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LINK

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

Spring 1969

One Shilling

LETTER FROM A MOTHER . . .

Loughton,
Essex.

Dear Editor,

I am writing this letter in loving memory of our son, Andrew. In the past few years I have read many stories in "Link" and it has filled me with dismay to hear mothers say they prayed for their newly-born spina bifida child to die.

My husband and I have just finished the best seven years of our lives. Although it has been a worrying time trying to keep our son well and healthy we wouldn't have missed it for all the world.

Our son was worth six of any normal children. He brought love, kindness, understanding, patience and tenderness which will long be remembered by everyone who knew him. He attended Brookfield House School for handicapped children, which gave him the last two happiest years of his life.

Many doctors and friends have advised us to adopt but in our opinion no one could ever take the place of our darling son. So we say to all parents of spina bifida children don't give up but try to treat your child like any normal child. Think of them as normal children especially when trying to explain your child's condition to people.

They get a picture in their mind that your child is ugly and deformed.

After two spine operations and nine valve operations followed by a bladder diversion, Andrew was far from being ugly. It is the hardest part to explain spina bifida to anyone who has not had any dealings with it.

We hope ASBAH gets on its feet very soon now and we all see something concrete done after all the effort put in by parents and friends of the Association.

We would like to thank the doctors, nurses and surgeons of University College Hospital for giving us seven years of happiness.

Although we have now lost our darling son, and cannot have any more children for genetic reasons after giving birth to two spina bifidas, we will still do what we can for ASBAH.

Yours sincerely,
Mrs. G. Crooks.

LINK

SPRING Vol. 1 No. 10

Contents

Editorial: Let's pull together

During my short stint as editor, and previously when I helped in the background, I have been deeply moved by the articles and letters which have been written by our readers. One of the most moving is the letter on Page 2, which is a courageous woman's tribute to a loving and much-loved son.

The bitterest pill to swallow is that some of our children will die. Our whole reason for existing as an Association must be to dedicate ourselves to ensuring that more children live, and that the quality of their living is as rich as we can make it.

It is my humble opinion that to do this we must put more of our eggs into the central ASBAH basket.

Of course branches must use some of their income to the benefit of their own members. It is a natural element of human nature that our own "families" have first call upon our energies and loyalties.

But what good is served in providing a child with a more streamlined baby bouncer or a better seat at the circus if we neglect the vital research which will ensure his survival or the structure of family life is falling apart for want of support in the home?

We naturally all care most for our own child. But if each individual child is to benefit we must care for every spina bifida child.

It is up to all our members to decide where the priorities really lie when it comes to spending any funds they have raised.

I would like to see each branch making interest-free loans to the national organisation to ensure its expansion instead of mere existence.

Even better would be regular contributions towards the running costs of the central office, to continuing the growth of "Link" and the provision of welfare services and publications.

Our medical advisers work tirelessly in their spare time to lecture to parents and to write articles to enable parents to cope with their children. Let us help them to overcome the frustrations they must feel when they see the clinical help they can give restricted by lack of money for research.

Our paid officials are working with real dedication to raise money, gain publicity and knit us into a truly national organisation. Let us ensure that their more ambitious schemes are not inhibited by a diminishing bank balance.

Let us, for our children's sake, all pull together to ensure that ASBAH grows into a giant oak tree to protect us all rather than each area having the dubious shelter of a slow-growing sapling.

If we do this I feel confident that the prognosis for all our children will improve. And "Link's" postbag will contain a greater element of triumph and optimism than it has in the past.

Stranger in the house

To become a foster-mother is in itself a courageous step. But Mrs. Olive Barnard found that she needed even more than that when her first "charge" developed hydrocephalus.

The telephone rang. "Could you please take an eight week old baby boy for a short period, say about six weeks?" It was the friendly voice of the Children's Officer. I was overjoyed. This was I hoped to be the start of many happy years of fostering. I had joined the gallant band of foster-mums in April, 1967. Now it was September and I was still anxiously awaiting my first "charge".

I was to meet the train on which Paul, the baby, was arriving, with a nurse. The Children's Officer called for me, and we set out for the station. I was excited, and frightened. It was rather like being wheeled into the delivery room, all fearful and apprehensive, but holding on to every minute.

Would I be able to cope? I wasn't getting any younger and my patience was wearing a little thin. I already had two grown children. We arrived at the station, the train had just pulled in, and there was a nurse with a small bundle of blue in her arms. I went forward and took the bundle. A little parcel of belongings was handed to me, and off we went, Paul and I, to enjoy what little time we had together.

Deep feeling

It's very strange to have a young baby in the house, especially one to whom you have not given birth. I began to feel a little afraid. He was a stranger, an unknown quantity. But after the first day or two I began to feel better, and I tackled all the messy jobs that come along with babies, and found myself actually enjoying them.

Nine days went by, some good, some not so good. I was concerned about the right feeding and clothing. I had begun to have an unusually deep feeling for him, and had promised myself that I would show him all the love I was capable of.

