

Link

Sept/Oct 1973 5p

The Association for Spina Bifida and Hydrocephalus (ASBAH)



HRH The Princess Richard
of Gloucester
Patron of ASBAH

Photo: Tom Hustler

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...

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Vol 1

No. 28

A Royal Patron

ASBAH is honoured to announce that HRH the Princess Richard of Gloucester has agreed to be the Association's Patron.

The Princess who comes from Denmark married Prince Richard last July. Following the tragic death of his elder brother William, in a plane crash, he is now heir to the Duke of Gloucester.

The Princess is President of WRVS London Region, and of Cambridge House. She works as a Staff Officer at the St. John Ambulance Brigade, having passed her First Nursing and First Aid examinations.

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Editorial

Things were getting too much for Joan, the young mother of a spina bifida child. What she needed was a short break—a holiday with just her husband away from the little girl—a holiday that they hadn't been able to have for eight years since the child was born.

But she pushed the idea of a holiday to the back of her mind, largely because it made her feel guilty—"I felt terrible about wanting a holiday without our little girl".

However, when she read the holiday feature in the Spring "Link" about short-stay holidays, she plucked up enough courage to write and ask ASBAH's Liaison Officer, Mr. Macfarlane, about them.

As a result Joan and her husband had the brief rest they deserved and the little girl enjoyed her holiday, too, in the company of others of her own age.

More and more people like Joan and her husband are finding out about short-stay holidays. About 20 families—more than ever before—were helped in this way this Summer by ASBAH's national office, who arranged weeks or fortnights for the children at various holiday centres, usually schools or homes taken over for the Summer by voluntary organisations running holidays for handicapped children.

But as the number of people applying grows, so do the problems of organising these holiday arrangements.

New appeal

The time seems right for ASBAH to set up a more permanent and organised system of short-stay places for spina bifida and hydrocephalic youngsters. And with this in mind it has just been announced that it will be launching an appeal later this year to raise money for this very purpose. (See appeals and publicity news on page 12.)

The details of how this money would best be used have not yet been finalised. One suggestion is the endowing by ASBAH of a specific number of places in existing holiday homes run by reputable organisations. This would mean that such places would be guaranteed for our children for certain times of the year.

Apart from these new plans for short-stay provision it would also be a worthwhile exercise to look to our existing resources to make even more places available.

For instance would it not seem a sensible idea for the holiday bungalows owned by the Local Associations to be utilised out of season? They could perhaps be staffed for say a month so that small groups of spina bifida children could holiday there without their parents.

In this way it might be possible to provide additional short-stay holidays to relieve the pressure on some of our families.

With holidays upon us "news from the groups" is scarce so in this issue we concentrate mainly on people rather than groups. "News from the groups" will return in the next issue of Link.

"Together we can cope"

Roger Tovey and his bride, Linda, on their wedding day in May this year. They are both physically handicapped and feel they can be a great help to each other and together build a good life.

Roger, who is 21, and suffers from spina bifida, met Linda, who is a spastic, at a PHAB club in Birmingham. He wrote and told Link about how their friendship developed from there:

"I have an invalid car and used to travel to see Linda. We got engaged 12 months later and started to make plans for our wedding which was on 19 May, one day before Linda's 22nd birthday.

"It was a lovely ceremony, and we were able to sit all through the service as we are unable to stand for long periods."

Linda attends a day centre for spastics two days a week, and Roger is a polisher in the jewellery trade in Birmingham.

Roger continued: "We are living with my in-laws in Warley for the time being and hope to get a flat in the near future. My disabilities are mainly in the legs, while my wife's are in her hands, so we have got to help one another to cope with everyday chores.

"We have applied to the Ministry to see if we can get a Mini, so that I will be able to take my wife out, as at the moment she is a bit housebound.

"My advice to other disabled people is to do what we have done and get married, as there is always some way of coping with everyday problems if you help one another."



Full cycle!

Jimmy Bates, left, was one of the lucky ones to receive a Thistle Trike as a result of the Christmas appeal by ITV's Magpie programme. A case of charity beginning at

home—Jimmy, 17, lives in Arundel and the Girl Guides there had contributed to the appeal.

Photo: Portsmouth & Sunderland Newspapers.

