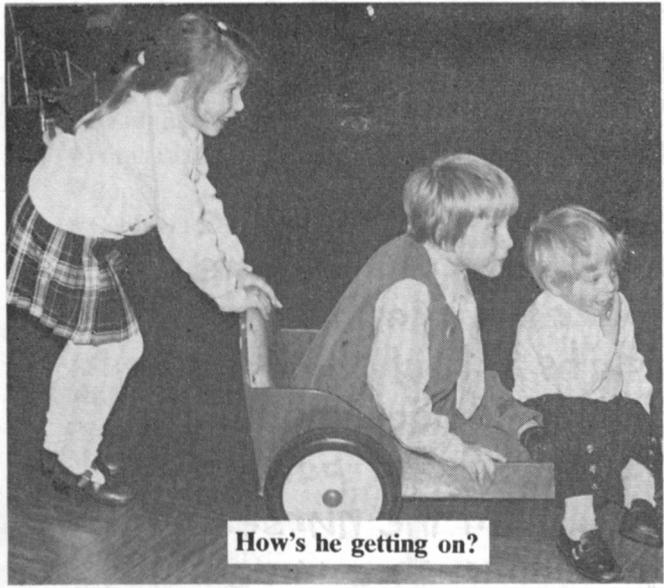


# LINK

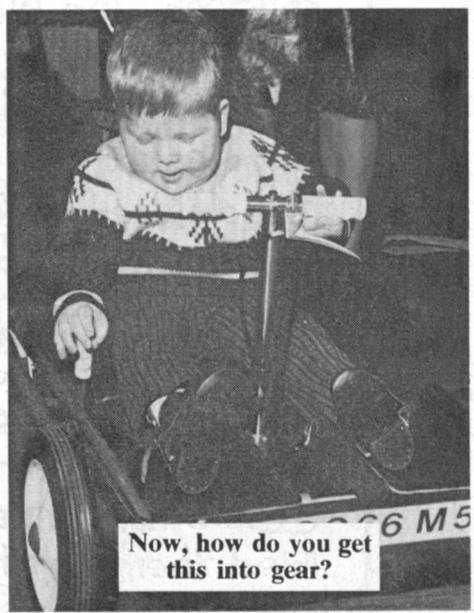


Summer 1973 5p

The Journal of The Association for Spina Bifida and Hydrocephalus (A.S.B.A.H.)



How's he getting on?

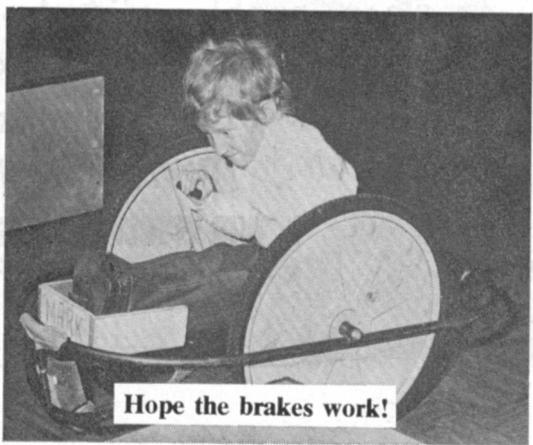


Now, how do you get this into gear?

## 'YOUNG WHEELERS'



A neat piece of parking!



Hope the brakes work!

SEE PAGE 3 FOR STORY

## a fairy story with a happy ending

Once upon a time there was a little roo  called Kanga. He hopped to the edge of the wood  where he saw a big house . He looked into the house and saw there were lots of nurses  with children, the nurses were saying that one of their biggest problems was incontinence. Kanga  did not know what this meant so he asked and they told him that it made the children  very sore and caused the nurses lots of work. Kanga had some clever friends who worked in a hospital laboratory  so he asked them to help. Next week he came back to the house  with some special pants  he had invented. When the nurses tried them on the children they were very pleased  because they were very comfortable and easy to change. Kanga's friends  are now working on other problems to help children — but if you would like to know more about the pants that Kanga's friends invented please write to Kanga at...

**LEWIS WOOLF GRIPTIGHT LTD.**  
**Pershore, Worcs WR10 2HW.**





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## COVER STORY: YOUNG WHEELERS

*Link's* cover picture shows members of the new Young Wheelers' Guild—spina bifida children from the Dudley and Wolverhampton Association.

Early this year 13 young members of the Association were put through a special "driving test" on their self-propelled vehicles. The test, devised by the Halesowen Road Safety Officer, Mr. D. A. Andrews and the Road Safety Committee aimed to give the young drivers a feeling of confidence and achievement. They were examined by uniformed men from the police, fire and ambulance services and the A.T.C.

Roller skating has its advantages. It is not only fun, but it is proving an invaluable aid in helping six-year-old spina bifida girl, Lisa Kenny (right), to walk more normally. To be able to skate she has to concentrate on straight, even steps. Skating also helps improve her balance.

Lisa, together with a young friend who is spastic, is pictured at St. Michael's School for physically handicapped children, Eastcote, Middlesex.

Photo: Hillingdon Mirror.

Some children were on hobcarts, others who find that this doesn't suit them, were on vehicles like the Thistle Tricycle, the Whizz Bang, Shasbah trolley, and in wheelchairs.