Then, suddenly I had a strong feeling that all was not well. I called on the doctor and voiced some of my fears. "Don't worry, a little boiled water, all that's needed." But still the worry nagged away. I called on the District Nurse for her help. Paul didn't look ill in any way. He cried during the day, but not excessively so, also during the night. He refused his bottle, and it was extremely difficult to get him to take any other liquid.

Another couple of days went by, and still no improvement. By now, I was certain that he must have something dreadful.

Another visit to the doctor, and this time a phone call to Southmead Hospital was made. Yes, a cot would be ready for him. Could I take him as soon as possible? Needless to say we took him that day.

Paul was undressed and laid in a cot. We went in to look at him and to say goodnight. The doctor turned to me and said, "I'm afraid he has meningitis".

Conveyor belt

I hadn't thought of that. I realised this disease had something to do with the brain, but I did not then know the full significance of it. I went back to the waiting room, sat down, and tried to collect my thoughts.

"That's it", I said. "My duty ends here, the child is in care of the hospital, and I can phone the officer, tell her details, and wait for another foster-child to come along, as though on a conveyor belt."

Why then did I feel as though my heart was being torn apart? Why then did my husband, feeling as desperate as myself, have to hold me tight to stop me shivering as we went out to the car?

Diagnosis was confirmed the next morning.

The next few weeks meant telephone calls night and morning, and visits to Southmead to see Paul through glass. The doctor didn't hold out very much hope, and he often mentioned brain injury. I think he was very open with us about Paul. He knew we weren't his real parents, and I suppose he felt that we wouldn't be so badly hurt. Paul just did not seem to be making progress.

Then a neurologist from Frenchay Hospital came to see Paul and diagnosed hydrocephalus.

Hydrocephalus? The name meant nothing. I was confused, and alarmed, and very kindly the doctor explained to me exactly what had happened.

Operations began—operations which at that time seemed terrible. Transfusions, blood infections, urine infections, saline drips. There seemed no end to the mounting feeling of despair. As the time went by, I grew used to all the hospital routines.

Paul had had eight operations. He survived a very critical period. He was saved only by the skill and the constant attention of the doctors and nurses.

I know there is the possibility of the tube blocking again, and that I shall have to live through the hours until I get to the hospital, the terrible sickness, and the loss of vision, and the pitiful crying.

How then do I feel about fostering a child with this distressing condition, never knowing what will happen? I could hand him back to the care of Somerset Council and say that I have had enough. Nobody would blame me, but then could I? I think not.

Her fear

Paul is as much of our family as my own very dear children. I have been called brave, stupid and downright mad. But I think I am extremely lucky to be able to care for and love Paul, and to be able to help him as much as is humanly possible, to live a full and useful life.

At the back of my mind is the fear that some day he may have to leave me. How will I face this? Looking at him when he is well, and even when he is so very ill, I find that no one could possibly take his place.

My grown children have wonderful plans for Paul, i.e. ice skating when he is bigger, lots of toys and picture books and places they want to take him to.

We would dearly love to adopt Paul, and we hope we may be able to this in the future. One thing I know is that I have never regretted keeping Paul, and would do it all over again knowing the full facts.

Help needed

Volunteers are wanted for the Leeds Marathon on Easter Monday. Proceeds will be divided between Leeds branch of ASBAH and Christian Aid. Offers of help in clerical, marshalling or catering to: Mr. Gibson, 2 Hilton Edge, Bramhope, Leeds.

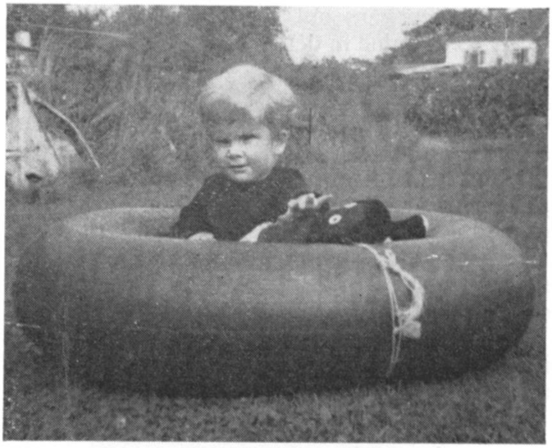
ASBAH's annual meeting will be at Bristol on May 17.

TAKE A TIP!

If your child does not sit too well try bathing him in shallow water lying on his tummy. He will love it and it is so much easier.

Swing-fun is possible for children who have very little leg movement without mum wearing herself out as the "pusher". Mrs. Jo Brookes-Parry, of Rhyl, ties a rope to a nearby tree so that Robert can pull the other end and swing as high as he wishes. For extra protection Mrs. Parry also puts a pram harness on her son, although the swing has wooden bars to keep him in.

