

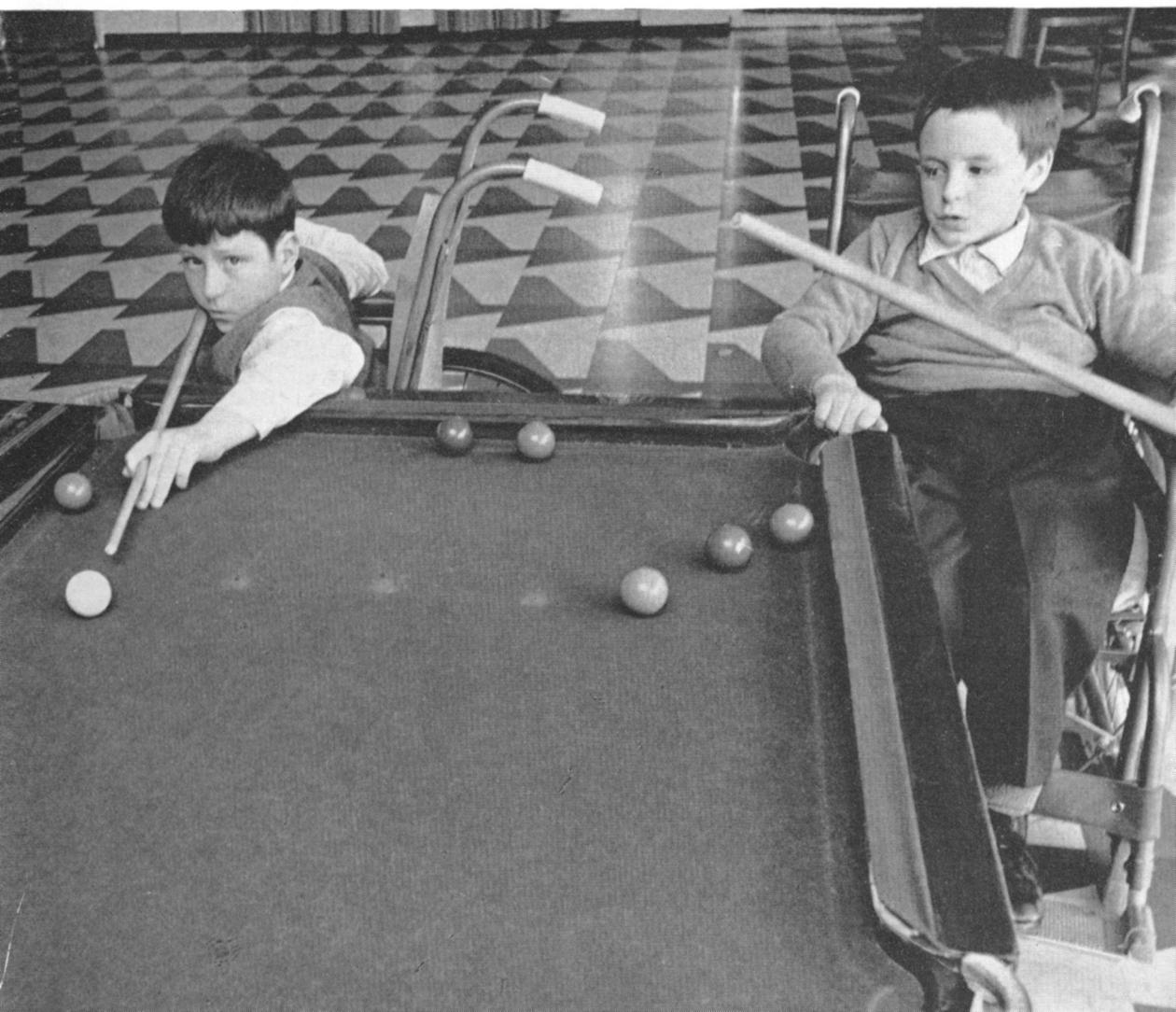
LINK



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

Christmas 1967

One Shilling



WOULD WE BE BLAMELESS?

Mrs. T. Sutton, of Rugby, told in our last issue of adopting a third child. Here she explains the reasons behind the decision she and her husband made.

We talked for hours before reaching the decision to adopt. My husband and I had always wanted three children.

Already we had a son, Adrian, born a few days after Christmas, 1962, and Jackie, our spina bifida daughter born two years later.

We still wanted a third child, but the birth of Jackie had added a complication—what would the child be like?

We waited for someone to say “Go ahead, you will be all right”, but no one would. All we were given were the statistics on the chances of giving birth to a second handicapped child.

I asked my doctor if an affected child could be detected early enough in pregnancy, thinking that with the new Abortion Bill then before Parliament I could have the pregnancy terminated if necessary. He said one could not tell early enough.

I then decided that we had no right to take the risk. There was the torture of waiting nine months with such a fear, not only for us, but for our families and friends who are also involved.

But the real risk is not ours. It is the child's we contemplated having. How can one knowingly risk having a handicapped child? How does one face a child and say, “We knew this might happen but we still gave birth to you”.