A first for Paul

The Thistle Trike has been approved by RoSPA as suitable for handicapped children competing for their cycling test. Young Paul Freeman of the Mansfield and Worksop Local Association was the first child to pass the Cycling Proficiency Test on the trike. There is, however, still a waiting list for general supply while orders from the Magpie Appeal are being met by the manufacturer.

Two youngsters right on target



Left, Philip Brown, 10, from Hull and right, Gillian Pepper, 10, from Flamborough, both had a successful day at the Humberside Disabled Sports Day in June.

Philip won two cups and two medals, coming first in the male bowls and first in the junior skittles. Gillian finished third in the junior skittles and throwing the club and was rewarded with two medals.

As the photographs show, both youngsters also have an interest in archery. They're obviously on target when it comes to sport!



Amidst all the violence . . .

The Lurgan and Portadown Local Association writes in its Annual Report that its work has been hampered by the high level of violence and unrest in the area. "Access by car to the town centres in both Lurgan and Portadown was impossible, and members were generally afraid to leave their homes at night. Public telephones suffered severely from vandalism. Parents who had to travel to hospitals in Belfast, particularly to the Royal, sometimes had to dash for cover when gun battles started . . .". Various plans had to be abandoned and home visiting was virtually abandoned, but the Local Association kept going and continued to demonstrate "that people from all walks of life and of all shades of opinion can still work together in harmony in this area in spite of provocations which all have suffered".

The last Link carried a story about Mr. Ted Bartlett's "Make it a Million" money-raising idea. We apologise that his address was given incorrectly. It should be: 1 Willow Way, Ampt Hill, Beds. Tel. Ampt Hill 8692.

Little Miss Courage

Long spells in hospital have not stopped Diane Whorrod, 10, playing an active part in first the Wallsend Brownie Movement and now the Guides. Diane, who is spina bifida, joined the Brownies when she was seven. Her achievement has now been recognised with the presentation of the Movement's highest award for fortitude, the Star of Merit.

New secretary in Scotland

Congratulations to Mrs. Gwen McIntyre who was appointed General Secretary of the Scottish Spina Bifida Association in June.

Mrs. McIntyre has had 30 years business experience in medical, orthopaedic and local government work and this should prove very valuable to her in her new post. In recent years she was Professional and Administrative Assistant with responsibility for the administration of the Social Work and Health Committees.

She has taken over from Mr. John King, who was Honorary Secretary to the Scottish Spina Bifida Association.



Letters



Letters



Letters

I understand there was an item on the radio earlier this year about the journalist, Quentin Crewe, who was refused entry to the Ideal Home Exhibition because he uses a wheelchair. I also understand that ASBAH had a representative distributing leaflets for a fund-raising competition there. As a member of ASBAH I should like to protest about this.

The restrictive conditions of entry applied to dogs and persons using wheeled conveyances (the regulations are worded in this order) are typical of the disability society inflicts upon wheelchair users. This makes the already difficult physical impairment of Spina Bifida hard to bear, by making it socially restricting.

The excuse given for this type of discrimination against physically impaired people is often that of "fire regulations": I think Associations such as ours should make it clear that if Spina Bifida children are to be kept alive then society must take the responsibility for altering building designs or fire regulations or both, so that a generation of second class citizens is not created.

Similarly, the "ideal" home offered as a prize in the fund raising competition would be inaccessible to a wheelchair user because of steps. It seems to me to be setting a bad example to discriminate in this way against our own members and their families, many of whom are wheelchair users.

While it is obviously important to raise money for research and welfare work, I think that the first duty of the Association is to see that its members' basic rights as people to enjoy the same things as able-bodied friends to the fullest possible extent, are maintained. All activity should follow from this. If in our enthusiasm for fund raising we treat our own members with less than complete equality (ensuring that anything we take part in is accessible to those using wheelchairs) then we cannot ultimately succeed in really helping people with Spina Bifida.

Mrs. E. Finkelstein.
London SE13.

A question of access

● Editors note

The fact is that decisions about the disabled are taken by and influenced by the able-bodied because most people in authority and most members of the public are able-bodied. Inevitably that means if we wish to mould public opinion and so influence the decision-makers we have to be prepared, to some extent, to meet them on their own ground.

The Ideal Home Exhibition does allow access to the disabled on three days each week until 1 p.m. when the crowds build up. Admission for the wheelchair user and friend is free. This compromise is inevitable to meet fire and safety regulations in view of the crush in the hall. More than one million people visit the show.