Mrs. Parry also solved the cot problem by placing hardboard down the cot sides. This saved her sleepless nights wondering if Robert had manoeuvred himself into a difficult position, hurting himself perhaps by twisting his legs between the cot rails.



Enterprising Mrs. Betty Topple solved the balance problem for her three-year-old son Robert with this large lorry inner-tube.

Hydrocephalus had resulted in young Robert having a poor sense of balance. He couldn't sit up on his own on the floor. So his parents went to a car breakers' yard and bought the inner-tube for 10s.

"What a boon it has proved", says Mrs. Topple. "I can even leave Robert to sit on his potty knowing that if he falls he will bounce on the tube and sit up again."

Apart from reducing Mrs. Topple's anxiety the tube has made Robert more adventurous. He can get himself out of his rubber cage now.

"Although a peculiar looking piece of contemporary furniture in a small bungalow, it is one we cannot afford to be without", says his mother.

SEARCHING FOR CLUES TO SPINA BIFIDA IN GENETICS

By J. Timson, lecturer in Medical Genetics, Manchester University

In the Department of Medical Genetics at Manchester we have been interested in the genetical problems of spina bifida and hydrocephalus for some time.

With Professor Emery, I examined the possibility that certain blood tests would help us to predict more accurately the chances of parents having a second affected child. Unfortunately, these particular tests did not appear to have any value for the purpose of this kind of prediction.

With the Manchester and District ASBAH, I have been carrying out a family survey in order to try to examine in detail certain aspects of the inheritance of spina bifida. This work has been greatly accelerated by the generous gift of a Casio AL 1000 calculator from the Manchester Association.

No results from this survey can be given at present, but it is possible to indicate the kind of problems being investigated. It has been repeatedly shown that as a woman gets older so her chances of having a mongol child increase.

It would be very useful to know if a similar increase occurs with spina bifida and hydrocephalus.

Better understanding

Here the authorities differ. Some investigators claim a definite increase, much less marked than in mongolism, but clearly present. Others, however, have been unable to find such an increase.

The importance of knowing the answer to this question will be obvious to all mothers. The father's age may also be important and this is being investigated.

The whole aim of the work in the genetics of spina bifida and hydrocephalus is to gain a better understanding of how these disorders are caused. To determine the mode of inheritance and its importance in causing spina bifida is essential if we are to be able to provide a really accurate answer to the question "Will it happen again?". One would hope eventually to be able to give an answer based on the individual family rather than one based on the average of a large number of probably rather different cases.

Some disorders are clearly genetic, which means that they are inherited—muscular dystrophy and haemophilia for example. Many diseases are not genetic, they are caused by a disease organism which must be contracted by the patient.

Some forms of hydrocephalus have been found to have a relatively simple genetic pattern but these are the minority of cases. Spina bifida is genetic in the sense that it is familial, it is known that the chance of a child having spina bifida is greater if the parents already have an affected child.

On the other hand the chances of the parents of a spina bifida child having a second affected child are much less than those of the parents of a child with one of the genetic disorders having another child with the same disorder.

Other factors

Spina bifida, therefore, does not seem to be inherited in any simple genetic manner. When parents ask: "What chance is there that it can happen to us again?", the answer will be based on what are known as empirical risk figures. Dr. Lorber in "Link" (Winter 1966/67) explained how these are obtained and the chances based on his findings.

Because it is not possible at present to fit the known facts about spina bifida to current genetic knowledge, some authorities have begun to suggest that other factors may be at least as important.

What these factors could be, if they exist, is not known although some possibilities are being investigated. A number of hypotheses have been put forward to fit the present data, but while some of these are more plausible than others I think it is probably fair to say that none at the moment is satisfactory.

It may be that as more data is collected and analysed, one of these hypotheses will be seen to be the most reasonable and no doubt more will be put forward as our knowledge increases.