All 13 children passed the test and were enrolled as the first members of the Young Wheelers' Guild, whose President is TV actress Noele Gordon of "Crossroads".

For information on starting branches of the Guild write to: Mr. Andrews, 36 Wesley Avenue, Cradley, Halesowen, Worcs.



## THE NEW LINK

*Link* should not be just a magazine—a collection of pages which may or may not be read. It should be, and to a certain extent already is, an important contact between a large number of people in Britain and abroad who have spina bifida, are parents of spina bifida children, or are concerned with this handicap. It should be a means of informing, stimulating, and helping, and of improving the services for those who are disabled in this way.

*Link* has proved that it is needed since it first came out in Spring, 1966. It now has a circulation of 8,000, with about 500 of these copies going overseas mainly to Australia, Canada and the U.S.A., but also to readers in 14 other countries.

It has now been decided that *Link* will be published every two months in future—starting with the next issue.

I was appointed as Editor last Autumn and have spent the last few months getting to know ASBAH and the way in which *Link* could best be developed. I hope it will look brighter from the next issue and the content will be more interesting and useful to all ages.

But *Link* will fall flat on its face unless people are prepared to participate. A link, after all, is a two-way affair. I need your ideas, your letters, your stories and photographs—I want to hear your problems . . . problems concerned with schooling, work, or whatever. I'd like to hear of successes, useful tips, advice . . . anything which you think would be of interest to others. So if you have any material of whatever kind or suggestions for *Link*, please do write to me.

Of course, I won't always be able to use them, but if not I'll let you know why, and hope you won't be put off trying again.

*Link* is your magazine, so why not make use of it?

The next *Link* will be published in the last week of August.

Susan Gearing

## 'ENJOYING BEING A HOUSEWIFE'

Twenty-eight years old, married and enjoying "just being a housewife".

That's a general description of a former patient at Chailey Heritage Hospital who has combated and is still combating problems to such an extent that she gets as much as possible out of life.

The person concerned is spina bifida, but has no hydrocephalus. She had only limited home teaching up to the age of 11. Eleven orthopaedic operations for hips, knees and feet were necessary: she had bladder neck resection for obstruction and a damaged left kidney: later she had an ileal loop. Stones had to be removed from the left kidney.

Recently she returned to visit the hospital looking "attractive and lively, but chair-bound". Later she wrote to the hospital telling of her experiences.

"When we were first married my husband and I faced the problem of living apart due to lack of accommodation. Because my husband is also disabled no building society would entertain the idea of granting us a mortgage, and the council didn't want to know.

Later the local authority found them a ground floor flat and a ramp, wider doors, lower sinks and split level cooker were installed. Now she manages, "most of my housework using the normal household equipment, the only exceptions being cleaning windows, and getting at high cupboards."

However, there was a bitter disappointment when a pregnancy had to be terminated for medical reasons. Now she says that her advice to someone getting married would be to seek medical advice on the question of having children.

The couple have a Ministry car so they can get out, but someone has to be around to load and unload wheelchairs. Nevertheless despite these inconveniences they feel that life is being pretty good to them. We wish them much happiness together.

## Mrs. Kate White, Appeals Secretary writes about special money-raising and publicity events

### Ball raises £5,000

Petula Clarke attended the Dorchester Ball and presented the bingo prizes (pictured right) and I am pleased to say that everyone who was at the Dorchester on the 22nd March seemed to be enjoying themselves. It was most encouraging to find so much goodwill towards our handicapped children and their families. The profit for this evening's effort will be just over £5,000. It was also good to see some of our members at the Ball.



We hope they enjoyed themselves, and it was certainly nice of them to come and give their support. The date for next year's Ball is Thursday, 28th March, 1974, again at the Dorchester and again with Nat Temple.

was most encouraging to find at the Ideal Home Exhibition how many people now know what ASBAH is about.



### Thanks-a-million

You have responded magnificently to my last appeal for Green Shield Stamps and we are now well over the million mark. At the time of writing this, we had 1,396,480 stamps, and we confidently hope that within the next two or three weeks we shall collect the balance of 103,520 and that they will be safely stuck into books. In the next *Link* we will let you have news of how these stamps will be used.



### Competition closes

The Dream House Competition is now closed, and we were rather disappointed that we did not receive more entry forms. We reckoned that we brought it to the notice, either through magazines or through handing out forms at the Ideal Home Exhibition, of around half a million people, and only 9,091 entries were received. However, more than half of these completed all 12 columns so we needed hawk-eyes to scrutinise the forms. The competition was judged by a panel of three independent judges, but no one submitted a completely correct answer. There was one entry which was very near to the correct answer, so the judges awarded a special prize of £5,000 to this competitor, who is thrilled with his prize.

This competition has generated publicity which I am sure has been very beneficial. It

### Appeal tops £30,000

We had promised to publish a full list of subscribers to the Spina Bifida Research Fellowship Fund, but this will have to be held over till our next issue due to shortage of space. At the time of writing the total stands at £30,193 given or promised and a boost will come from the profits of the Dream House Contest. To those of you who have contributed so generously, we are all most grateful.



Meet Maria Freeman—not only a pretty bridesmaid—but at the ripe old age of five, she is also becoming a globe-trotter.