ASBAH feels strongly that all public places should be adapted to allow free access for the disabled, wherever possible. But one has to take into consideration the economic factors which work against the conversion of somewhere like Olympia. In participating in the exhibition ASBAH accepted these realities of life and also the opportunity to meet and influence a very large number of people.

Free access to all public places is the goal. But ASBAH does not believe the best way to achieve it is to make unrealistic demands and opt out if they are not met.

Admittedly the wording of the conditions of entry is unfortunate and we are sending a copy of Link to the authorities in the hope that they might amend them.

As far as the Dream House Competition was concerned, we were again appealing for support from the public at large. The prize had to be attractive to them. The house would have been suitable for some disabled people and there was a cash alternative.

Link welcomes letters for this page on any subject concerning those with spina bifida and hydrocephalus. They will be published at the Editor's discretion and according to space

available. Please try to keep your letters as brief as possible. Send to: The Editor, Link, ASBAH, 30 Devonshire Street, London W1N 2EB. Mark your letters "For publication".



Aids and equipment

The Central Council for the Disabled recently staged a National Aids for the Disabled Exhibition and Conference at the Hotel Metropole in Brighton.

ASBAH had a stand in the charities section and this proved to be a very worthwhile venture. I was in attendance throughout the exhibition and was pleased to see many familiar faces. Those members of our Association who came were very impressed with the exhibits, and those who could not get there missed seeing a very comprehensive selection of aids.

Many commercial firms were showing new developments, the charities showed ideas for their particular disabilities, and there was a corner for individual inventions. Sussex University were

NAIDEX '73

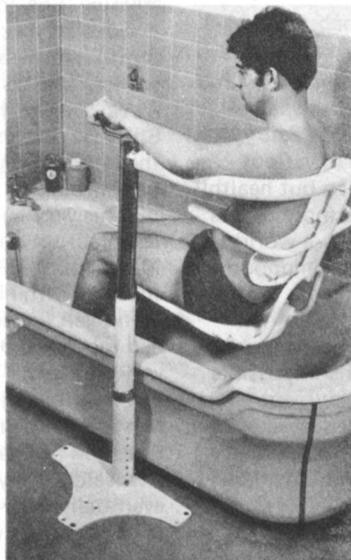
showing plans of their new residential block for disabled students. This is an exciting development and shows that our children can look forward hopefully to better chances of further education, but while I applaud the University's consideration I am not sure that I agree with the concept. I feel an effort should be made to contain disabled students in the existing halls of residence, and when new halls are being designed the needs of disabled students not to be segregated should be a prime consideration.

Among the many items of interest to our members that were on display by the manufacturers, I have chosen the following:

(1) A seat to put inside the Major Buggy. Very often there comes a time when a child is too big for the Baby Buggy and yet seems lost in the Major Buggy. The firm have produced a separate seat attachment with sides and two straps which fits inside the Buggy Major and makes the child much more comfortable.

(2) Mecanids Limited, of Mercia Road, Gloucester, is a firm well known in the field of hoists and aids, and they had on show a small, compact, self-operating bathroom hoist called the "Autolift". The foot of this can fit under the bath, or as in the illustration, and it will fit either side of the bath. Retailing (at the moment) at £85, this gives the disabled person the privacy in the bathroom that is every person's right.

(3) In the Inventors' Corner there was an adaptation to the type of wheeled chair used in ambulances to enable a person to be taken up and down stairs with the minimum of effort by the operator. Further details about this can be obtained from: Impey's Products and Invalid Appliances, 89 Dunoon Drive, Bolton, Lancs.



This will be my last column in Link, as my term of office with ASBAH has now ended. I would like to thank all the many friends I have met and made for the help and co-operation I have received. I leave with many happy memories, and hope that what little I have been able to do has helped some of you some of the time. I hope to keep in touch as I expect to be active in different fields of the Association.

**Olwen
Nettles**

Against all the odds Mary builds a full, happy life

The odds were heavily against a disabled child born to an ordinary working family in the 1920's . . . a child like Mary Brine, for instance.

She was born in 1925 with spina bifida. She had a deformed spine—scoliosis—paralysis in one leg and deformed feet. At three months she was strapped to a backboard and the doctor did not give much for her chances of sitting up, let alone of ever walking.

