to a wheelchair, so they are obviously anxious about their own child's prospects.

JAN 12th. Called in to see Mrs Dhoot. Manjit, her son, has hydrocephalus. He has been back in hospital five times with valve problems. After each operation they are sure he is going to be o.k. He is so happy and alert in between times, that it is hard to accept when yet again something is amiss.

Received a phone call from the hospital. A spina bifida baby has been born to a young couple, the Coopers. It is their first child. The baby's condition is described as "fair". Surgery has been suggested and is to be done at a regional centre.

Mrs Cooper was still in the Maternity Ward. I contacted her and arranged to meet both parents at visiting time. I asked one or two questions and they gradually found the words to describe how shocked they were and how sad and bewildered they felt, because they had so looked forward to having a baby.

We discussed how hard it is not to blame yourself and to wonder what you've *done to bring this on the baby; also the peculiar attitudes of other people and how unintentionally hurtful they can be.*

I know it will take time for them to adjust to what has happened and then, over the weeks and months, as it becomes clearer how handicapped the baby is, I hope I can go on meeting them.

Mr Cooper told me he was glad that someone outside the family had been around. It had been helpful to air their feelings, he said. In time they would like to meet other parents with spina bifida children, so they could share their problems and worries and learn how other people cope. They were glad to have information about spina bifida and interested and reassured by all the research that is being done and by the fact that ASBAH produces its own information books for parents.

These last two examples illustrate that families feel reassured to know that I have the backing of our local association, and behind them the knowledge and expertise of the National Association. It helps people to feel that they are not alone in their problems.

WE SHARE our world with animals, but it is all too easy—particularly for town dwellers—never to have any contact with any kind of animal, never to know the fascination of watching an animal, or experiencing the pleasure of caring for one.

Owning a pet, being involved with looking after it, training, watching it grow up, can be very rewarding. It can bring much pleasure to a child who is physically handicapped and not able to enjoy other more active pursuits.

Provided you are sensible in your choice of pet, and not too ambitious, there is no reason why every handicapped child shouldn't have a pet of his own, whether it's a cat, dog, goldfish, guinea pig or budgerigar.

Be sure to read up about the particular animal before buying one. Pet shops can help with suitable books, or a wide range of free booklets about the care of different animals can be obtained from the RSPCA, The Causeway, Horsham, Sussex RH12 1HG. Tel: Horsham 64181.

Meanwhile, here is some advice 'straight from the horse's mouth', so to speak. Mrs Kristina Batchelor who lives on a farm in Sussex, has three boys—one of them Tristan, 8, has spina bifida. They share their farm with quite a wide range of pets . . .

Kristina Batchelor and son Tristan h[illegible] intro

IT'S ANIMAL MA

Some first introductions. The horse is big but friendly. And the sheep does its best to make the young boy feel at home.

PLAYGROUND PETS

THE PICTURES (left and above) have been provided by the Handicapped Adventure Playground Association. All the Association's playgrounds provide a good variety of activities and interests for disabled children.

For more details contact HAPA office at Fulham Palace, Bishops Avenue, London SW6 6EA.
Tel: 01-736 4443.

WE HAVE, in our house, the following—one dog, two cats, two goats, five guinea pigs, some chickens, and a calf sometimes, too . . .

duc[illegible]o the goat to the pet guinea pig.

A boy's best friend . . . Mark, the dog can obviously put up with a lot of this.

AGIC

. . . The queen cat loves to sit on Tristan's lap in his wheelchair. She likes a lot of fuss made of her. The tom is also a very affectionate cat. But please make sure that cats are worm free as they will have a lot of handling.

The guinea pig hutches are at a height that can be opened whether Tristan is walking with his sticks, or on his bike, or in his wheelchair. He can have access to them at all times.

The goats get most fuss in the Spring and Summer when they are out most days. Goats are only possible if you have plenty of grassland for grazing.

Hamsters are not really very good as pets as they sleep most of the day and are active at night—unless you have a child who suffers from insomnia!

Mice and gerbils make good indoor pets, but gerbils can also be sleepy during the day.

Dogs are very rewarding companions, but remember somebody active has got to give them daily exercise.

Please remember to worm and flea cats and dogs. Both child and pet will benefit from this!