Jackie is paralysed from the waist down—another child might suffer a more severe handicap. With Jackie we had no idea. We had never even heard of spina bifida. We can look her straight in the face and say we are blameless except for some genetic fluke over which we had no control.

We would not be innocent a second time.

So our decision to adopt was for various reasons. Although we always wanted three children, we would not have persevered for ourselves alone.

But we felt we should for the sake of Jackie and Adrian. For Jackie it would be another brother to love and be loved by, and the knowledge in the future—please God she has one—that she did not restrict the size of our family.

For Adrian, someone to share his sister's love and a brother to love for his own self.

We felt, too, that if the worst happened he would have someone to share his grief. Most certainly Adrian's life will not be so empty when Jackie has to go away to school.

Our decision to adopt a boy was deliberate, too—so that Jackie will not feel so acutely her restrictions as she would with a sister only two years younger.

What of David himself? He is not just a child for the convenience of his brother and sister. He is our third child to share our love as the other two do.

He will grow up knowing the circumstances of his life and ours, and knowing that he is very much part of our family.

Adrian knows that David is being adopted. If we needed confirmation that we have done the right thing we had it the other day when he said: “David is very lucky to have a brother and sister ready made. I do hope we can keep him”.

This is the way we chose to solve our problem. The final judgement can only come from two people. Two adults. Jackie and David. We will do our utmost to make them both glad.

Toy offer

Members buying gifts for children might like to consider the range of ten toys offered by ASBAH. The toys—from the reliable ‘Pedigree’ range—are offered by post at normal prices and the profit will help the Association.

Prices range from 9s. 3d. (for a polythene racing car) to 45s. 3d. for a 6 ft. high wigwam with bamboo poles. There are several cuddly soft toys (teddy, panda, zebra, etc.) and a doll called Michele. Also featured is Dougall of ‘Magic Roundabout’ fame. There is a money-back guarantee.

For a brochure illustrating all these toys send a stamped addressed envelope (preferably 9" × 4") to ASBAH Toy Offer, 36 Craven Street, London W.C.2. Arrangements are being made to continue the offer after Christmas.

Our cover boys

With the eagle eye of a Joe Davis, the young snooker player on our cover prepares to “pot” the black under the critical gaze of his opponent.

Our picture—taken at Coney Hill School—demonstrates that relaxation is an important part of the curriculum there.

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Editorial: The chicken or the egg

With every month we take one step nearer to our campaign "launch date", and the next four months will be the most critical of all.

My postbag continues to confirm that the campaign is urgently needed, although not all groups are as yet fully supporting the programme.

Recent letters make startling reading for mid-20th century Britain. A newborn baby "wrapped in a sheet of newspaper and left in his cot", the parents not being told that anything was wrong. One of the foremost treatment centres reports that "the load on the nursing staff has become so great that we have had to stop all list admissions, however urgent, for at least the next three months, and possibly for the next twelve months".

One girl has been waiting a year to get into a suitable training centre, and another, having been trained, cannot get a suitable job. And so we go on.

Surely anyone not wholly for the campaign is not living with reality.

In some ways, the T.V. programme on October 31 was disappointing, but in other ways interesting and useful as a piece of interim publicity. Disappointing in that the doctor who

suggested death by starvation as an alternative to positive action was not criticised severely enough by the film producers.

Interesting because it highlighted the fact that the difference between positive action and lack of action depends entirely on which doctor happens to be in charge when the child is delivered.

So this is really where we came in.

We need publicity for our cause; to inform the public and to convert the doubters in the medical profession. We need money to promote the right kind of publicity and money in vast quantities to sponsor the medical and educational programmes which we know to be needed, but which are not forthcoming from public funds.

There is no doubt that we will not get these sums of money without ambitious national publicity.

Which comes first, the chicken or the egg? Publicity or money?

At this stage it is vital that we raise enough money to be able to afford the right kind of campaign—to ensure that there is sufficient money to tackle the urgent problems which confront us.

Taking their first steps

An orthopaedic surgeon devotes this article to spina bifida patients suffering paralysis of the lower limbs. He tells of the patience and training needed before they take their first steps.

In most cases where the use of the lower limbs is lost, the arms and upper part of the trunk are unaffected. Although the intelligence is impaired in some of these cases, in others it is perfectly normal.

The prognosis for life, for employment, is not yet known. What is known is that unless well supervised these children can quickly develop sores, urinary infection, contractures and deformities, and subsequently fractures near the stiff and deformed joints.

But having saved the lives of these children by new surgical techniques, it is up to us to see that they have every chance to enjoy an education commensurate with their capabilities. We must make the most of what is left to them.

Home tuition has frequently been their lot—and this often limited to only four hours a week. After abortive attempts to get them walking in calipers they have settled for a wheel chair existence, using their hands within the limits of their mobility.

Pioneer work by Stoke Mandeville and other paraplegic centres has shown the possibility of getting these patients walking.

Provided mental ability and the will to persist is there and that the correct techniques are used, much more mobility is possible than is usually allowed for these children. This is true, even where intelligence is much lower than normal.

It is essential however that the methods developed at these centres should be understood and applied persistently and correctly.

No use is served by fitting these youngsters with calipers and crutches then expecting them to develop walking skills in the same way as a child with polio, or one recovering from severe fractures of the lower limbs.