So where is Mary today, if she is still alive?
Lying in hospital, somewhere, perhaps?

Link found the answer in Storrington, Sussex, where Mary is happily married and leads a full and busy life, looking after her bungalow home and taking an active part in the community. It would be difficult to find a warmer, more sincere person than Mary, or a more contented one.

Yet the transition out of darkness to light was not an easy one. Mary had many struggles to achieve her independence. But her determination and that of her parents saw her through the grim round of hospital visits, long spells in bed, pain and frustration.

Mary's schooling was virtually non-existent because of the difficulty of getting to and from school and periods in hospital.

School life

It wasn't until she was 13 that she had any kind of settled school life. This was when she spent three years at Heatherwood, the orthopaedic hospital school in Ascot where she had various foot operations. Life there was spartan but healthy and spent outdoors on the verandahs more or less all the time, day and night. It did Mary a world of good, building up her strength after a childhood in smoggy London, lurching from one illness to the next.

In what should have been her gay teens and twenties, Mary was struggling with the impossible task of earning a living. Outside employment proved virtually out of the question because of the limits imposed by her handicap and the difficulty of daily travel. As for getting work at home, Mary tried everything from painting lead soldiers at 1s. 6d. a gross, to making Army first-aid bags at £1 10s. for 1,000.

But Mary was determined to be independent. Her parents couldn't hope to keep her all her life. She remembers the struggles they had to buy her an invalid vehicle, before the days of National Health.

It was obvious she needed a training, so at the age of 25 she went to the School of Stitchery at Bookham, Surrey. Three years of training were followed by three years in the sheltered workshops, producing elaborate hand-embroidered goods—banners, altar cloths, table cloths. Mary was happy there on the whole and made many lasting friendships, but she didn't want to stay. She felt hemmed in by the close sheltered life, and the wages were quite inadequate.

Against her parents' wishes she threw up her training. She and a friend at the school, Joan, decided to make a go of things on their own. They found a furnished flat in Leatherhead and took work in a local factory. Mary started winding clock coils at the Goblin works in Leatherhead. She speaks highly of this firm where she stayed for the next eight years, and where she eventually met her husband.

This very happy period of her life was brought to an abrupt end with the sudden death of Joan. Mary's mother—by then a widow—was able to move in with her and so she didn't have to relinquish the council bungalow that she and Joan had moved into a few months earlier. But life was very changed.

Another major crisis then arose. All her life, Mary had had trouble with pressure sores and ulcers on her paralysed foot. She was in and out of a wheelchair trying to heal up the sores. But eventually a very bad ulcer developed and when Mary was 33 it was decided the leg would have to be amputated.



Horace and Mary Topper on their wedding day. Mary knitted the dress herself.

But five years later Mary experienced the happiest day of her life when she was married to Horace Topper, a widower, who worked with her at the factory. This move took courage and determination. There was some opposition from her mother who didn't want to lose her, and it proved difficult to find anywhere suitable to live.

Eventually, however, they found the ideal bungalow in Storrington, West Sussex, and started life together there after a very happy honeymoon at Ashwellthorpe Hall, the country hotel run by the Disabled Drivers' Association.

Mary has a well-ordered life so that she can fit in everything. She and Horace are active Christians and try to be good neighbours in the real sense of the words, doing all kinds of jobs, from caring for a neighbour's cat during the holidays to going in every evening to help an elderly handicapped neighbour to bed. Mary belongs to two women's church groups. She does mending for the RAF, and undertakes all manner of sewing and knitting jobs for friends.

It is just as well that Horace has taught her to drive, so she can now use their car—a Daf automatic—in the evenings and at weekends, and also has her own trike during the day. She and Horace are also members of the Disabled Drivers' Association and of Sussex Spina Bifida Association.

Mary said they both wanted in some small way to help make the way easier for other disabled people. Certainly the happy life she now leads with her husband must give hope to younger people with spina bifida.

Link sends its very best wishes to Mr. and Mrs. Topper as they start on their tenth year of married life.

Miss Oughtred in accident

Most readers will be aware that ASBAH's General Secretary, Miss Mary Oughtred, was involved in a car accident on 31 May.

She is now convalescing and we wish her a very speedy recovery and return to work.