Maria, whose permanent home is in Cambridge, is proof that spina bifida need not prevent one from enjoying an adventurous life.

The Freeman family travel a good deal, because Mr. Freeman is a football coach. They have lived in the U.S.A. for some months, and at the moment are spending a lot of their time in Norway. Already Maria can speak Norwegian.

“Maria has had a shunt fitted, and she also uses calipers, but so far she hasn’t found any problems with treatment in Norway,” said her Aunt, Mrs. Margaret Borley, who like the Freemans, is a member of the East Anglian Association.

news from all around:



news from all around:

The picture was taken at Little Shelford, Cambs., at the wedding of another of Maria’s aunts. Maria’s eight-year-old sister Lisa is to the left of the picture.

Photo: ‘Cambridge Evening News’.

### Who wants to be a Millionaire?

**Bedfordshire:** Mr. Ted Bartlett of Amptill, Beds, has a money-raising idea which he hopes might be taken up by Local Associations. Mr. Bartlett suggests that they might be able to set up groups of “strolling players” who would raise money locally by performing musical comedy acts, sketches, song and dance routines, etc. With the hope that they might “Make it a million”—raise £1 million—he suggests they could be called groups of Millionaires. Mr. Bartlett, a founder member of ASBAH and a member of North Beds and Northants Association, would be glad to hear from anyone interested in following up the idea. Contact him at 5 Willow Park, Amptill, Beds.

### Something to float over!

**Bournemouth, Hants:** Congratulations to this branch for winning two awards—a cup and a silver bowl—at Boscombe and Bournemouth Carnival, for the best float in a particular class and for the best entry over all.

### In their Easter bonnets

**Cannock and Walsall, Staffs:** This Local Association celebrated Easter in high style with a very successful Easter Bonnet Parade. A large number of people in the area turned out to see the children parade in the Easter bonnets they had made themselves.

# news from all around: news from all around: news from

## "What shall we do tomorrow?"

**Mansfield and Worksop, Notts:** Congratulations to this Association for an excellent appeals film made to interest the general public in spina bifida. "What shall we do tomorrow?" lasting 23 minutes, is in full colour, and shows the problems and achievements of spina bifida youngsters, with comments from parents and teachers, and closes with a tribute from Harry Secombe. It also gives a good indication of the kind of money-raising activities of the Mansfield and Worksop Association and the need for funds. The film was shot in the Mansfield area, mainly at Parkhall School for physically handicapped children, over a period of about 18 months. It was produced by professional cameraman Arthur Rowell, a member of the Mansfield group, and cost only about £700 to make. Any group interested in borrowing the film should contact the Secretary, Mrs. Ethel Freeman, Mansfield 26860.

## Full marks for effort

Bognor Regis, Sussex: **Joanne Scott, of the Sussex Association, and a pupil at Rose Green County Primary School in Bognor Regis, recently won the Keen Cup for her efforts in working hard and trying "that little extra bit" at school. Joanne, who has spina bifida, was awarded the Cup for her perseverance with her walking exercises and her constant cheerfulness and good temper.**

## New holiday home

**Selsey, Sussex:** Sussex Association has a new mobile holiday home at the White Horse Caravan Park, Selsey, near Chichester. It was paid for by Thames TV's Magpie Appeal, and replaces a 12-year-old caravan. It is a three-bedroom home on this convenient and well-equipped site near the beach. Details of holidays at the mobile home from Miss Gwen Clarke, Badgers Copse, Rudgwick, Nr. Horsham, Sussex.

## Information Service

### THE FAMILY FUND

The Joseph Rowntree Trust are administering the sum recently made available by the Government to supplement existing provision where necessary for a family with a **SEVERELY congenitally disabled child (to 16 years of age).**

The Fund is new and its use will depend to some extent on needs as they become known. It is intended to augment and fill gaps in existing provision.

Applications are to be phased, and until 1st August, 1973, only families with children between 10 and 16 should apply. Applications must be from the parents concerned, but anyone may help to prepare this. No detailed forms are being issued, to keep things as simple as possible. The Trustees will want to know the age and some details about the severity of a child's disability together with information about the help you are seeking.

Any reader who would welcome help with an application from the National Association is invited to let the General Secretary know.

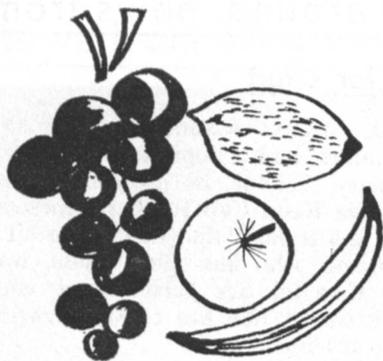
### ATTENDANCE ALLOWANCE

Readers will know that the Attendance Allowance is being extended by stages to cover those who need attention by day or night. Those who qualify will receive two-thirds the amount payable to those needing full-time attendance. Those over 16 should already have applied.

Payment for those eligible who are between 2 and 16 will start in September, and application will be invited in June or perhaps slightly before. Watch the papers for an announcement. ASBAH will notify Hon. Secretaries when the date is announced.

### PLAYGROUPS ASSOCIATION

Playgroup leaders will be interested to hear that ASBAH has now joined the Pre-school Playgroups Association. This means that you will be able to get discount on materials and equipment, as well as preferential playgroup insurance. If you are interested in taking advantage of this membership contact ASBAH's General Secretary.