Much preliminary training is necessary before the child is even fitted with calipers.

A normal child begins to learn to walk the day it is born. All its reflex activity and development of movements are directed towards the production of balance. Head balance comes first, then sitting position balance, then standing balance.

Treatment of spina bifida babies should begin as soon as recovery from the operation to close the defect is complete.

An intelligent mother makes a good physio-therapist and can be instructed in the early stages of treatment. The upper limbs, upper part of the trunk and head and neck movements are normal in most cases—so their use should be encouraged as in a normal child.

All the joints in the paralysed limbs, too, should be put through a full range of movement twice daily, according to the therapists' instructions. Special attention should be paid to stretching any tight or spastic muscles to prevent them causing contractures and deformities.

It is important for a mother to know the developmental phases of a child's activities.



A youngster is helped to balance on one hand. Learning balance is an essential part of early training.

Although many of these cannot be achieved actively, the mother is shown how to put her child passively through the various movements while encouraging as much active movement as is possible as the child grows older.

The more movement a child is encouraged to make the more quickly will he develop the important balance reflexes. So the child is rolled from side to side, pulled up to sitting, nursed on his mother's knee, encouraged to lift his head from the prone position and encouraged to try and do everything a normal baby does. Under instruction from the therapist his mother moves the paralysed limbs.

And so the ground is prepared for the child's first steps on calipers. In the next issue I will discuss this and preparation of the child for schooling.

WHAT KIND OF SCHOOL?

Once a child is on the move, education becomes the next vital step. A teacher at an Ayr primary school—with three spina bifida children in her care—discusses the arguments for and against normal schooling.

First of all, I must say I am definitely in favour of spina bifida children attending a normal school from infant stage. However, there are several important points to consider. It is most definitely a great strain on the particular teacher concerned, especially if it is the first spina bifida child she has taught.

These children require a bit of individual attention which is quite a consideration with a class of over 40, but could be managed with around 35. They require more encouragement to work, and are often unwilling to try to write at first or do much written work.

We must, therefore, consider whether the child would be given a satisfactory scholastic education in such a class, as compared with the extra attention and experienced teaching he would receive in a school for handicapped children where the teacher would have more time to spend with him.

There would also be physiotherapy and other aids for physical education which has practically to be ignored at a normal school. There is also the building layout to be considered; for example, whether the school has stairs.

The children must also become much more aware of their physical disability within a normal

school curriculum. We are not, however, softening this blow if we delay it till adult life—indeed we are probably making it all the worse. The sooner the child learns to find a place for himself the better.

I have mentioned the main reasons against normal schooling and now I shall go on to give the reasons for it. The benefits to spina bifida children are as much indirect as direct. The teacher is given an insight into the condition. She will have a more relaxed approach without paying undue attention to physical disability. All the children grow up together and accept each other. There is little chance of embarrassment or misunderstanding with them in later life.

The more that is seen and understood of spina bifida by adults and children alike cannot fail to be beneficial to both. As a teacher myself, I am very grateful for having had the opportunity to teach a spina bifida child.

The benefit of the social education the children get is of course obvious. They are able to continue a normal home life—going to school every day and sharing family life at home at night. They are setting a place for themselves in society, just as the other children are adapting their play to include them—something children do quite naturally. It is usual to see the other children playing with crutches and wheelchair enviously.

Most difficult

The scholastic side is definitely the most difficult for a child and teacher. It is difficult for the young child to conserve his energy for this, as he is too busy learning to walk or play and often daydreams during lesson time.

It is also difficult for the teacher if the child has been spoiled at home and does not react favourably to firmness from the teacher. This can impose a great strain which is difficult to overcome. To help with these scholastic problems, I would advise parents to try not to forget the importance of giving the children plenty of experience of hand control—cutting, building toys, scribbling, painting. This will help with writing and concentration.

It is clear that there are difficulties in spina bifida children obtaining a normal education, but I am sure as we have more experience in teaching them we will find ways round the problems.

In our next issue we will publish a report on a different school—one that has a specially built-in spina bifida unit.

ABROAD — WITH A WHEELCHAIR

Thinking of taking your holidays abroad next year? It need not be the formidable task that it seems at first sight. Here, a mother tells how her family overcame the problems.

We have two daughters, Susan aged six who was born with spina bifida, and Gillian aged four who is perfectly normal. Susan can walk with the aid of callipers and crutches, and her legs are mobile but unable to carry her without buckling up. She has also had a successful operation for ileostomy. She is healthy and this year learned to climb up and down our open-tread staircase on her hands and knees.

Just after last Christmas, we decided we ought to do something about a summer holiday, bearing in mind the wheelchair, callipers, crutches and other special items we would need before we thought of ordinary luggage. This is how we set about it.

The South Hants Group, of which we are members, received a minibus from the Southampton Bonhome Society in October last year. Mr. Rae, our secretary, said that it would be available for members to use for personal outings and holidays this summer. We were told we could book the minibus for our holiday in August. Some friends then offered us the use of their large frame tent and all the necessary equipment for a camping holiday—something quite alien to us at that time.