Booklet completes set

The fourth booklet in the series "Equipment and Aids to Mobility" by Mrs. Olwen Nettles is now available to complete the set.

It costs 5p from ASBAH National Headquarters in London.

For those people who haven't seen the previous three booklets in the series, the whole set of four is available for 25p from the same address.



Towards normality

As physiotherapists we have one principal object to assist the child as far as possible happily to fulfil his potential towards normality and independence as a member of a family group and of society. We also must help the family to understand, accept and actively work towards that goal.

To understand with the parents, the child and his abilities or disabilities and thereby plan and execute a realistic programme, we must assess and record the developmental progress in large or Gross Motor activities as in sitting, standing and walking. Fine Motor activities involving co-ordinated use of hand and eye (or manipulation and vision). Speech and communication or realistic language production and the personal and social activities of self-care and social and emotional interaction with parents, strangers and other children. From these observations we can deduce the lack of ability to control big physical movements for walking or even sitting and therefore obtain suitable walking and/or sitting supports.

We may find (particularly in the hydrocephalic child) lack of concentration or of physical co-ordination for fine movements such as those required for holding, let alone guiding a pencil, lack of ability to know, recognise or interpret his position in space, leading to difficulty when changing posture, this problem also demonstrates itself in lack of ability to distinguish shapes and textures leading to reading and writing troubles in class. Sensory skin loss may result in burns and skin abrasions and the child's frustration at his own limitations may produce behaviour problems and family tensions as he grows up. We must, therefore, know the child, teach him and his parents the difficulties and, as far as possible, solutions or ways around these handicaps before they become problematic.

Depending on our findings under the direction of the referring hospital Consultant, the physiotherapist will work out a programme, preferably with the co-operation of and in conjunction with

**Ann Grimley, MCSP, SRP, of
Royal Manchester Children's Hospital,
takes
a look at
the physio-
therapist's
role**

both parents, aimed at achieving as far as possible normal developmental milestones at the pace suited to each child.

Such therapeutic treatment will very probably involve:

1. Stimulation of the child's awareness of his surroundings.
2. Encouragement in rolling over and head raising.
3. Development of awareness and usage of both hands together and separately.
4. Initiation and control of good (not "jack-knifed") sitting posture by provision of suitable support, special chair, adapted cushions, cut-out tray.
5. Encouragement in crawling . . . if the child needs support recommending use of a scooter board or crawling stool on free-wheeling castors.
6. Arm and upper trunk strengthening exercises to aid awareness of both hands, and improve head control and general body balance.
7. Use of a baby bouncer to encourage trunk control and awareness of position of body in space and with a mirror, the body image.
8. Advice will be given on the suitability of appropriate aids towards standing and walking, e.g. standing boxes, walking bars, weighted prams, and trolleys, plus how to teach and encourage the child to fall, then walk fearlessly, roll over, sit up, stand up, walk and manage on stairs. Also how to feed, dress and toilet or bath himself as independently and as soon as possible to be responsible for himself.

Although bladder, orthopaedic and valve revision surgery sessions may take place throughout early childhood, all surgery, other treatment and the provision of appliances and equipment is geared towards living and enjoying as independent a life as possible.

(continued on p. 14)



Family page

LINK begins the first in a series of family pages with some hints on indoor gardening. Something for all the family.

HOME GROWN!

An indoor garden is something to work on and enjoy during the long winter months. About the easiest plants to grow are root vegetables, such as carrots, beets, or white turnips. First trim off most of the vegetable, leaving just a stub and the leafy top. Place the stub in a shallow dish of pebbles and water. If you keep it watered and in a light place, new shoots will appear within a few days.

Make your window look lovely with a climbing plant. In a flower-pot or glass, plant some sweet-pea or nasturtium seeds, or a cutting of ivy, clematis or honeysuckle. Keep the plant in a sunny window and as it starts to grow tack a few strings up the window for the stems to climb on. The stems will twine themselves around the string, and in quite a short time your window will be framed by a beautiful creeper.

A tiny orchard can be a lot of fun to take care of. Seeds from almost any common fruit, such as apple, pear, orange, grapefruit, or even a date, can be started between two layers of damp blotting-paper. Keep paper moist for three to four weeks. When sprouts appear, set them in a coffee tin filled with earth. Keep your little orchard in a sunny window and water it.