It will only be possible to try to think of ways

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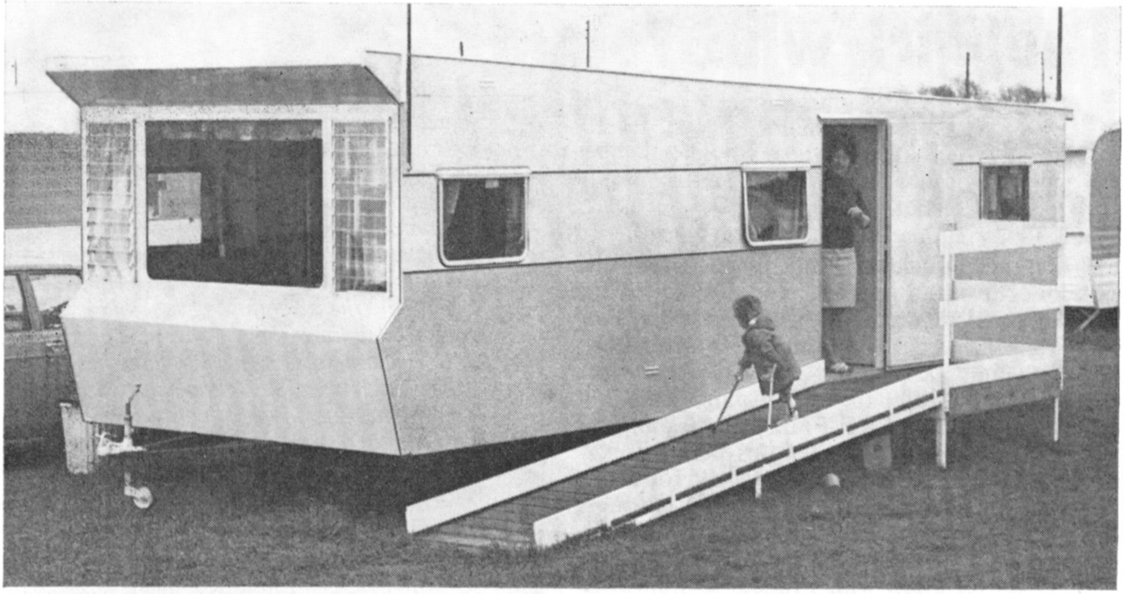


Annaliese White, aged four, of Watford, was the first spina bifida child to have the benefit of South Mercian's holiday caravan.

Finding a suitable spot to park the caravan presented a bigger headache for the committee than raising the money to pay for it. After many months of searching a suitable site was found adjoining Eccles Beach, Lessingham, Norfolk.

The caravan has been well modified to allow handicapped youngsters as much independence as possible as well as holiday fun.

Many members' families enjoyed holidays at the van last summer, and it is likely to be very popular for many years to come.

But branch members have not confined their activities to providing this marvellous holiday facility. They are now on the verge of achieving their objective to raise £500 for medical research.

Continued from previous page

of preventing spina bifida when we have a coherent theory of its cause compatible with all the known facts. This is why research into the causes of spina bifida is concentrating on surveys of various kinds.

We need to know much more about the families into which spina bifida children are born. Are they a random sample of the population or are there features that set them aside from the general population?

Common sense suggests that in some way we should be able to determine which families are more likely to have children affected with spina bifida or hydrocephalus.

The girl who found her own school

Education is one of the biggest problems parents of spina bifida children have to face. Their biggest wish is that their youngsters will have the opportunity of a normal education at schools near their homes.

We have had many disappointing reports of refusals by head-teachers who refuse to believe that these children can integrate successfully among their "normal" pupils.

Here headmistress Miss Patricia Minns, of Riverview Infants' School, Gravesend, tells how one small girl convinced her that it was worth a try—provided the child is intelligent and the school has easy access.

We hope her article will help parents to convince other heads that it can be done.

I first met Frances one morning as I returned to school from an appointment. She hailed me by name and requested my permission to come into the school playground. Unfortunately, this was not possible as we have a steeply sloping path from the playground and not knowing the nature of Frances's disability, I did not feel able to give her this permission.

Instead I stood and chatted to her for a few minutes and the thing that impressed me most was her bright and lively manner and the intelligence with which she answered my questions.

This conversation with Frances so impressed itself upon me that I went out of my way to find out more about this little girl and what was being done for her educationally. The local health visitor made some inquiries and I discovered that her parents were very anxious to keep her at home and that she should be educated in a normal school if this were possible.

Some reluctance

So I set the wheels in motion and tried to get permission for this child to be accepted in my school, which is a normal state school. With some reluctance, the authorities granted permission as a temporary experiment.

The problems which might arise from the admission of a physically handicapped child had not been uppermost in my mind, but now I began to have some misgivings about the undertaking I had accepted.

Teachers fell over themselves to volunteer to have Frances in their class so this aspect was not a problem at all. The parents talked over their problems with me so that we should have a clear picture of what we were about to face.

My knowledge of spina bifida and its resulting physical difficulties was nil. I cannot praise too highly the parents of this child whose co-operation with the school was excellent.

The first difficulty was the presence of a wheel chair on a playground built for 400 energetic infants. This was easily overcome by the mother bringing Frances to school a few minutes after session began in order that she did not meet up with the arriving "hordes". At the end of each session Frances remained in classroom to wait the arrival of her mother and so again solve the problem of Frances leaving at the same time as the other children. An amusing conclusion to this late collection by her mother was that she was so keen to continue working that her mother inevitably had to wait while she finished the piece of work she was doing.

The children accepted Frances as a member of their class quite naturally. At first very obviously they were very keen to push her wheel chair and fell over themselves to help. Soon, however, they accepted that Frances was quite capable of doing most things for herself.

At first, she did not join with the class for physical education, but after consultation with the medical authorities, we were permitted to take her out of the wheel chair and sit her on a mat and she worked with small apparatus. The children in the class took it in turns to work with her, throwing, catching, reaching and lifting.

Frances joined in with great enthusiasm and was able at a later stage to pull herself up and down a low inclined form which did much to help her strengthen the muscles of her arms.