Two essentials

As we now had transport and a “roof” over our heads all we had to do was decide on a suitable place to visit. With two essentials in mind—fresh air and sunshine—we decided to go to France. The spot we chose was just below the Loire Estuary on the Atlantic coast, which would not involve too much overland travelling. Moutiers-en-Retz, about 200 miles from Cherbourg, was our goal. We live at Cowplain, near Portsmouth, only 45 minutes from Southampton and the car ferry trip to Cherbourg is five hours.

We were then very busy, booking the ferry and the camp site plus, it seemed, a hundred and one other things. Mr. Rae gave us a great deal of assistance, and gradually everything worked out. Some friends of ours with no children became so enthusiastic that they decided to hire a tent and join us, which made things even more exciting.

After leaving Cherbourg, we travelled about 90 miles to Mont-St. Michel, where we pitched

tent for the first time. Susan and Gillian were quite warm and comfortable in their sleeping bags on the floor of the tent. They were happier like this than on the camp beds we had.

We travelled on to Moutiers on the second day and arrived at the site in the afternoon—it was called “Dolce Vita” and it was just what we were looking for. The camp had all mod. cons., including hot and cold showers, a shop, a bar, and we were just two minutes from a nice sandy beach. Once we were really settled in, we soon got the hang of things, and then the sun came out to stay, which made everything just right.

We had heard various tales about French toilets, so we took Susan’s potty chair with us, for which we were extremely grateful, even though the toilets were quite acceptable to the rest of us.

We wondered if the ileostomy would be a problem, but everything worked well and I changed the plaster only once while we were away. When we knew that we were staying on the beach all day or away from the tent for some time, Susan wore her night bag instead of her day bag, which, being larger, avoided any emptying problems.

By and large, we found camping hard work as the fresh air made us all very hungry, and we never seemed to stop cooking. We took all our own food with us and only bought essentials like milk, butter and bread. Fresh fruit and wine made a welcome change from food out of a can. Altogether we spent eight days lazing around in the sunshine.

Our sea trip home was quite smooth, and we arrived back at Southampton sporting the best sun tans that we have ever had.

Susan went into the Eye Hospital in Portsmouth a week afterwards to have her right eye straightened. This is now healing quickly and she is happily looking forward to being able to return to school, and tell everyone about her visit to France.

Having proved to ourselves that this sort of holiday is possible with Susan’s disability, we would love to go further afield next time, perhaps to Spain. We will have no more qualms about holidaying abroad.

Wanted—a home

Wanted: A home for an appealing, bright-eyed little boy with spina bifida. Unless this appeal is answered 10-week-old Paul Michael faces a future of emotional starvation.

Paul is illegitimate. And it was discovered that he had a spina bifida.

The young woman who gave birth to him could not accept this enormous burden without the support of a husband. There are few who would condemn her in making the decision which must tear any woman in two—to abandon her child.

Little Paul has grandparents who are willing to offer him a home—but welfare officials have decided that strength is almost as important as love in bringing up a child with this disability. They have reluctantly told the couple that they are too old to adopt their grandson.

So Paul is destined for a children's home—unless someone can find a place in their heart for him.

Surgeons are confident that his future prospects are good.

At St. Thomas's Hospital, London, they have performed what a parent of another spina bifida child describes as "a very neat back job". Surgeons took the added precaution of implanting a valve before he was in any danger from hydrocephalus, so there is no head enlargement.

Paul is recovering rapidly from his operations. There is movement in his tiny legs, although it is probable that he will be incontinent. He is strong, eating well and showing early signs of taking note of the world around him.

A home of his own would ensure that it is a world worth noticing. If any member or friend would like to adopt Paul will they please write to: Sister E. Spivey, 4 Duncombe Place, York. (York 23289.)

MISLEADING T.V.

Many of your readers may have seen the television broadcast and may have been upset by some shots and some remarks that were made. The broadcast gave the impression that children with hydrocephalus may grow to look like an 8 year old boy who was shown. In fact this is true, but the boy shown on the programme did not have any treatment for his hydrocephalus until a few weeks before the film was taken. That is the type of case that should never happen if correct treatment at the right time is carried out as it usually is these days.

The remark which may have worried parents was made by a paediatrician who implied that blindness is a common feature in hydrocephalus and it may come on very suddenly. Although it is undoubtedly an unfortunate truth that children may become blind as a result of hydrocephalus, this is commonly the case where the hydrocephalus has not had proper treatment at the right time, and again should be a very rare occurrence these days. It is also true that a blockage of the shunt occasionally could lead to sudden blindness, but it is also true that if the blockage is corrected speedily the eyesight returns completely. I have seen that many times myself.

J. Lorber.

Children's Corner

Dear Children,

No competition this time, but here are two things to try and make over the holidays.

The first one is a fir-cone animal. You will need a fir-cone, a packet of pipe-cleaners, paper and paint.

Paint a fir-cone a suitable colour. When the paint is dry twist a pipe cleaner round the cone's centre stalk about $\frac{1}{2}$ " from one end so that long 'legs' hang down. Do the same with a pipe cleaner $\frac{1}{2}$ " from the other end. Now you have four legs.