# FOOD FOR THOUGHT



Mrs. Anne Nicholas, Dietitian at Queen Mary's Hospital for Children, Carshalton, Surrey, talked to *Link* about the overweight problem of so many spina bifida children. She suggested that some ASBAH's might like to start up weight-reducing groups.

"It is upsetting to see so many children who are overweight particularly when they are spina bifida. It is so bad for these children to be too heavy as this affects mobility and limits exercise and progress in walking. Also it may contribute to the development of pressure sores.

"Spina bifida children have weak legs, and it is difficult for them to cope with walking without having the added problem of excess weight. Therefore, it is quite true to say that obesity generally impedes them in their endeavours to lead as normal and active a life as possible."

Mrs. Nicholas, who has four youngsters of her own, is very much aware of the foods that are favourites with children—sweets, cakes, biscuits, crisps, etc., heading the list—rather than the protein foods, fruits and vegetables.

She went on to say that she fully realised that for the mother of a handicapped child it could be even more difficult to be firm. Mother tended to want to overfeed her handicapped baby to show her love and concern in the form of sweet treats.

Sometimes even if mother could avoid doing this her efforts were spoiled by well-meaning relatives, who showered the child with sweets and other 'goodies'.

Obesity is the result of taking in more calories than we can use up and release as energy.

Because spina bifida children are generally less active than others, they tended to need less food, and certainly fewer calories.

A mother of a child hospitalised for long periods has the desire to "build up" her child while he is at home. This, of course, is bad, said Mrs. Nicholas, and mother must be firm with her child.

"He will be happier, stronger and healthier on less food—but the right kind of food," she said. "Protein foods, eggs, meat, fish and cheese being the most important, and unfortunately the most expensive, too. But let us remember that the cheaper cuts of meat and cheaper fish are just as nutritious as the more expensive cuts.

"Fruits and vegetables should be introduced into the diet at an early age. Children are creatures of habit, and once established on a régime it is very difficult to change them. So let us remember that these children should start on a suitable diet from the time they are weaned."

Mrs. Nicholas said that protein foods should be introduced early—give baby egg yolk instead of too much cereal, give him meat, liquidised or minced; fish, flaked in a sauce; vegetables and fruit. Always limit potatoes and fats—and put only a thin scraping of butter or margarine on bread. Get baby used to unsweetened drinks as early as possible.



She felt that possibly the only satisfactory way of dieting was in a group—both mother and child benefiting from this—the children enjoy the comradeship and competition, and mother benefits from the support of other mothers.

“I run a weekly slimming clinic for obese children, other than those who are spina bifida. They are referred from medical clinics at St. Mary’s. These are local children and this weekly group works very well indeed. But because of distances this would not be possible for many spina bifida children,” she said.

Mrs. Nicholas wondered, however, if local ASBAH’s would like to arrange weight-reducing groups. Perhaps a prize could be given to the child who loses most weight each week.

She felt that this kind of group therapy could be made to work very well.

Before saying goodbye to *Link*, Mrs. Nicholas said she must stress that a child must not be put on a diet unless authorised by a Doctor, and the diet must be one properly calculated for a child by a qualified Dietitian.

She pointed out that dieting was very important, and has to be done properly, sensibly and under supervision, or it could prove dangerous.

## Dr. John Lorber comments

“I fully agree with Mrs. Nicholas’ concern about obesity in our children. Many readers of *Link* will know that the children who are in special schools for the handicapped do have a strict diet whilst at school. The kitchen staff at the schools is instructed on the type of diet which suits the children best and they get a nutritious diet of low calorie content. It is most important when children are on holiday that this routine should not be interrupted.

“Another important point to mention is that most spina bifida children who are more severely affected are also much smaller than children of the same age. Therefore their weight cannot be compared to children without handicap of the same age. Their weight must be related to their height, otherwise parents might get the impression that their children are normal or even underweight, when in fact they are too fat. Often the appearance of the child is a better guide to obesity than actual weight.”

Mrs. Nicholas continued: “It is not an easy problem to diet a child, and mother will need constant help and encouragement. As mothers we all know how much easier it is to give in to a child rather than have a constant battle at mealtimes.

Ideally I should like to see all mothers at regular outpatient clinics, but, because of distances and transport problems this has proved impossible. On the occasions when they attend the hospital it is difficult for mother to find time to see me. She often has had to cope with a long journey, and has a tired, disgruntled child, with a day of many appointments at the hospital stretching ahead, and transport home-wards booked for a particular time.

“The children I see often do extremely well. But others, quite understandably, do tend to relapse into obesity.”

## Reader's hints

I have had the following letter from a reader.

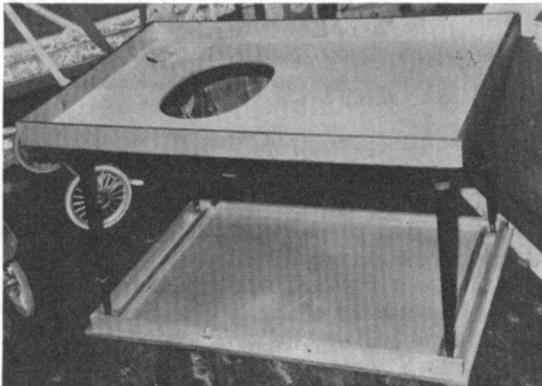
Dear Mrs. Nettles,

Here are two ideas which parents of spina bifida children may find helpful.