The highlight of her life with us, for me at least, was the day that Frances misbehaved. Most people tend to do everything for handicapped children and do not expect them to behave generally like normal healthy children. To her surprise, and even anger, that she had to be spoken to rather sharply, was really the turning point of her life in school. For it seemed that from that moment on she became such an

This is Frances McCloud, now aged eight, of St. Francis Avenue, Riverview Park, Gravesend, who was given a great start to her education life. Her parents belong to the Kent Branch.

accepted part of the pattern of the school life that one forgot completely her inability to move as freely as other children.

This was brought home very forcibly to me when a Senior Inspector from the Department of Education and Science who, after visiting the classrooms, remarked that I had not mentioned that we had a physically handicapped child in the school.

By this time to the staff and children, it seemed almost as though she were not handicapped in any way at all. She had been completely accepted in every sense, both in the physical environment of the school and by the staff and children who worked there.

She took part in every part of school life and, with one exception, no special concessions were made for her. If the occasion arose when she might do something for the school, such as present a gift to an important visitor, she was chosen. This was not really necessary, and we were probably only pandering to our own emotional reaction to Frances.

One regret that I have is that Frances was not able at the age of seven to transfer to the neighbouring junior school, as this was a building built on varied levels. Fortunately we did find a junior school nearby built on one level and to which she was able to transfer. Obviously my contact with her will be more limited than it would have been had she been able to attend the junior school on our site.

When Frances reaches secondary school level, the problem will be more acute, but I personally feel that she has gained a tremendous amount from being a member of a normal school.

She has learned to accept with patience that people usually try to do things for her that she is perfectly capable of doing herself. She has learned to accept the wrongly placed pity that adults so often have for her. Most important of all, she has learned to accept that she can become a perfectly normal member of society and can take her place in it, even if it is somewhat limited, and be of value to the community.

If I should be asked to accept a child of this nature in my school again, I would accept without hesitation, for I feel that a normal school has a great deal to offer a child like Frances and a child like Frances has a great deal to offer the school.

There is, however, one very serious obstacle that could affect my acceptance of a handicapped child and that is when the child is affected mentally. Frances was an intelligent, lively, personality in her own right. Her only personal difficulty was her physical handicap, but had this been combined with a mental handicap, the situation for a normal school would have been very different.

I hope that Frances will be the first of many children who suffer from spina bifida to be accepted into normal state schools, for I felt that, for us, Frances was an unqualified success.

Our cover

Ian Bettinson, aged seven in June, cried when our cover picture was taken because he did not like wearing his calipers. Nor did his mother enjoy fastening 12 buckles several times a day. One day, perhaps, all caliper fasteners will be made of velcro.

Meanwhile, Ian does not let his calipers prevent him from enjoying life. He attends a special class for handicapped children in an ordinary state school at Crawley, where he lives.

In his spare time he horse-rides and plays ten-pin bowls. It is hard to believe that he was not expected to live longer than 24 hours at birth.

CALLING ALL NEEDLEWOMEN

If you cannot manage the crochet shown in our last issue, you should be able to knit one of these simple triangles.

Every row is a knit row; no purl stitches at all. Simply cast off one stitch at the beginning of every row to make the shape.

Use two or more colours from any one of the lists included in the last article. Change colour as often as you like and wherever you like, as long as it is at the beginning of an odd row, so that all the ends of wool are on the same edge and all the mixed-colour rows appear on the same side. Make sure you join the wools with a firm knot and sew the ends in on the wrong side.

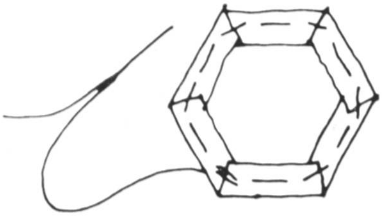
		Number of stitches to cast on	
Thickness of yarn	Needle size	Firm knitters	Loose knitters
3-ply	10	68	64
4-ply or quickerknit ...	8	54	50
double knitting ...	7	50	46
6-ply or treble knitting	5	40	36

The triangle should measure about 9 inches across its base.

How to make fabric hexagons.

Use any fabric as long as it's not too hairy, nubbly, stretchy or transparent.

Draw a hexagon on paper with each of its six sides measuring 1¾″. Paste this on to thin card (a breakfast cereal packet will do) and cut it out neatly. This is called the template. For every fabric hexagon you wish to make, draw round the template with a sharp pencil on to thin card and cut round your pencil line. Then cut out a piece of fabric about ¼″ larger all round than the hexagon, fold the edges over and tack them down, right through the card as shown below. Don't stitch fabric to your template, use it only for drawing more hexagons.



Continuing our article on how to make a £25 bedspread, we turn to the woman who prefers to knit or sew to raise money for ASBAH.