Right at the end of the cone, twist another pipe cleaner end so that the long piece sticks up this time; bend the top over. Stick paper over the 'head' and paint it. Stick the two 'feet' in plasticine and your animal is finished.

The second article is a pretty tile that can be used for a teapot stand. You will need an old tile or piece of smooth wood, some plasticine, some pretty shells, pebbles, beads or bottle tops.

Cover the tile with plasticine. Stick the shells or pebbles, etc., all over the plasticine without leaving any spaces in a nice pattern.

Cheerio for now, Faith.

LEARNING TO LIVE



We all have to learn to live. It's just that for some of us, some things take a little more time and a little more effort.

Take these two people from Coney Hill School, for example. Climbing into a car or getting up the stairs doesn't take much out of the majority of us. They are things we do scores of times a day without even thinking.

For these two people, it means frustration, patience and practice until they have the knack of overcoming their own special problems.

But at the end is the reward for all the efforts. The triumph at having succeeded in learning to live.



Our readers' column

What a lot of sound sense there is in Elsie Wilson's article in your excellent summer issue—"Kindness can be a handicap". I wonder, though, whether the Scottish public are so very different from people in the South.

Our daughter is nearly 13, and we find that her difficulties are made far worse by the cruel curiosity of passers-by, especially those of the older generation. She is inevitably the subject of the most rude and penetrating stares wherever she goes in her wheelchair, and one is unable to deal with the problem because the searching eyes are not diverted from her for an instant. One sometimes thinks one ought to have a handful of really rude leaflets ready to hand out as one walks along!

It is particularly distressing when the summer holiday is spoiled for the child, for the seaside promenade seems the worst place for this kind of misplaced curiosity.

I must add that there is no special reason for this, as our daughter is a perfectly normal-looking child, with no appearance of hydrocephalus or "spasticity".

Have other readers found this a problem and if so how have they coped with it? We really fear the teenage years, when girls are in any event self-conscious, and wonder what effect this may have on her development.

Perhaps ASBAH should produce some leaflets headed "Your curiosity will cost you a donation"!—*Ordinary Member* (name and address supplied).

Happy child

My little son who has spina bifida and hydrocephalus, and is aged 7, is attending Thieves Wood residential school, Mansfield, and has been there for about 18 months. It was very heart-breaking when we first left him at the school.

But after a few weeks John was very settled and happy. In those 18 months he has become a changed child, full of self-confidence and much more independent. The children have a devoted staff who give the handicapped child plenty of love and understanding.

If all residential schools are like the one John attends, Mrs. Sutton ("And then we were five"—last issue) need have no worries about her little girl. My husband and I have never seen such

happy children as during the past 18 months.—*Jean E. Brook (Mrs.), 14 Coppice Road, Worksop, Notts.*

A life to live

Mrs. Sutton asks, "What is it like to be disabled?" Depressing.

Being handicapped can cause much emotional worry through the knowledge of one's physical appearance and disabilities.

I have spina bifida, but have never had hydrocephalus, and at 22 I get around quite a lot under my own steam. My life is therefore as normal now as it is ever likely to be. I have a job and am learning to drive a Ministry of Health car. My artificial bladder operation was a success, and I have had little bother with it since. Bowels are controlled by pills, and I admit that, compared to some, I am very mobile and have little to fuss over.

However disabled you are, you still have a life to live. How will your child accept this when he gets older? Do you think he will try too hard to do things like a normal person, or perhaps not try at all because it is not worth the effort?

A disabled child is usually closer to his parents than he would be otherwise. Therefore, if the child is told by his parents the truth of what to expect from the world, rather than what he would like to expect, he will have a clearer version of the future.

It is important to decide as soon as possible the hobbies and interests which can be taken part in. In this way no boredom is experienced at the ages when other children are taking part in more active interests.

I went to a school for the disabled. I preferred this to being at a normal school. The education wasn't good, but even so I think I would have found it too frustrating competing with normal children.

But I do think it is most important for a disabled person to work with normal people. To be on the same level, working under the same conditions, and being accepted as the same is a great asset to me.

The future is a great problem. Why, for example, isn't there a disablement pension for cases like me?

Marriage is a thing most girls want. Is this possible? Many things have to be taken into consideration, but I think that if two disabled people get married it is more likely to be a success than if one is not disabled.

The best thing to remember is that you are human first, handicapped second. Accept the things that cannot be changed, change the things that can, and have the wisdom to know the difference.—*Miss Margaret Danter, 32 Award Road, Crookham, Aldershot, Hants.*

Some sort of pudding

I wish the national campaign every success. It will be a wonderful day when spina bifida is recognised as a handicap and receives understanding. When the words are mentioned now, one is given a blank, uncomprehending stare and asked: "Is it some new sort of pudding?" or something similar.—*Mary Floyd (Mrs.), 16 Dukes Wood Avenue, Gerrards Cross, Berks.*

The independent feeling

I am 17 and am paralysed from the waist down. Although I had a very happy school life, I feel that now things are beginning to happen to make life more worthwhile. For instance, I am learning to drive an "Invacar", which is really something different, and gives me a feeling of independence.