The first is for boys who wear a pubic pressure urinal. First unpick part of the inside seam of whichever trouser leg holds the bag, and then insert a zip fastener. I find the type that has metal parts painted is best, because it blends with different colour trousers, thus making the zip less conspicuous. My son, Tony, finds it a great help.

My second idea protects him in the rain. I cover him and his wheelchair with a plastic adult bicycle cape.

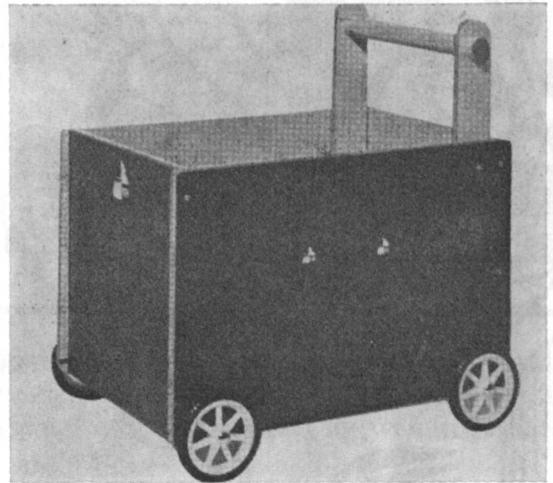
Yours sincerely,  
B. McNally (Mrs.).



## Standing table

The makers of the SHASBAH trolley are making a table with a hole (see illustration). The legs fit neatly into niches in the floor and when not in use the floor fits into the top of the table to convert it into a coffee table. The legs unscrew for storage and fit between the two tops.

The price is expected to be about £12.00 and enquiries from Mrs. K. Charrett, 2 Marchwood Road, Southampton.



## Storage cart

NICOLTOYS Ltd. of Station Road, Robertsbridge, Sussex, are makers of high quality wooden toys and in their catalogue is a storage cart (photo above) that might be a very useful walking aid for our children. It sells at about £6.23 (retail).

It is very sturdy, is virtually untipable, and has plenty of room for carrying favourite playthings around.

## Rubber corners

I have been shown some self-adhesive rubber corners for fitting on to corners of tables, shelves or anything that projects and so may be a hazard. They are made in soft black rubber and cost £1.45 for a set of four or 0.76p for two. There is a special price for Associations such as ours of 0.25p per unit if bought in quantities of eight units or more. Cash with order please to "ALANS", 6 Nightingale Grove, Freemantle, Southampton, Hants.

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● Please mention "Link" when writing to firms.

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## *Handbook for Parents with a Handicapped Child.*

This is a handbook intended to show parents of young handicapped children how they can find help that is available and what they should do when there appears to be no help at all. It tells how to get information on subjects ranging from statutory provisions and babysitting to parentcraft and the National Equestrian Centre. From: CASE Publications, 17 Jacksons Lane, Billericay, Essex. 15p (including postage).

## *Access to University and Polytechnic Buildings.*

Students interested in further education will find this recently published handbook very useful. It shows how accessible university and polytechnic buildings are for wheelchair users. It also lists the courses at each university which most disabled students would be able to undertake. The Handbook is 20p (including postage) from: Central Council for the Disabled, 34 Eccleston Square, London, S.W.1.

# BOOKS

## *Growing up with Spina Bifida*

This booklet, written by Olwen Nettles, is a sequel to *The Spina Bifida Baby*. It deals with the problems which parents and children will encounter as the child grows. After outlining the medical background the booklet goes on to stress the importance of encouraging independence, looks at the types of caliper available, and advises on some of the ways of dealing with the problem of incontinence. The booklet also covers some of the general problems of childhood, education and the importance of the family setting. It concludes with a glance at the future and a number of individual success stories. 20p from the Scottish Spina Bifida Association, 7 South East Circus, Place, Edinburgh EH3 6TJ. (25 copies cost £4.25; 50 copies £8.)



We should like to acknowledge the help of Tatchbury Mount Hospital, and voluntary work of the members of Southampton and District Spina Bifida and Hydrocephalus Association to make this Trolley.

All enquiries to:—Mrs. K. Charrett,  
2 Marchwood Road, SOUTHAMPTON.  
Telephone enquiries: TOTTON 3365  
(Mr. Mortimer)

### **THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN**

PATENT APPLIED FOR IN  
U.K., Commonwealth Countries, U.S.A., Canada.

This Trolley was designed by Mr. Ken Charrett of Southampton for his daughter who was born with Spina Bifida. It was soon found that here was a chair that would enable a child paralysed from the waist down, to become mobile.

The Trolley weighing only 14lb. is strongly constructed, completely manoeuvrable and easily propelled by the child. Due to the low centre of gravity and rear caster action it is virtually impossible to be overturned.

The Trolley is finished with foam upholstered durable vinyl and comes in a wide range of attractive colours, this is to give the child the impression it has a toy. The child soon learns to use the Trolley, which adds much happiness to the child's life.