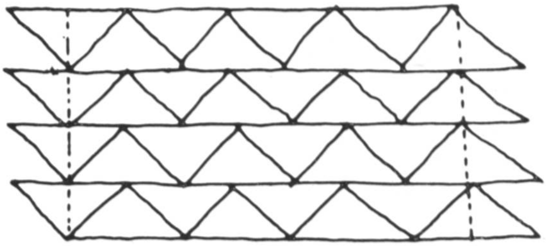
How to sew the pieces together.

Each person could be asked to sew together enough pieces to make a pram-cover. This size is referred to as 1 unit in the tables below. Spina bifida patients or other volunteers would then sew the units together as required.

	Size (width first)	No. and angle of units	No. of rows, side to side	No. of rows, head to foot	No. of squares
Pram	20″ x 25″	1 ▯	4	5	20
Cot	25″ x 40″	2 ▭	5	8	40
Single bed	75″ x 100″	15 ▭	15	20	300
Double bed	100″ x 100″	20 ▭	20	20	400

Knitted triangles (each 9″ across base and 5″ from base to apex).

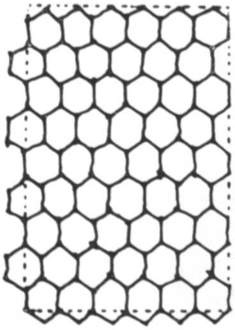
The pram-size units will be as sketch below. These units interlock to make the sizes shown in the table below. All zig-zag edges would be sewn under on completion of bedspread. Dotted line on sketch shows where unit would be hemmed if it were to be sold as a pram-cover. *Unhemmed sizes are given in table.*



	Size (width first)	No. and angle of units	No. of rows, side to side	No. of rows, head to foot	No. of triangles
Pram	20″ x 40½″	1 ▯	4	8	32
Cot	40½″ x 40″	2 ▭	8	8	64
Single	76½″ x 100″	10 ▭	16	20	320
Double	112½″ x 100″	15 ▭	24	20	480

Hexagons (3½″ from point to opposite point).

One unit would look like the sketch below. The dotted line indicates where a lining would be stitched on to the back. The units would then be sewn together as required, with the edges interlocking and the linings sewn together at the back. On completion of bedspread all the bits of hexagon overlapping the edge would be folded under and stitched down. Table gives *un*-hemmed sizes.



	Size (width first)	No. and angle of units	No. of rows, side to side	No. of rows, head to foot	No. and angle of hexagons
Pram	18″ x 24½″	1 ▯	9	6	⬡ 54
Cot	24½″ x 36″	2 ▭	12	9	⎔ 108
Single bed	73½″ x 90″	15 ▭	30	27	⎔ 810
Double bed	90″ x 98″	20 ▯	30	36	⬡ 1080

In praise of 'Link'

"Link" has been a great help to me. I live in an isolated area and so am unable to attend ASBAH's parents' meetings, but thanks to the magazine I have learned a lot.

The article on Softdown Nappies was a help because recently my son was in the Sheffield Children's Hospital and I was surprised when he came home that his sore bottom was healed completely. I had tried all ways to get it better.

When I saw that these nappies could be bought for home use, I decided to cut down on something and so be able to afford them as I am sure the nappies did the trick.

I am sure there must be many people like myself who rely largely on "Link" for information and so I am holding a raffle and will send all the proceeds towards keeping "Link" going.—Mrs. J. Murphy, Aston, Sheffield.

The general secretary

Our first general secretary will need no introduction to the branches she has so far visited since she took up office last August.

Here, for the benefit of members who have not yet met her, are some details of her experience which helped to convince your Executive that here was the right woman for the job.

Over a number of years Elizabeth Cleverdon Skellon has been concerned with many human problems both in this country and overseas.

Working first in a government post amongst destitute refugees she witnessed a disaster caused by an act of sabotage in which hundreds of refugees were drowned. This convinced her of the need for voluntary organisations to protect those people caught up in the machinery of politics and bureaucratic rule.

Since that time, she has worked with various organisations including the Red Cross and has been concerned with the problems of old people, poverty, hunger and physical handicap. For her work with refugees she was awarded a decoration.

She was the Projects Publicity and Films Officer for the Freedom from Hunger Campaign and for the last four years has been with the Shaftesbury Society organising their National Appeal for projects on spina bifida, muscular dystrophy and general handicaps.

Also at one time she was vice-president of Inter Allied Clubs in Central Europe.

Mrs. Skellon has done many programmes for the BBC and is an experienced broadcaster. She is a member of the British Association of Women Executives, the British Branch of Femmes Chefs d'Entreprises Mondiales.

Jennifer King lines up proudly among the winners of a Butlin's Junior Princess contest

THE THIRD LITTLE 'PRINCESS'

The competition was keen when 60 pretty little girls lined up in the Junior Princess contest at Butlin's Minehead camp. But the judges had no hesitation in placing three-year-old spina bifida girl Jennifer King in third place.

It was a proud moment for Mrs. Sheila King when she helped her little girl forward for the winners' photograph to be taken.