Never get a pet on impulse. See how the child reacts to the particular pet and also how the pet reacts to the child. There is no good in buying a pet which is trying to get away all the time.

Budgies are fine as pets, depending on the child. A nervous child can find the flapping of their wings very frightening. Personally I feel that birds look very restricted in cages, and I feel they want to have freedom of movement.

KRISTINA BATCHELOR

Puppy Love

BARBARA Woodhouse, well-known dog trainer and author—particularly renowned for her successful quick method of training dogs—is very keen on handicapped people building up a relationship with a pet.

In a letter to LINK she writes: "I suggest that a dog (a small one) is trained by an expert, and the handicapped owner feeds it, grooms it, etc.

If the person is in a wheelchair the dog can trot happily alongside for exercise. I feel that the jerky movements of calipers might upset a dog, but no doubt he would soon get used to this.

Tone of voice matters terribly, and I am sure that anyone with spina bifida would have no trouble in making a dog happy. It all depends on how much character they have and how much love and determination.

I trained three dogs some time ago for a paraplegic patient and she gets enormous pleasure from them, and they are tremendously fond of her. They are exhibited in shows by a friend of hers and they win top honours.

- 'Dog Training My Way' by Barbara Woodhouse. Hardback £2.40. For this and a list of other books about dogs write to Barbara Woodhouse, Campions, Croxley Green, Rickmansworth WD3 3JD.

Aids to independence

—*useful items "tried and tested" at the Independence Training Weeks*

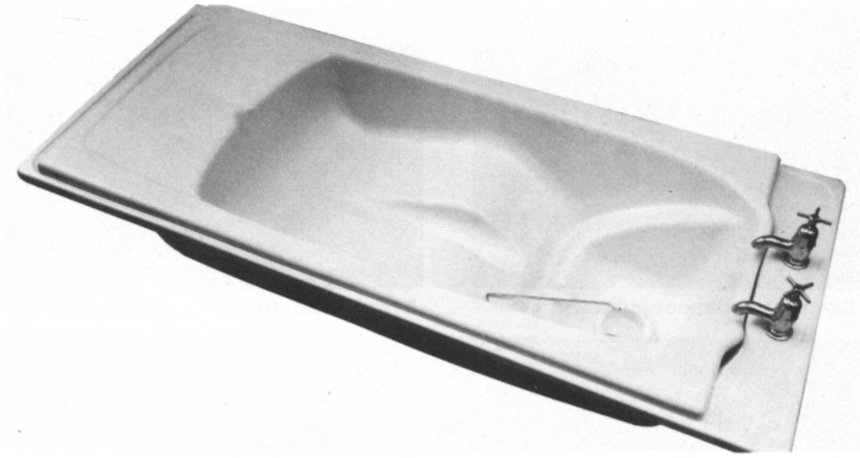
Young ASBAH—LIFT—has now run six Independence Training Courses in various parts of the country, for "young people" between the ages of 8 and 32 years!

There are several aids that we find useful and recommend on every course, and that you might not know about:—

Stayput mirror

Some young people with a urinary diversion can sit on the edge of a chair, or stand to change their appliances, but many have to learn to cope lying down, and of course, this is impossible if you can't see to position the bag accurately over the stoma. The Stayput mirror was designed to solve this problem. Hydrocephalus can cause perceptual problems and so learning to use a mirror may be difficult for some—it's a good idea to practice slowly at weekends or in the holidays, rather than in a panic before the school bus arrives! The mirror is also useful for checking the skin for potential pressure areas. It can be fitted with a bed triangle to fit under a mattress, or with a clamp to fix it to a floor stand or wheelchair.

Available from: Marc Appliances, Claybank Road, Copnor, Portsmouth. Tel: Portsmouth 696731
Cost: £13.62 for mirror with bed triangle.



Sunflower "sit-in" bathliners

The Sunflower bathliner fits inside an ordinary bath, and doesn't need to be plumbed in or fixed to the wall. The handicapped person can transfer onto the platform at one end and then swing his legs round and ease down into the bath. Many children and young people can manage to get in and out completely independently using a bathliner, and may not need more complicated or expensive hoists. The liner can be lifted out so that the rest of the family can still use the ordinary bath.

These liners should be supplied through local social services departments.