The only thing I am worried about is the fact that I have been waiting for a year now to hear whether I am going to a training centre to learn a trade. I must point out here that I discovered there are only three training centres in the whole of the country which take any kind of disability, and only one of these takes young people straight from school. This is the one I am supposed to be going to.

In spite of the problems, I think that on the whole I lead a happy life.

I think it is important for a handicapped person to get away from their family for one week in the year at least. You would be surprised what a difference it makes. So when your child gets older, and has the opportunity to go to a suitable place on holiday, do please let him go, because everyone enjoys themselves.

Also I think that all parents of young spina bifida children should remember that when the children are 17 there will most likely be many more opportunities than there are now—better education, better training facilities, etc. Once the period of operations and learning to walk is past I don't think things are all that difficult. It is really up to the individual.

Finally, is it possible for other teenage spina bifidas to write to me telling me their age, interests and other things. I would like to start a small pen-friend circle for those between say 11 and 20.—*Miss Susan Whiteley, 31 Lanshaw Terrace, Belle Isle, Leeds 10.*

Helping ourselves

To those who read the article in the Spring edition of *Link* about the Florence Treloar School, I am writing this for the benefit of parents whose children have to attend special schools.

I have been a member of the school at Alton, Hampshire, since its opening in September, 1965. I am 13 years old, and am at present in the first year of the 'O' level syllabus.

The main aim of the school is to give independence. Though there is a nursing staff, we are to do as many things as we can for ourselves. I myself have become much more independent, being able to bath myself, make my own bed, etc.

The dormitories are spacious so that wheelchairs can go in and out easily. These vary from six beds to single rooms, and here any personal belongings and clothes are kept. We have our own uniform, but for weekends we can wear our ordinary clothes.

A lot of the girls are in wheelchairs, but usually everyone is willing to lend a helping hand when we can.

The school is built mainly on a ground-floor level, but there are some dormitories upstairs, a lift being fitted. A lot of special aids are fitted; the baths, for example, have rails over the top so that girls can bath themselves.

All kinds of handicaps are found here, including a few spina bifida. I am a sufferer of spina bifida, my parents belonging to ASBAH.

We try all kinds of sports. We have our own heated swimming pool, and a great number of us are able to swim.

Also a great part is taken in social life. We have our own Guide company, societies, and, this term, our own orchestra. Some of us play instruments we thought we would never be able to play. I play the 'cello.

We go on many excursions to places I thought would be inaccessible to wheelchairs, such as the National Gallery, Longleat and Windsor Castle.

Altogether, it is a marvellous place, and parents whose daughters come here should have nothing to worry about.—*Karen Sellors.*

THE NATIONAL CAMPAIGN

March, 1968—this is the target date fixed for the launching of the national fund-raising and publicity campaign for Spina Bifida and Hydrocephalus.

A blueprint for the campaign has been drawn up by our consultants and full details were given in the November edition of *SB News*—the occasional bulletin issued in connection with the campaign project.

Special coverage will also be given to the campaign in the next issue of *Link*.

National fund-raising is restricted at present by the need to avoid “jumping the gun” on the campaign. But preliminary appeal to trusts has been mounted, and, with many still to make a decision, had brought in nearly £900 by the time we went to press. The campaign office made all arrangements for the Christmas draws being run by several associations, by organising them centrally we were able to secure first-class prizes (home movie kits and Colston dish-washers) and save on printing costs.

Useful progress

An advertisement for an appeals manager to implement the campaign plan will have appeared in the national press by the time you read this.

Although we shall not make our main onslaught on the mass media until nearer the launch of the campaign, some useful progress has already been made in the press relations field.

Articles on spina bifida were due to appear during November in two of the “quality dailies”. *Nursing Mirror*, *The Medical Officer*, *District Nursing* and *Midwife & Health Visitor* have all agreed to carry articles in the near future. Another feature was due to appear in the November issue of *Mother & Child*.

The news that ASBAH has established an office in London has been reported in numerous professional journals

A small ad was placed in the personal columns of the *Times* and *Daily Telegraph* to appear the morning after the BBC TV programme about spina bifida on October 31.



Here is a little girl who is doing her bit to ensure a rosy financial future for ASBAH. Anne Murphy, 8, is a model fund-raiser. She recently donned a flower-power dress and “hippy” bells for a Mexborough fashion show in aid of the Don and Dearne Association. Mannequin Anne, of Wath-on-Dearne, Yorks., is not spina bifida, but has spent half her life in hospital and recently had an ileostomy.

Three items of print are available on demand from the ASBAH office: (1) the introductory leaflet “Give Her a Life Worth Living”; (2) the toy offer brochure—take some to show your neighbours and friends at work; (3) a display card suitable for notice-boards in clinics and any places where it might be seen by parents.

The card explains why ASBAH has been formed and has space for a local address to be written.

Limited quantities of any of this material will be supplied free on request to Mrs. C. Whalley, ASBAH, 36 Craven Street, London WC2. For more than 50 copies of the general leaflet there is a charge of 14s. per 100.

News from the Groups

DEVON AND CORNWALL

In June, Mr. Sercome, handicapped persons officer to the Devon County Welfare Department, discussed various services which are available in this area for the handicapped. Facilities provided by local authorities vary throughout the country and, as they are generally not publicised, it is up to local groups to discover what is available in their areas.