**Standard Model** for children one to five years old cost £7.50p plus postage 55p approx. **Large Model** for children five to ten years old cost £10.50p carriage 75p approx. in United Kingdom. Overseas prices on application.

Produced by the

**Southampton and District Spina Bifida  
and Hydrocephalus Association**

For two days in April, 120 people representing the medical profession and local spina bifida associations, as well as teachers and social workers had the chance of meeting together at Reading University.

The occasion was the second national conference organised by ASBAH, and the subject chosen was "The Severely Disabled Spina Bifida and Hydrocephalic".

The conference hostess was the Lady Jean Mackenzie, and ASBAH's Chairman, Mr. R. B. Zachary, opened the weekend by drawing attention to the importance of long-term planning for the future of the severely disabled, from medical, educational and social standpoints—subjects that were covered more fully by the five conference speakers.

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**Medical Care, by Dr. E. P. Quibell, Medical Director of Chailey Heritage Hospital and Craft School.**

**INFANCY:** Dr. Quibell expressed his concern for the parents of a severely disabled baby. He felt that too often they did not receive enough support, and were not told enough about the handicap and the long-term programme for their child. Visiting their child in hospital should be made as easy as possible, and mother should be involved with the care of her baby, even while in hospital.

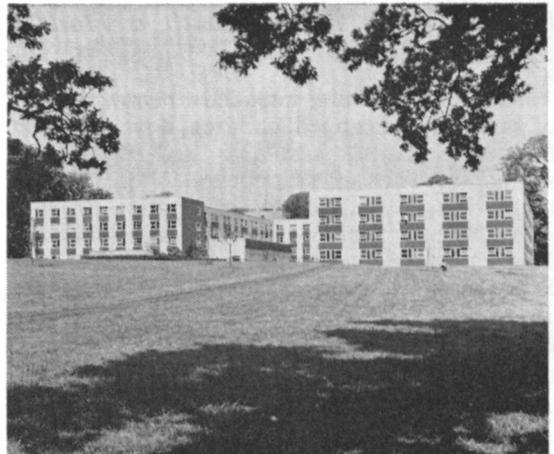
**CHILDHOOD:** This stage involved further surgery for orthopaedic problems, urological management, and neurosurgery, said Dr. Quibell. He also listed some of the main complications which could arise.

**ADOLESCENCE:** A time for all-out effort to achieve the maximum independence; the management of equipment and advice on puberty were particularly important, said Dr. Quibell.

**MARRIAGE:** This involved great understanding and sympathy between the partners, and it was an area which is probably the least discussed at all, as yet.

**SURGICAL PROGRAMME:** Dr. Quibell gave details of the surgery carried out on 54 children with hydrocephalus and myelomeningocele who had valve shunts.

Dr. Quibell stressed the importance of the follow-on services and their co-ordination



**Childs Hall, Reading University—the scene for ASBAH's Spring Conference.**

## **SPRING CONFERENCE**

# **"The Severely Disabled Spina Bifida and Hydrocephalic"**

when the children grow up and come within the young adult services. He felt that more stoma and urological appliance clinics should be set up.

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**Sheltered Employment and Occupation, by Dr. F. S. Cooksey, Medical Director of Papworth Village Settlement and Enham Alamein Village Centre.**

Dr. Cooksey said that motivation and mental outlook were all important. In determining a person's future the degree of physical handicap was not the real problem. He stressed the need for full vocational assessment and guidance for the severely disabled. Not only should the chosen job be within the person's capabilities but it must also be good enough for him. The severely disabled should be fully occupied all the week, and the work should be real and necessary industrial-type work, and not merely "hobbytype" occupation.

Dr. Cooksey felt that while it was desirable for many severely disabled people to remain in their own homes and the communities they

knew, some would find it too difficult to cope with ordinary life and work, and would need sheltered situations.

He described Papworth and Enham where disabled people lived with their fit relatives and children in village settings. The combination of disabled and able-bodied meant that the communities could be competitive in industry. Unfortunately people were moving to the villages too late in life. He hoped to attract the disabled sufferer earlier so they could make their whole working lives in the villages.

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**Education, by Mr. John Fish, H.M.I., Department of Education and Science, Cambridge.**

Mr. Fish said he was aware of the big gap between the needs of handicapped children and the existing provisions. Since April, 1971, some education had to be provided for every child. While the compulsory school age was 5-16 years, education authorities, at their own discretion, could provide special schooling from two years to 19, if it was felt that this would help the child.

For severely handicapped children, objectives must be realistic to enable the children to obtain a sense of achievement.

Handicapped children relied on the patience, skill and knowledge of adults around them, and it was important that adults help them by encouragement, by using their imagination, and by teaching them how to learn, rather than cramming them full of facts.

He suggested that in future special schools would benefit from improved staff ratios.

Mr. Fish said that many local authorities should be doing more to make it possible for more handicapped children to gain access to ordinary secondary schools. He felt, too, that some children would always benefit from special schooling . . . a range of educational facilities was the important thing to aim for.

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**Long-stay residential care, by Dr. Margaret Agerholm, Consultant in Physical Medicine at Banstead Place Rehabilitation Centre.**

Dr. Agerholm emphasised that residential care was a complex matter and had to be very varied to meet everyone's needs.

The absence of a normal family life, and the lack of ordinary everyday experiences were very real handicaps for children living in hospital or long-stay residential care.