Available privately from: F Llewellyn and Co Ltd, Carlton Street, Liverpool. Tel: 051 236 5311
Cost: Approx. £55

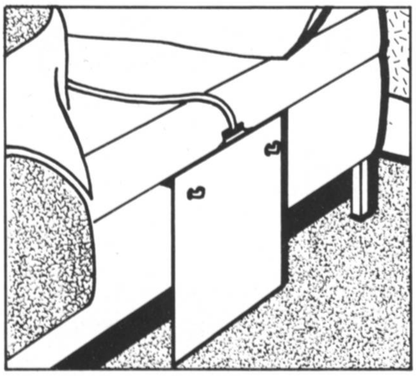
Kanga "Fancy Pants"

You probably already know about the ordinary Kanga pants, for severe urinary incontinence, and doublet pants, for double incontinence.

Kanga Fancy Pants are now available for those who have only a slight degree of incontinence, eg, if you normally have good control, but need extra protection in case of accidents, or maybe if you have an indwelling catheter, where there might be a slight leakage of urine.

There is a front opening pouch to take any kind of pad, and the pants are made of a polyester fabric, with a waterproof backing. "Fancy Pants" are more attractive than most types of incontinence pants, and are appreciated particularly by older girls.

Contact: Kanga Hospital Products Ltd, PO Box 39, Bentinck Street, Bolton. Tel: Bolton 46226
They will give further details and a list of retail suppliers.



Night drainage bag holder

For older children, an ordinary urinary diversion bag may be too small to hold the quantity of urine produced at night, so an extra extension bag can be fitted (these are available on prescription from your usual suppliers).

Downs Surgical Ltd, are now making a night drainage bag holder to fit ordinary divan beds. We have had several accidents on independence courses when helpers have trodden on bags trailing on the floor!

Available from: Downs Surgical Ltd, Church Path, Mitcham, Surrey. Tel: 01 640 3422
Cost: £3.25 for night bag holder and cover.

Local Associations might like to consider buying some of these aids for older members instead of some of the more usual buys. They can be of immense help towards achieving independence.

Please contact me if you would like more information about these or any other aids.

Jill Vernon

Remembering to look on the bright side

ONE "ADULT'S" PERSPECTIVE

THIS weekend I spent most of my time in bed recovering from my latest bout with my bladder. At the sign of my first symptoms (Friday afternoon) I knew my plans for the weekend would be drastically altered.

As I am a fairly active person the spectre of my forced confinement frustrated me no end. I was angry and I wanted to rebel against what I felt was the injustice of my predicament.

At this point I should tell you I have had an in-dwelling catheter for several years. Before that I used nothing, which is to say I wore napkins. I do not think I need tell you what that was like. The catheter had been available to me before I turned 17 but I chose to stick with the napkins because that was all I knew and I felt safe with them. However, as the time to go away to college drew near I made the change. I have never regretted it.

Learned

Yet that solution has been far from perfect as the weekend's experience will attest. Over the past eight weeks alone I have been in and out of the doctor's for the same problem. It does not really matter though. I know no available solution is one hundred per cent perfect.

From this experience I have learned just how far I have to go sometimes to accept myself as I am. I will never be normal (Whatever that is) nor will I always be able to do all the things I want to do.

Some days I will not be able to go swimming or have lunch with friends. Some days I will not even be able to go outside the door. During these times it will be easy for me to get depressed, like I did this weekend, but I know now that I do not have to stay that way.

Firstly, I can remind myself of all the things I have today. I have quite a lot. Second, I can turn my thoughts to the things I can do, like call a friend or read a book.

Accept

I have learned over the years I cannot blame others for my problems. Doing so would be pointless as I have no control over others. Besides I am not the only one who has problems. Everybody has them, be they physical or emotional. Rather, I have to think of what I can do for myself under the conditions I am in. I must accept where I am today and do the best I can with what I have.

Spina Bifida does not have to be a curse any more than a nose that is to big or ears that stick out too far. Perhaps having spina bifida creates more problems for me than if I had not been born with it. But it really makes no difference. There is still a lot I can do with my life and I am going to do it, with or without the bladder problems. It is an inconvenience I have learned to live with, nothing more.