Narcissus bulbs produce beautiful flowers. Set them in a bowl of pebbles and water, always keeping the base of the bulbs wet. Keep in a dark place for about ten days until the roots are formed. Then move to a sunny window. Bright blooms will open in four to five weeks.

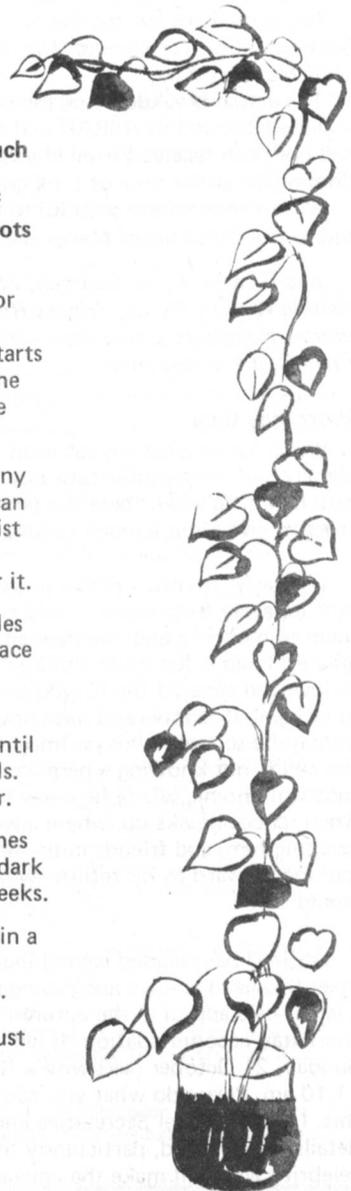
You can grow a miniature green forest by spreading a single layer of lentil beans over a saucer. Add enough water to moisten, but not float, lentils. Keep moist and in a light place. In about ten days green sprouts appear.

Lilies of the valley will make a pretty plant, too. Chop off all but 2 inches of the root and place it in a bowl of pebbles and water. Keep it in the dark for ten days. After it is moved to a window, it will blossom in three weeks.

Take a small sponge, moisten it, and roll it in grass seed. Then place it in a saucer of water in a bright window. Keep water in saucer, and in a few days your sponge will be covered with a growth of brilliant green grass.

French marigolds, or sweet alyssum are easy to grow in the window. Just sow the seeds in a small pot of soil, and water every day. Keep the pot covered with a piece of paper until seeds sprout. If you give the little plants plenty of sunshine, they will have tiny flowers in two months.

Reproduced from McCall's Golden Make-it Book, published by Hamlyn, price 95p.





Appeals and publicity

The girl with £15,000 appeal

The Appeal by Miss Sparks, Lynn Cartmell, raised £15,000 which goes to Local Associations, and at the specific request of Miss Sparks, to the ASBAH Research Fellowship Appeal.

Recently a cheque for the money raised was handed over by Marks and Spencer Director, Mr. Salisse, to ASBAH's President, Lord Maybray King.

The actual breakdown of the £15,000 to determine how much shall be allocated to ASBAH and the Research Fellowship Appeal had not been received from Marks and Spencer Staff Social Committee at the time of Link going to press.

We are enormously grateful to Miss Sparks, to all her colleagues, and to the Directors of Marks and Spencer.

Miss Sparks, Lynn Cartmell, whose Appeal raised £15,000, visiting Wyvern House, Princes Risborough, a small home for spina bifida youngsters. She is seen with Martin, the youngest, and Francis, the oldest child.



Short Stay Care

We all know what a great need there is for homely and loving substitute care for our children with handicap when there is a domestic crisis, or in order to give Mum a much-needed rest.

Similarly, to give Johnnie or Jane a chance to venture away from home would be a way to help them to maturity and independence. Perhaps the greatest need is for those children with no parents to love and support them, who are accommodated in residential schools and have nowhere to go during the school holidays. Imagine the misery for the child—not knowing where he will be sent. A substitute home, where he knew he could return when school breaks up, where a welcome would be awaiting him, and friends in the neighbourhood, looking forward to his return—what a godsend it would be.