Dr. Agerholm referred to young disabled people going into residential care at 16—some of them found they could not cope with everyday life, others wished to leave the “smothering” atmosphere of their own homes.

Particular problems she drew attention to were the many children at residential schools with nowhere to go in the school holidays, and also the lack of staff, particularly of well-qualified staff, for residential care positions.

She felt that far too many people were living in hospital who would be better suited in some other kind of residential care.

She listed the important ingredients of residential care: security, care, employment, integration into the community, privacy, freedom, mobility, civil rights and financial help.

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**Statutory Support, by Miss L. Faithfull, Director of Social Services, Oxford.**

Miss Faithfull stressed the importance of a working partnership between the new Social Service Departments and the voluntary organisations. The aim, she said, was to meet the need of every individual and his family.

The severely disabled and their families needed supportive help within their own communities, to take some of the strain off the families, and also to stimulate and help the handicapped themselves.

She mentioned specific resources that were to be developed more fully—play groups, short-stay and day care, the home-help system, further education (in partnership with the chief education officers) and housing. Miss Faithfull felt that not enough thought had been given to the adaptation of housing for the disabled.

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During the Conference there was also plenty of opportunity for informal discussions on all aspects of the care of those with spina bifida.

The experience gained will assist the Association in planning for the needs of the severely disabled, either alone, or preferably in association with other organisations.

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**A full Conference Report will be sent to delegates and to Local Associations, and can also be obtained by writing to ASBAH National Office in London.**

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# What of the future? ---

The letter we print here was sent to a paediatric consultant. It concerns one of his patients who has now reached adolescence. The person concerned is lucky in that he comes from a well-off family, but the problems which remain are clearly pinpointed in this letter.

"Unfortunately he developed another big water blister on his bottom about 10 days before he came home from school. This meant he was off his feet all holiday as the doctor would not allow him to walk in case of pressure bursting it. His healing powers in his paralysed parts are so slow. We suspect that he is largely to blame for this occurrence as he admitted he had not been walking anything like as much as he should as it's so much easier to keep up with the other boys in his wheelchair.

He is happy-go-lucky about it all and the headmaster and matron both agree that the importance of walking and drinking plenty of fluid doesn't seem to register with him. They attribute this to his hydrocephalus and lack of concentration in lessons. He does his best—is not a slacker—but it's quite obvious he is unable to concentrate for any length of time, which of course is very worrying to us and his headmaster as where does his future lie?

His severe physical disability presents a major problem in itself as whatever lies ahead

for him he will always require certain attention if he is to survive. We can give him this at present and for some years to come (we hope) but we are *not* in a financial position to provide for his future in a non-state residential establishment, so the only alternative seems to be an institute of some kind which is the last place one ever hopes to go.

As his headmaster says, "Everything is done to provide for their schooling—what then?"

He would like to see hostels built all over the country, with a small residential medical staff, where the severely handicapped, needing care, could return after their day's work. There's no such thing as far as we know, neither do we hear of such prospects for the future. Our problems, like many other unfortunate parents, are starting when the respective sons and daughters are reaching the end of their schooling. The future for many is bleak indeed until such steps are taken to provide for the severely handicapped adult.

We are determined that our son shall in no way interfere with his sister's future. That would be wrong. Her conscience may dictate otherwise so there's another sacrifice being made for the handicapped person."

Editor's note: *There are some hostels, flats with wardens, and similar facilities—mainly in the London area. But we do agree with the writer that such facilities must be extended to cover the whole country.*

## LEARNING TO WALK ---

"I often write verses to amuse my children and when my 12-year-old daughter said, 'Write something for Mary' this poem was the result. Mary is our spina bifida foster daughter."

Mrs. S. A. Kurn, Albury, Nr. Guildford.

Each morning between eight and nine  
Whether the day be wet or fine  
When Mum has finished her toast and tea  
I know what she will say to me,  
Into your calipers you must go.  
It's time for you to walk you know,  
And every time the same old cry,  
Today we're really going to try.

So off I go between my bars  
From here to the end it's not too far.  
Hand, leg, hand, leg, right to the end  
Then turn round and back again.  
That was quite good, now just once more  
Each day a little better than before.

Now the sticks, these are more fun  
Dog and cat had better run  
For these sticks I like to swing  
And I can hit most anything  
So off across the kitchen floor  
And soon we've walked to the back door.



## INTER-ASSOCIATION HOLIDAY OPPORTUNITIES

**Cleethorpes.** Three-bedroom Bungalow to accommodate 6-8 persons situated at Humberston, Fitties, Nr. Cleethorpes, Lincolnshire. Further information from Mrs. W. Steele, 59 Louth Road, Holton-le-Clay, Grimsby.

**Great Yarmouth.** Self-contained 6-berth caravan. Situated Caister Beach Caravan Camp, nr. Great Yarmouth. Details from Mrs. N. E. Barefoot, 23 Marlborough Road, Southall, Middlesex. Tel. 01-574 5067.

**Lessingham, Norfolk.** Well-appointed 6-berth caravan. Sea 100 yds. Vacancies. Apply Mr. P. White, 12, Swallow Gardens, Hatfield, Herts. Tel. Hatfield 63018.