ANONYMOUS

Rehabilitation engineering in Northern Ireland

"FOR MANY years engineers have assisted doctors in solving clinical problems. Cardiac surgery, kidney dialysis and joint replacement, could not have developed without the involvement of engineers.

More recently the concept of rehabilitation engineering has emerged, which is concerned with the care of the long-term disabled. It is a combination of expertise and attitudes.

The Doctor looking at a disabled child trying to walk mainly sees bones, joints, paralysed muscles and sensory loss. The engineer seeing the same child mainly notes forces transmitted to and from the floor and the resultant forces causing the joints to buckle. By the doctor appreciating the engineer's problems and vice versa, a formidable team can be created.

Rehabilitation Engineering Centres evolved in the United States, and proved their worth. Such a centre is now functioning at Musgrave Park Hospital in Belfast.

The Centre provides clinics where patients with long-term disabilities can be referred and there is a workshop where appliances and aids that can not be provided from commercial sources, are made. There is also a commitment to provide education in prosthetics, orthotics, and aids and to carry out clinical research.

The Northern Ireland Association for Spina Bifida and Hydrocephalus has had a big interest in the creation of the Centre at Musgrave Park Hospital, and supports its research role.

J. J. Egar

The writer is a Fellow of the Royal College of Surgeons and is a qualified engineer.

'The spina bifida family' today

Looking at some of the needs

Professor Neville Butler, Professor of Child Health at the University of Bristol spoke to ASBAH's Spring Conference in April, and LINK unable to 'do justice' to it in the last issue, now has pleasure in devoting these two pages to his paper.

Professor Butler emphasised that the needs of all the family should be considered when the future of a new spina bifida baby is assessed, and a great deal of thought needs to be paid to the help and support system for the parents of those babies on whom it is decided *not* to undertake early surgical treatment.

He continued: "One should perhaps stress what the modern approach is at birth to children born with spina bifida. Most units in this country now require a reasonable chance of the child having normal mental function which usually means no hydrocephalus at birth, some evidence at least of function of the lower limbs with a reasonable prospect of later ambulation, and an absence clearly of other severe congenital defects, such as heart disease or spinal deformity such as severe kyphosis or scoliosis. Bladder function is often impaired at birth and eventually gives problems in 80-90% of the cases of spina bifida, but this is usually not taken into account at birth.

Important first day

From the outset a complete understanding between parents and professionals, and also a co-ordinated team approach between the professionals themselves, can make all the difference between a child and the family becoming well-adjusted to the various assessment and hospitalisations which may be ahead.

On the medical side, the first day is a vital period for assessment and decision-making. Inevitably and rightly, parents should be involved in this, though the depth in which the matter is discussed will depend upon many factors, not the least the feelings of the mother herself. We doctors are busy and are sometimes poor communicators and enough time must be given. Bonding between mother and baby is probably even more important in the handicapped than the non-handicapped baby and the mother and baby should, where possible, be allowed close early contact.

The baby may have to remain in hospital for some time while the state of the head and the urinary tract are assessed. This is a time when parents require full support both from the hospital and community services, and here the general practitioner, health visitor and social worker come into the picture. All need to be informed.

Another stressful time is when the baby goes home, by which time the co-ordinating team on the therapeutic side will have come together—neurosurgeon, paediatrician, physiotherapist and others.

The period when the child needs to become ambulant is often very stressful. Strain on the family can be lightened by the multi-disciplinary centre, often jointly funded or equipped through official and voluntary agencies. This has proved a great advance.

Friendly hospitals?

Are hospitals necessary evils and on the whole are they friendly institutions though stressful as far as worried parents concerned? The present generation of children operated upon non-selectively may have 12 or more hospital admissions in the first five years of life.

Control of hydrocephalus which is present in 90% of cases of spina bifida sooner or later, is a major source of worry to doctor and parent alike. The shunt necessary to correct the hydrocephalus requires constant attention. Indeed, many children outgrow their shunt after early childhood and over 50% have to have it reinserted.

Urinary tract infection has to be guarded against. The bladder may need to be expressed regularly and chemotherapy given. The status of the kidneys, ureter and bladder must be assessed at regular intervals, so that long-term effects on renal function can be avoided wherever possible. The problem of incontinence is a major one, but the outlook has been improved greatly by such procedures as the ileal loop, particularly for girls who do not manage to get bladder control.