For Jennifer, of course, it was all very bewildering.

Jennifer's grandmother, Mrs. Eileen King, of Swindon, Wilts., sent this photograph to "Link" because she was doubly proud of her grandchild's achievement.

"I see it often said that it is a great shock to a young mother whose child is born spina bifida", she wrote. "What then can it be to a mother who is also handicapped herself by deafness?"

At birth, Jennifer was whisked away to Bristol for a closure operation. Her parents were delighted to find that her hearing was perfect.

Surgeons found mild hydrocephalus which did not increase. After two operations Jennifer's deformed feet were corrected and she is able to walk in surgical boots and calipers.

Jennifer's intelligence is well up to average and she often "talks" silently with her lips to her mother.

The little girl has probably forgotten about her holiday triumph by now, but her parents and grandmother hope this picture will help newer parents to realise that the future is not hopeless.

NEWS FROM THE GROUPS

Bromley & District

Following the branch's "birth" in May members have forged ahead in gaining a foothold in their area.

Numerous activities included a sponsored walk from Hayes, Kent, to Rochester in which 65 walkers took part. Bad weather conditions did not deter the marchers who had to battle against a gale and pouring rain.

Spina bifida boy Lee Grayson, 14, started the walk and completed the last two miles with a £1 a mile sponsorship.

Apart from the fund-raising potential of the march, the officials secured maximum publicity in the local press.

Central & North London Association

Progress has continued in forming local "cells" to personalise activities for members living in a wide area. Six local groups are now flourishing in Ipswich, Ashford and Staines, South Essex, Walthamstow, Finchley and Barnet, and Ealing.

Essex

Alderman J. Sibley, Mayor of Havering, organised an inter-clubs swimming gala, attended by singer P. J. Proby, and raised £104 for the Essex branch.

Branch chairman Mr. Mee ran a bazaar on the same day which resulted in a £126 contribution to funds. During the autumn meetings were addressed by Miss Fowler of the Essex County Council Welfare Department and midwife Ball who showed films of Guide camps for the handicapped.

Huddersfield

An annual toy fayre in November brought in £40 towards branch funds. Children of pre-school age can now attend Rawthorpe Primary School for one day each week.

Hull and District

Formed 10 months ago, this branch now has 40 members and has been busy raising money and organising a children's Christmas party.

Jersey

A letter from Mrs. Cindy Hansford, young mother of a spina bifida daughter, to the Jersey Evening Post resulted in the formation of this branch 18 months ago.

The Lions Club of Jersey heard of the parents' efforts and offered to help. A public meeting at Jersey Town Hall resulted from the Lion's interest when surgeon Mr. Herbert Eckstein explained some of the aspects of spina bifida and hydrocephalic disabilities.

Following the meeting, the Association got under way with a busy programme of social and fund-raising events. Refreshment canteens have been organised at local fetes and at the Lions' Donkey Derby. Raffles are always being held at Jersey hotels to swell funds.

So far the branch has been able to embark on a welfare programme to help members. A telephone has been installed for one family, another has been helped with air fares to the mainland; yet others have been supplied with push chairs, baby bouncers, etc.

"Link" readers may be interested to hear of another project sponsored by the Lions—the Maison des Landes Holiday Hotel for the Handicapped.

The hotel caters for all types of physical disabilities and branch secretary Mrs. Ursula Emmanuel says it would be ideal for a family with a spina bifida child.

Interested parents should write to the Matron, Mrs. Ashton Edwards, at Maison des Landes, St. Ouen, Jersey. Parents who do venture across for some Channel Island sunshine should not hesitate to contact the Jersey branch. "We would be more than pleased to meet anyone coming to Jersey who may care to get in touch with us", writes Mrs. Emmanuel.

Kent

A Gravesend dancing school provided the highlight of this year's Christmas party with a special display.

About 116 children and 80 adults enjoyed extracts from the pantomime "The Wizard of Oz" which was staged by the school. Games and singing and a visit from Santa Claus, who gave each child a present, completed a wonderful day.

Mid-Ulster

The decision to start up a third branch in Northern Ireland was taken in October. Members of Belfast branch helped in the formation of the Mid-Ulster off-shoot at a meeting in the staff canteen at the Daintifyt Factory, Cockstown, Co. Tyrone.

About 40 people attended the meeting and the new branch's members plan to hold monthly meetings and do everything possible to further the aims of the Association.

Spenborough

Mr. James Corrigan, proprietor of the Batley Variety Club, donated four free seats to one of his All Star Shows for the branch's Christmas raffle.

The branch were delighted with the gift because his shows are so popular that the seats are normally booked up months in advance.

The branch was given a large helping hand in getting started by committee members of the Huddersfield and Halifax Associations. Spenborough officials hope to be able to re-pay the generous supplies of leaflets and posters, as well as time given to helping them, in the near future.