**Looe.** Bungalow, two bedrooms, spacious accommodation, situated in Millendreath Holiday Village, Nr. Looe, Cornwall. Mr. Keith Jackson, 202 Exeter St., Plymouth.

**Mablethorpe.** Self-contained 6-berth Chalet situated at Golden Sands Estates, Mablethorpe, Lincolnshire. Further details from Mr. Ken Hall, 17, Walhouse Street, Cannock, Staffs.

**Mablethorpe.** 25ft. self-contained 6-berth caravan. Situated at Golden Sands Holiday Estates, Mable-28 Deerpark Crescent, Wingworth, Chesterfield, Lincolnshire. Details from Mr. J. Cannon, Derbyshire. Tel. Chesterfield 78952.

**New Forest.** Well-equipped chalet, sleeping six people. Situated within easy reach of Bournemouth, Beaulieu, etc. Swimming pool, paddling pool, restaurant and playground on site. Details from Mrs. A. Rae, 16, Clifton Road, Lee-on-Solent Hants. Tel. Lee-on-Solent 550242.

**Rhyl.** Open Plan 6-berth caravan, partitionable into three, situated at the Robin Hood Holiday Camp, Coast Road, Rhyl, N. Wales. Bookings available 1st May-30th September to Liverpool Association, 46 Manchester Street, Liverpool 1.

**Selsey.** New well-appointed, self-contained 16ft. x 30ft. 6-berth mobile home for families with spina bifida members. Sited at Selsey, Sussex. For full details please send s.a.e. to Miss G. M. Clarke, Badgers Copse, Rudgwick, Nr. Horsham, Sussex.

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Walking is so easy for you  
Your legs do what you want them to  
But for all my friends and me  
It's not so simple as you can see  
So next time you run to catch a bus  
Or about shopping make a fuss  
Before you start to yell and cuss  
Please, just spare a thought for us.

● *Link* recently had another verse sent in—this time anonymously, but postmarked Enfield, Middlesex. It was a moving poem telling of the birth of a spina bifida son. We have been unable to include this in *Link*, but nevertheless do send our thanks to the writer.

## NATIONAL ASSOCIATION, PUBLICATIONS AND PUBLICITY MATERIAL

“Your child with Spina Bifida” by J. Lorber, M.D., F.R.C.P., 15p.\*  
“Your child with Hydrocephalus” by J. Lorber, M.D., F.R.C.P., 15p.\*  
“The Spina Bifida Child in School” by D. H. Lee, 10p each.\*  
“Equipment and Aids to Mobility” by O. R. Nettles, M.C.S.P., O.N.C., 3 booklets in a folder, 20p complete.\*  
“Clothing for the Spina Bifida Child” by Barbara Webster, S.R.N., R.S.C.N., 15p.\*

General Information Leaflets: £1 per 100.  
Leaflet for Young People: £1 per 100.

Posters:

Double Crown 5p each.

“Future Bright” 20p for 10.

Flag Day Emblems 50p per 1,000.

Cards for Notice Boards 10p for 10.

\*Special rates available to Local Associations.

### Booklets published by the Scottish Spina Bifida Association

“The Spina Bifida Baby” by O. R. Nettles, M.C.S.P.,  
“Growing up with Spin Bifida” by O. R. Nettles, O.N.C., 10p per copy.  
M.C.S.P., O.N.C., 20p per copy.  
Single copies of these booklets are obtainable from the ASBAH London Office. Bulk supplies from the Scottish Spina Bifida Association, 7 South East Circus Place, Edinburgh EH3 6TJ, at special rates.

### LOCAL ASSOCIATIONS OFFER:—

**SB Badges.**—Silver and green enamel with pin fastening. Replica of the Spina Bifida emblem: 20p plus postage. (Single badges, please enclose s.a.e.). Enquiries from groups welcomed for quantities.

Apply: Mr. K. McKenzie, Badges Secretary, Salisbury and District A.S.B.A.H., Ballard Down, Gomeldon Road, East Gomeldon, Nr. Salisbury, Wilts.

**Badges for Children.**—Good quality 1½in. diameter incorporating the SB symbol and the words Spina Bifida Children in black on a green background. For sale in the following quantities: 25 Badges for 75p, 50 Badges for £1.40 and 100 Badges for £2.65 including P. and P. Cheques or postal orders should be crossed and made payable to “S.A.S.B.A.H.” and sent with order to: Mrs. I. Olditch, High Lea, Turners Green Lane, Wadhurst, Sussex.

**Car Stickers.**—“Support the Spina Bifida Campaign.” Transport stickers 5p each plus postage from Staines, Hounslow and Districts Association, c/o Mr. E. G. West, 13 Princes Road, Ashford, Middlesex. (Minimum order 50.)

**Ties.**—N. Hampshire, S. Berkshire and W. Surrey Association has ties for sale—the SB symbol on dark blue or dark green. The ties are washable terylene of a heavy weave and cost £1 each. Cash with order to Mr. Bernard High, 10 Woodruff Avenue, Burpham, Guildford, Surrey. Please state colour required.

**Blackpool.** Homely accommodation for severely disabled children and families. Well equipped. Self catering. Convenient for promenade, beach, shops. Available all the year round. All enquiries to: Mr. J. H. Lawes, 18 Kenilworth Gardens, Blackpool. Tel: 47992.

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