Dr. David Owen, M.P. for Sutton, gave a challenging talk on government policy, stressing the need for an integrated approach with one department responsible for all provision for the disabled. Dr. Owen believed the Association's chief concern should be with the education of our children.

At Exeter an interesting experiment in absorbing children into the normal school structure is in progress. The City Health department have arranged for spina bifida children to be placed free of charge in selected sympathetic playgroups near their homes. Each playgroup has taken one child until the success of the scheme is determined.

Fund raising activities included sales of cards and pens. A St. Leger Draw organised by Mr. J. Behenna of Plymstock raised £71.

Members and children visited Paignton Zoo in September in a coach provided free by the Plymouth Friends of Disabled.

FLIXTON

The group organised a stand at the New Urmston Show, which was held in late August. Thanks go to all members, a local photographer, a signwriter friend, and local Rotary Club members, for making this possible. One volunteer made a Wishing Well, which collected £9. The tricycle shown on the cover of the Spring 1967 edition of *Link* was also on show, and about 700 of the latest A.S.B.A.H. leaflets were handed out. Although the original intention was for publicity, net profit on the day was about £30, and the stand was seen by the majority of 6,000 people who attended the show.

The group's latest venture was the third in a series of cheese and wine evenings, held in a member's

home, attended by about 60 people. A raffle was held and several bottles of wine auctioned, and the evening realised just over £33.

HUDDERSFIELD

A trip to Flamingo Park was organised for about 40 members and children on September 2. The staff of St. Luke's Hospital held two jumble sales on behalf of the group, raising £22 and £78. Mrs. Bowyer held a jumble sale at Paddock Church Hall, raising £19. Thanks go to the vicar for his co-operation. A donation of £100 was received from the proceeds of the Mayoress's Spring Fayre. A Toy Fayre has been arranged for November 25.

LEICESTER

Association member Mrs. P. Keeling's latest effort in aid of the Richard Fund was a sale of work and bring-and-buy sale, held at her home on November 9. Dr. Lorber gave a talk morning and afternoon, and over £190 was raised.

LEEDS & DISTRICT

Parents are now running this group themselves but are grateful to the "caretaker committee"—made up of staff and friends of the Potternewton Mansion School—who founded the group.

Membership is increasing and at present there are 30 spina bifida children on the books. Meetings are being held monthly at Mencap House, 142 Chapeltown Road, Leeds 7, by permission of the Leeds and District Society for Mentally Handicapped Children. A cash book and minute book were presented to the group with the compliments of the Leeds Haemophilia Society.

Mrs. K. M. Podesta, a member of the nursing staff of Potternewton Mansion School for Handicapped Children at Leeds gave a talk about the school and hints on caring for spina bifida children. The last meeting was attended by a neuro-surgeon, Mr. R. M. Gibson, and Dr. J. M. Littlewood of the Spina Bifida Clinic at the Leeds Infirmary.

A recent grand draw raised £50 and very successful coffee mornings have been held at the homes of members and friends.

SHEFFIELD

At the annual general meeting held in October the headmistress of Thieves Wood School for the physically handicapped, near Mansfield, gave an interesting talk and slide show. Mrs. Flowers held a Tupperware evening in aid of funds. A toy fayre is arranged for December 2.

SCOTLAND

Scotland has taken the bold step of no longer charging a membership fee for parents of spina bifida children or those suffering from spina bifida. It is hoped to balance this move by increasing the associate membership (associate members continue to pay 10s. per year, which entitles them to *Link*, Scottish chat-sheets and other literature).

The membership list continues to grow and the mailing list now numbers almost 550.

It is realised more and more that increased mobility, which means increased independence, is one of the greatest contributions parents can make to their children's lives and to this end parents are seeking to extend facilities for physiotherapy, occupational therapy, improvement of aids, etc.

There are now 11 groups functioning throughout Scotland, giving "new" parents an opportunity of meeting others in their own area, and resulting in increasingly improved facilities at local level.

SOUTH BERKS., NORTH HANTS. AND WEST SURREY

At the group's annual meeting, progress on the national campaign was outlined and the Secretary stressed the vital need for members to supply him with information about their children's education. This is essential for the statistical data which is being collected to form a basis for the national appeal.

A rally and fete at Queen Mary's Hospital for Children at Carshalton on July 1 was well attended by members of the group who heard a talk given by Mr. Zachary, the national chairman, on "Overcoming physical handicaps" and saw some of the equipment used at the

hospital. Members also had a chance to meet Mr. John Holter.

The Secretary gave details of this year's Christmas card arrangements. Last year, members sold over 9,000 and it is estimated that this will easily be exceeded this year.

Mr. Ivor Davies, who has been secretary since the group was formed, did not stand for re-election because of the pressure of work involved in being on four committees of the national executive. Members expressed their appreciation for the vast amount of work he and his wife have done for the Group, and similarly to Mrs. Worsell who retired as press secretary.

As a further fund raising effort a "stop watch" competition has been organised.