Now what about the parents themselves? Help and succour is needed while the child is in the pre-school period. Mothers can be over-stressed and much has been done by opportuniy groups, special play-groups, other day-care facilities and schemes for baby sitting and holiday relief. Day-care helps the growing child to socialise and to be prepared for schooling at normal age hopefully in an ordinary school.

Bristol Study

The health service also provides statutory help for families of handicapped children, but many parents either do not know about all the facilities which are available or do not take advantage of them. This came out in a recent Bristol study* in which we studied the families of over 200 children with severe mental and physical handicap. One-third of the physically handicapped suffered from spina bifida. Many of the families would have benefited by minor or major alterations to their houses, installation of ramps, widening of doors, improvement to toilet and bath facilities, and sometimes by the installation of a lift.

Many parents felt that the advantages of the support they received locally from friends and neighbours in their present housing outweigh the advantages of being re-housed in new areas, however modern and "inviting" the new housing maybe.

About 12% of the brothers and sisters were having problems at school which might be attributable to the presence in the family of a severely handicapped child. The families with spina bifida children had more self-care problems, more dwelling problems and more transport difficulties than any other group.

We administered a mental health rating to mothers of all the severely handicapped children and the increased stress on parents became evident. In our area, co-operation with social services is excellent, yet only half the mothers remembered being visited by a social worker in the past year. Nearly all the families belonged to ASBAH however.

We shall probably not see such family problems and severe handicaps again with changes in policy about early operations and improved management techniques. Let us go ahead in the knowledge that parents, doctors and professional workers will continue to work hand in hand with the help of voluntary organisations and statutory bodies, until such time as, with the help of future research of the kind being sponsored by bodies like ASBAH, this affliction no longer exists.

Prof. Neville Butler, MD, FRCP, DCH

** Ref: N. Butler, R. Gill, D. Pomeroy and J. Fewtrell. "Handicapped children—their homes and life styles". Dept. of Child Health, Univ. of Bristol 1978.*

A perfect gem!

MAY SAW the second Crown Jewel Ball to be promoted at the Dorchester Hotel in aid of the Association. Five hundred guests joined us for the evening and we were honoured by the presence of our Patron, HRH The Duchess of Gloucester. The Marchioness of Londonderry again acted as Hostess and Chairman.

Master Neil Evans charmingly presented Her Royal Highness with a bouquet of flowers on her arrival. It was appropriate that Neil should have this honour as it was his birthday two days later and, quite apart from meeting the Duchess, he was delighted when Esther Rantzen, one of our celebrity guests, came over to have a chat with him.

Financially the evening was a great success, the estimated net profit being approximately £10,000. Proceeds came from the sale of advertising space, tickets, donations, a tombola and of course our traditional game of bingo after dinner, called by Mr Bryn Williams, which produced the magnificent sum of £1,600.

There was a parade of evening wear by Franka with jewellery by Collingwoods and shoes by Bally and the fashion show was compered by television personality Shaw Taylor.

All in all it was a most memorable evening and if any of you would like to join us for the Ball next year, we have provisionally booked the Dorchester for April 16!

Photo courtesy of RAF.

The RAF drops in

ASBAH was lucky enough to be visited by two groups of people recently. The first visit was from members of local associations who came to Tavistock House in order to have lunch and a short respite from their sightseeing activities. Simultaneously, a deputation of five officers and men from RAF Hendon arrived in the Appeals Office, in order to present a cheque to the Association.

It was particularly nice for these gentlemen to have an opportunity of meeting some of our members and I think a number of friendships were struck up as a common interest in football soon emerged, as is shown in the photograph of two of the corporals with a young Liverpool supporter.

- **At a recent Council meeting ASBAH was delighted to receive a generous cheque towards its Research Fellowship from North Staffordshire Association.**

Dinner with the stars

FOLLOWING on the successful Literary Dinner held in the Royal Pavilion, Brighton in March, a similar Dinner is now being organised by the special events organiser, Barry Mishon, in the truly magnificent Crypt of the Guildhall in the City of London on Thursday evening, July 26.