ASBAH has decided something must be done to meet this need and we are getting ready to launch a large scale appeal in the autumn to finance short-stay accommodation. It will be launched on Sunday, 21 October next with a Radio 4 Appeal at 11.10 am. Please do what you can to publicise this. I will let Local Secretaries know as soon as details are arranged, particularly the name of the celebrity who will make the appeal.

Making friends

The number of organisations who have befriended us is growing—the Christopher Lee Fan Club has been joined by the International Petula Clark Fan Society and their members support us in all sorts of ways, not only financially. We are most grateful to the Independent Order of Foresters, who have adopted ASBAH for the next four years, to certain Lodges of the Royal and Ancient Order of Buffaloes who likewise are working on our behalf, and to the Loyal Order of Moose and the Greater London District of Inner Wheel Clubs who have made ASBAH their charity of the year. We thank also all those schools, groups, societies and individual donors who have helped our work along.

I was particularly touched by the cheque for £50 sent by girls from Chorleywood College for Girls with Little or No Sight, who raised this money mainly by a sponsored swim 'to go towards helping a child with spina bifida'. I feel there's a moral in this somewhere.

* * * * *

We've made our target of 1½ million Green Shield stamps and a thousand thanks to all of you who made this possible. The aim is to have a super list of prizes (purchased with the stamps) for a super draw or sweepstake in 1974.

Kate White

Words of encouragement

I am writing this in the hope that it may encourage others facing difficulties which I have been able to overcome, writes Ann Atherton.

I was born in 1951 and at eight days old underwent a successful operation to join the lower spine. The associated hydrocephalus then settled of its own accord. An ileostomy operation in 1959 also proved a great boon and I now lead an active and almost unrestricted life.

I was able to attend local schools and thoroughly enjoyed my school days. With help from all concerned I was able to participate fully and obtain six "O" levels and two "A" levels.

I began my working career with three years in the Civil Service, firstly in Newcastle and then in my home town. I resigned last year because I was not enjoying the work, but I feel that I gained an invaluable taste of independence.

I then applied for a place at Queen Margaret College, Edinburgh, on a two-year study course in Institutional Management.

I came with many misgivings having lived a fairly protected life, largely in the company of older people. However, I soon settled happily, and have enjoyed my first year very much—both the work and an active social life. I have found everyone—staff, and my contemporaries—kind and ready to help without fussing.

In conclusion may I here pay tribute to everyone who has helped me in so many ways, most especially my family. My father died in 1968 but my parents, and my sister who is two years my junior and now at teacher training college, have been an unfailing source of encouragement and support.

There are friends, too numerous to mention, to whom I owe a great deal and, of course, many doctors and nurses, whose skill and patience have given me a life worth living.

It is my real hope that this will hearten others who I know face difficulties far greater than mine.



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
UK, Commonwealth Countries, USA, 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 castor 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 costs £8.25 plus carriage.

Large model for children five to ten years old costs £11.50 plus carriage.

These prices include VAT which has now to be paid on these aids in the UK. Overseas prices on application.

Produced by Southampton and District
Spina Bifida and Hydrocephalus Association

Employment: a new look

The government is reviewing the regulations governing the employment of disabled workers. A consultative document, "The Quota Scheme for Disabled People" has been published. It is available from local offices of the Department of Employment and any comments should be sent to the Department by the end of 1973.

The document is part of a comprehensive review by the

Department of Employment in order to develop and adapt policies and services for helping disabled people to obtain and keep employment.

It looks at the operation of the quota scheme which has been running, largely unchanged, for 30 years, and considers possibilities for the future. These include stricter enforcement of the present quotas or rigid

enforcement of a reduced quota. Another idea is that cash payments might be made to employers who recruit severely disabled people, thus encouraging voluntary action on the part of employers.

The review is being carried out in consultation with the National Advisory Council on the Employment of the Disabled.

A bright idea . . .

It probably never occurred to you that nappies could be any other colour than white. But it did strike Mrs. Kathleen Tomlinson as being rather dull.

As a result "Katy-Naps" were born—shaped nappies in 100% cotton terry and in three bright colours, pink, blue, and yellow, as well as traditional white. What's more, for a little extra they can be embroidered!

People we know who have tried them report very favourably. They are colour fast and because they are shaped have the advantage of not being bulky between the legs. There is a pocket in the double-layered crutch in which pieces of Paddi roll or cellulose wadding can be placed to make them more absorbant.