South Mercia

A member of the South Mercian association is anxious to obtain a hand-propelled go-kart for her three and a half year old son who cannot move fast enough in his Chailey chariot.

"I am sure many other children are in need of such a vehicle", writes Hon. Sec. Mr. A. S. Dale.

If any reader can name manufacturers, supply plans or advise on conversion of conventional karts please write to Mrs. D. F. Hobgen, 88 London Rd., Stapleford, Cambridge. Your editor would also like details, so that they can be passed on to the "Link" readers.

Apart from buying a holiday caravan and raising £500 for medical research, members visited a day school for P.H. children and heard a talk by the headmistress. They embarked on a coach outing to Chessington Zoo, heard a talk by Dr. Lorber, chairman of ASBAH's medical advisory committee, and enjoyed a social for parents.

Salisbury

Salisbury and District Group now have supplies of metal lapel badges of the spina bifida emblem. Local secretaries are invited to obtain supplies for their members at £2 2s. per dozen plus postage.

Badges will be supplied to individual members on receipt of a stamped addressed envelope and a postal order for 3s. 6d. Cheques and postal orders should be made payable to "ASBAH Salisbury and District".

Address: Mr. Dennis Callaway, 17, Ridgeway Road, Salisbury, Wilts.

Surrey

Patience and long-term planning helped to notch up a fund-raising success of about £500 for Surrey branch, as well as a measure of local newspaper publicity. The money was raised by two carol concerts given by the Epworth Choir and their conductor Walter Deacon at Woking's A.B.C. Cinema.

Peter Purves of "Blue Peter" television fame made an appeal at one concert on behalf of the Spina Bifida Campaign and the Spastics Society. Actress Sylvia Syms pleaded the two causes at the first concert. The cinema was filled to capacity on both occasions, ensuring further publicity.

Steps were taken by Surrey officials to enlist the choir's support as far back as September, 1967. An approach to conductor Mr. Deakin resulted in the choir's committee agreeing to support the Spina Bifida Campaign at a later date.

"Mr. Deakin went even further since we were unable to provide a show business personality to speak on our behalf", explained chairman Mr. Michael Stedman. "He kindly arranged for Mr. Purves to make our appeal for us."

Mr. Stedman feels there is a need for ASBAH to set up a national "celebrity supply" scheme similar to the Spastics Stars Organisation so that such problems do not occur in future.

Warwickshire

During 1968 the branch grew in strength, not only in members (130 families) but also of programme and money raising efforts. Among the latter, £450 was raised at a garden party, which was increased by a donation of £100 from a local businessman and £400 by a bazaar. A dance and raffle of four autographed footballs by the cup semi-finalists raised £238. Jumble sales, wine and cheese, coffee mornings and various other dances have brought in sums from £25-£50 each. Two other major efforts in the autumn on behalf of the Association were made by Edgbaston Round Table who organised a Grand Ball at the Top Rank Suite Birmingham, and by the Birmingham and Midland Operatic Society who performed "The Quaker Girl" at the Birmingham Theatre for two weeks.

The educational side included talks by Dr. Varley, Consultant Psychiatrist, Mr. A. E. Tansley, Inspector for Special Education in Birmingham, Dr. A. L. Wolfe, Secretary of the Association for Research in Spina Bifida and Hydrocephalus and a Forum of Employment Officers from the Midlands on Youth Employment for the Handicapped.

The Children's Christmas Party was held on December 14, and all the presents were donated by a group of ladies from a local factory who had contributed weekly throughout the year.

A group of our children are at this time taking a course in typing and there will be more news later of the results of the rapid "Sight and Sound" Technique which should be important to parents of school leavers.

Wirral

A new project is a handicapped play group which has been set up in a local hall. This is providing much needed pre-school experience for lively minds. On November 30, a Christmas party was enjoyed by 100 members, friends and children.

Spina bifida boy Lee Gayson, aged 14, starts off Bromley branch's fund-raising walk

Young Samantha Eagle was determined that a hip operation would not prevent her from enjoying the fun at her local branch's Christmas party.

Her hips had been reset and Samantha was confined to lying on her stomach in a plaster cast which went up to her waist. Ingenuity came to her rescue and Samantha joined the other kiddies at the tea-table by lying on her stomach on an adjoining table.

It was the first party held by the North Hants, South Berks and West Surrey group. Verdict of Samantha and the other young guests: "Smashing".

The new editor

A paid editor is now taking over "Link" to ensure that the magazine appears on time.

Eventually it is hoped that "Link" will be expanded so that more issues are produced.

It is essential that local associations support the new editor by providing a steady flow of material because it will take some time for a stranger to our Association to find his feet. Without material the best editor in the world cannot produce a magazine.

Please continue sending material to Mr. H. L. Parsons, ASBAH, 112 City Road, London, EC1. Branch news should arrive by April 10. Other articles earlier.

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Twentieth Century Press (1912) Ltd., T.U., 8-13 New Inn St., E.C.2—R161