The committee and members expressed congratulations to Miss Rose Hibbard and Mr. Lawrence Chapman who were married on June 24, and presented them with a floor polisher. The happy event was reported in the *Observer* on June 25, and the newspaper loaned the couple their chauffeur-driven car to drive to the reception!

SOUTHAMPTON

The group report a steady flow of orders for the trolley which appeared in the Spring issue. The cost is £5 10s., plus postage; any enquiries should go to Mr. K. Charrett, 2 Marchwood Road, Southampton.

SOUTH HANTS.

For the first time, the directors of Bristol Zoo allowed a special block booking on May 21 for a joint venture by the Bristol and South Hants. groups. The expense of this outing was met from jumble sales in Southampton and Portsmouth, each raising over £20, while the Social Committee of the Motor Vessel *Halifax*—home port Bristol—generously provided finance. The children had free admission, box lunch, soft drinks and 1s. each to spend in the zoo. Various firms in Bristol donated towards the food.

Mr. Mabbott, with able support from members of his group, organised the arrangements and accepted a trolley as a memento of the

occasion. The 200 members thoroughly enjoyed their day and a lot of friends were made.

A return venture took place on September 17, when the Bristol group went to Southampton. Mr. Mortimer, ably supported, made the arrangements. An excellent buffet lunch was provided at the Shirley Warren Working Men's Club for the 150 members of the two groups.

After lunch, the *Southampton Belle* embarked the groups for a conducted tour round Southampton docks to see the great liners. Back on shore a visit to Southampton Zoo and a picnic on Southampton Common completed the day.

YORK

A garden fete was held in August and, despite pouring rain, the group managed to raise £70, due to the generosity and hard work of members and friends. The group are in close contact with their local health department, and have been pressing for adequate provision of education and other amenities for members.



The Bristol and South Hants groups at their joint outing.

NOTES FOR THE OLDER GROUP

By S. J. TEIDEMAN,
an adult spina bifida

A new minor relaxation in the £50 foreign travel limit made by the Treasury allows physically disabled people to apply to take extra money. But we are not told how disabled people are going to obtain this extra money.

The law as it now stands does not allow spina bifida sufferers and some others who are handicapped by congenital disabilities to obtain any pension to supplement any income they may be able to earn, often in competition with able-bodied people.

Professor Peter Townsend, Professor of Sociology at the University of Essex, as a result of a survey carried out in London, Essex and Middlesex, found that pensions and allowances were fixed without logic. Estimates were based not on need or circumstances but on the cause of the disability and other "irrelevant factors". Professor Townsend writes this in a booklet recently issued by the Greater London Association for the Disabled.

The law says, in effect, that if your disability has been caused by an accident at work, you may be entitled to a pension. If, through no fault of your own, you were disabled on the day you were born and, therefore, unable to work at all, you definitely cannot get a pension or allowance of any kind, however sunk in poverty you are, except through the Ministry of Social Security.

I have learned through experience how difficult it can be to obtain an even adequate amount.

Care and attention for spina bifida children and provision of facilities to help them when they

leave school and go out into the world to earn their own living are wonderfully improved from what they were only a few years ago, we can confidently look forward to even brighter conditions in the years ahead.

We can now be assured that spina bifida sufferers will more and more, in future, live and work as happily as the average able-bodied citizen and will do a job that is worth while alongside, not in competition with, those not so handicapped.

When they reach retiring age, most of them, I hope, will look forward to many years of serene old age. I believe parents of spina bifida children should take a long-term view of the future and start now to provide just that little something extra that may be the means of keeping their children in reasonable comfort in their later years.

One way of doing this is to give all the support they are able to the Disablement Income Group, DIG for short, whose aim is to secure adequate pensions and allowances for all who are disabled, regardless of the cause of the disability.

This association was started in 1965 by two housewives who are themselves disabled and it has now become a nation-wide organisation with more than thirty branches all over the country. The object is to secure payment of a national disability income with special allowances.

Only when Parliament introduces legislation along these lines will spina bifida sufferers be able to enjoy their old age on equal terms with able-bodied people.

News of the Older Group

Suddenly, I have been inundated with letters and the membership has risen from 8 to 22. This is very cheering and means that I have been able to send them all a list of members and put people in touch with others that share their problems. I am continuing to be in touch with all of them myself to keep the group together.

Many of the older ones are having, or have had, difficulty with finding employment and I feel that this must spur ASBAH on, not only to educate people to know about spina bifida, but to insist that our children are given a good education and real training.

We still have not found a suitable name. I object to Oldies as I still feel quite young!

The DDA are trying hard to get 2-seater cars for invalid car users. We are all most grateful for our invalid cars as they open out pastures otherwise unknown. Because of financial insecurity it is difficult and inadvisable to enter into the purchase of a private car which could be converted.

People in York keep asking me to join all manner of clubs and associations, which I am on the whole unable to do because I have

so many other commitments. However, I mention this because they are all very willing to help me and absorb me into their midst while making generous allowances for my disabilities.

This is worth remembering because many disabled people tend to stick to activities for the disabled, feeling that they will not be accepted elsewhere.

More members will be welcome. One refused to join because he wasn't a "do gooder". Ugh! I enjoy being in contact with others and gain far more than I give.

Faith Seward.

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