They come in one size, but by folding them in different ways they would fit a tiny baby (even a premature one) up to about a two-year-old, and they could also serve as trainer pants.

Mrs. Tomlinson is offering a very special price to Link readers. A pack of six nappies in blue, pink, yellow, white, or mixed at an introductory price of £2.25. Add 10p per nappy for embroidery.

A gift box with six Katy-Naps, two snaplock safety pins, lengths of nappy roll and a dozen cellulose pads costs £2.75. They can be packed to include sterling silver bracelets or napkin rings at extra cost to make a pleasant Christening gift. Post and packing free. Embroidery designs are golden coronets/pussies/mice/flowers/seagulls/or ships.

Send to the Nappy Centre, 27a Marine Parade, Worthing, Sussex. Cheques or postal orders made out to "K.T. Products". Mention Link when writing.

Ralph Chawner, Secretary of Warwickshire ASBAH, feels that other parents might be interested to know of the large-sized napkins which his wife bought recently. The napkins, of a very good quality and measuring 30 in x 30 in, are £3.82 per dozen including postage, obtainable from the Spastics Society, Supplies Dept., 12 Park Crescent, London W1. Money should be sent with orders.

(continued from page 10)

The parents' contribution

Parents of these children have a very important role to play not only in enabling their child to gain maximum independence as advised, but also to ensure that their child obtains maximum social acceptance and enjoyment.

The mental abilities of these children vary as widely as any other groups of children. A pre-school play group can help tremendously in starting the education of the children by helping them mix with others, thus encouraging social interaction and assisting mother, not only physically but also the Mother/child "weaning" process.

Traumatic new school problems are minimised if the child has had the opportunity to mix with others. Pre-school learning activities are along developmental lines although enjoyably so rather than as a formal exercise.

The physiotherapists are only too pleased to advise the play group leaders as to the aims, methods and problems which they need to know prior to acceptance of the children in regular play groups.

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 Street, 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, Mablethorpe, Lincolnshire. Details from Mr. J. Cannon, 28 Deerpark Crescent, Wingworth, Chesterfield, 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.

ASBAH publications and publicity

By J. Lorber, MD, FRCP: Your Child with Spina Bifida, 15p*. Your Child with Hydrocephalus, 15p*. By O. R. Nettles, MCSP, ONC: Equipment and Aids to Mobility. A folder of four booklets, 25p complete* (Part 4, which is now available: 5p).

By Barbara Webster, SRN, RSCN: Clothing for the Spina Bifida Child, 15p*.

General information leaflets: £1 per 100.

Leaflet for young people: £1 per 100.

Posters: Double Crown: 5p each. Future Bright: 10 for 20p.

Flag Day emblems: 1,000 for 50p.

Cards for notice boards: 10 for 10p.

(*Special rates available to Local Associations.)

All available from: ASBAH, Devonshire Street House, 30 Devonshire Street, London W1N 2EB.

Scottish Spina Bifida Association booklets:

By O. R. Nettles, MCSP, ONC: The Spina Bifida Baby, 10p. Growing Up with Spina Bifida, 20p.

Single copies of these booklets from ASBAH (as above). Bulk supplies from: The Scottish Spina Bifida Assn., 7 South East Circus Place, Edinburgh EH3 6TJ (at special rates).

Postage on all these items is extra *outside* the UK.

Local associations offer:

SB Badges. Silver and green enamel with pin fastening. Replica of the Spina Bifida emblem: 22p plus postage. (Single badges, please enclose s.a.e.) Enquiries from groups welcomed for quantities.

Apply: Mr. K. McKenzie, Badges Secretary, Salisbury and District ASBAH, 111 East Gomeldon Road, Gomeldon, Salisbury SP4 6LZ.

Badges for Children. Good quality 1½ in. 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 "SASBAH" 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. (Min. 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.

Colour film

"What Shall We Do Tomorrow?"

This 16mm colour film runs for 22 minutes and shows the problems and achievements of spina bifida youngsters. It was produced professionally for the Mansfield and Worksop Local Association, Notts.

Price: £75.89 per copy.

Hire charge: £3, plus compensation fee and postage. Contact: Mrs. Ethel Freeman, 23 Melbourne Street, Mansfield, Woodhouse, Notts. Tel.: Mansfield 26860.

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