The Evening will follow the same theme as Brighton, in as much that there will be 20 celebrities to host individual tables of 10, and invitations are being extended to those from the world of film, theatre, music, politics, sport, fashion, etc. At the time of this report acceptances have already been received from Nanette Newman, Bryan Forbes, George Melly, Pete and Tricia Murray, Patric Walker, Russell Harty and Joan Collins.

Tickets are £20 a head to include all drinks. It's just possible that some readers will be able to make a last minute purchase. Please make immediate contact with the organiser on (01) 388-1382.

JUDY KAY

ABOUT ASBAH

Continued from page 4

Management Committee the possibility of expanding and integrating the Social Work and Field Officer schemes. Mr Rod Harper and Mr Macfarlane (''Mac'') explained the preliminary planning ideas to the meeting.

Five Oaks

I TOLD members of the work currently in progress at Five Oaks. The occupancy at the House is much improved on last year, but still gives cause for concern at ''off peak'' periods. Since 1st April we have had an Activities Organiser, Miss Mary Barton, in post and the hope is that she will make contact with schools and encourage them to use Five Oaks as a school journey base, as well as ensuring that all our residents, whether holiday or long-term have plenty of interesting activities arranged. Staff turnover at Five Oaks has been small and this is a great encouragement. Miss Gillian Harrison remains Head of Home.

Meetings

WE DO realise that giving up a Saturday for a Council meeting is difficult. Everyone has many demands on his time, but it is important that the work of National ASBAH and the conduct of its business is discussed by as wide a representation as possible. It is also appreciated that sending delegates to London is very expensive for some Local Associations. Mr Austin Crowther raised this point. It will be discussed again and it may be that a central fund will be established. We are lucky in that we can hold Council meetings within our own office accommodation. Catering is difficult, but we serve a very superior version of a Ploughman's Lunch! and members have the opportunity of talking to one another informally. The national staff hope that we shall have the pleasure of meeting many Local Association representatives in the future.

Moyna P. Gilbertson

LINK readers will be delighted to hear that Dr John Lorber is now a Professor of Paediatrics. Congratulations Professor Lorber.

Growing Concern?

Your concern - and ours - is to help incontinent youngsters and adults maintain their confidence.
Incontinence is a problem, but it can be solved in a word - **INCO.**

The combined range of **INCO** products offers complete protection which aids both the wearer and the family at home.

Inco garments - made from supple PVC with a drop-front for easy changing, are available in seven adjustable sizes to ensure a perfect individual fit.

Inco pull-on pants - especially suitable for more active patients. Made in five sizes, the elasticated legs and waist give the wearer complete protection.

Both garments are washable, waterproof and suitable for either sex.

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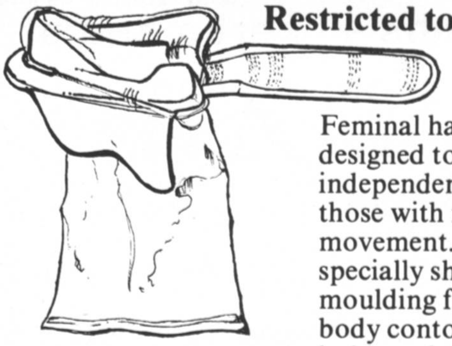
NEW **Feminal**

FEMALE URINE COLLECTION DEVICE



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: Dundonald 4947

Charity Football Matches, etc., can also be obtained, all completely free of charge. For further information contact: Mr J. A. Alter at the above address or tel: 01-953 1600 Ext. 171.

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THRUPP GLOS GL5 2AZ
GRIFFIN MILL

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Joan Collins.

Tickets are £20 a head to include all drinks. It's just possible that some readers will be able to make a last minute purchase. Please make immediate contact with the organiser on (01) 388-1382.

JUDY KAY

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CLASSIFIED 'ADS'

Adverts for next LINK must be in by August 5. The address is: LINK Advertising, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.

Rate: £1.00 for up to 25 words. £2.00 for 25–40 words, £3.00 for 40–60 words. Please send remittance with your advert. You may like to pay for a whole year's advertising in one go.

HOLIDAY ACCOMMODATION

CAMBER SANDS: Well-equipped and adapted chalet (sleeps 6). Bookings taken from January by Mrs J. Wilson, 23 Sunnydale Gardens, London NW7. Tel: 01-959 2962.

WINTERTON-ON-SEA, Nr Gt Yarmouth: 6-berth chalet, indoor swimming pool, shop, play areas. Details: Mr R. Morris. Tel: High Wycombe 32184.

MABLETHORPE, Lincs: Two well-equipped chalets, self-contained, 6-berths, at Mablethorpe Chalet Park, Links Road, Mablethorpe. Details: Mr. B. Guest, 57 Bloxwich Lane, Walsall.

GOLDEN SANDS, VORYD, RHYL, N. Wales: 8-berth caravan. Mains water, electricity, gas, shower, television. Every facility on site, right by sea. Details: Mr S. Foster, 84 Elmwood Drive, Blythe Bridge, Stoke-on-Trent. S.a.e. please.

WESTWARD HO, North Devon: Chalet Bungalow for 6 people. Excellent site facilities. S.a.e.: Mrs Cattell, 1 Rushwood Close, Mellish Road, Walsall, West Midlands.

FOR SALE

Leisure Wear: White cotton **Tee Shirts** with green Family symbol and words 'Support Spina Bifida' £1.60 each size 22"–30", £1.85 each small, medium, large. Also quality **Sweat Shirts** with reverse colours in all sizes including extra large adults. All at £4.50 each plus postage. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks. For Bucks/East Berks ASBAH.

Local Association changes

THE FOLLOWING changes of Honorary Secretaries have taken place since the last LINK. A full list of Associations will appear on the back of the next LINK:

BEDFORD & DISTRICT
Mrs M. McCormack,
34 Box End Road,
Kempston, Beds.

DUDLEY & WOLVERH'PTON
Mrs Lorna J. Wootton,
14 Leveson Road,
Wednesfield,
Wolverhampton,
W.Midlands WV11 2HF.
Tel: 0902 738724

GLOUCESTERSHIRE NORTH
Mrs I. M. O'Neill,
29 Bishop Road,
Shurdington,
Cheltenham.
Tel: Cheltenham 862517

LONDON, CENTRAL & NORTH
Mrs Christine King,
24 Hawthorn Avenue,
Palmers Green, N13 4JT
Tel: 01-886 7286

OXFORDSHIRE
Mrs A. Elbrow,
10 Bowyer Road,
Abingdon.
Tel: Abingdon 25712

NORTHERN IRELAND
(Belfast Branch)
Mr F. D. Hunter,
55 Wanstead Road,
Dundonald,
N.Ireland.
Tel: Dundonald 4947

ASBAH booklets etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	25p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	20p
The Nursery Years, by S. Haskell, MA, Ph.D, and M. E. Paul, Dip.Ph.H	15p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	30p
The Care of an Ileal Conduit and Urinary Appliances, by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
Clothing for the Spina Bifida Child, by Barbara Webster, SRN, RSCN	15p
Aids and Equipment	60p
Sex and Spina Bifida by Bill Stewart ... ... (75p to LIFT members).	£1
Information leaflets	100 for £1.30

All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 9p per booklet.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida	*30p*
The Spina Bifida Baby	30p

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

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Best Foot Forward 20 × 30 in.	**10p each**
Best Foot Forward 15 × 10 in.	**10 for 40p**
For local publicity 15 × 10 in.	**10 for 40p**
Car Stickers	**2p each**
Plastic Lapel Badges	**3p each**

All available from Appeals Dept.—postage extra.

The Appeals Dept. carries a range of fund-raising items, i.e. pens, balloons, calendars, tabards, car stickers. Send for list and order form.

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

FREE SERVICE

THE DISTRICT Advertising Company of EMI Elstree Studios, Shenley Road, Boreham Wood, Herts. WD6 1JG, offers a special service to Charities. They produce Telephone Address & Notebooks. These are a unique way of raising funds, also Fundraising Charts with Socks attached for Donations. These also help promote your cause and recruit new members, and are displayed in public houses, restaurants, on factory notice boards and other prominent places. Calendars, Diaries and Programmes for Fetes, Donkey Derby's, Bazaars, Charity Football Matches, etc., can also be obtained, all completely free of charge. For further information contact: Mr J. A. Alter at the above address or tel: 01-953 1600 Ext. 171.

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