

Link

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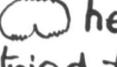
Association for Spina Bifida and Hydrocephalus (ASBAH)



A Royal
visitor

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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Link No. 30

Association for Spina Bifida & Hydrocephalus (ASBAH)

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Patron: HRH The Princess
Richard of Gloucester.

ASBAH Chairman:
Mr. R. B. Zachary, FRCS
Hon. Treasurer:
Mr. E. S. Gower, FCIS, FHA

Front cover: Four-year-old Julie Wells presents a posy to ASBAH'S Patron, Princess Richard of Gloucester during her visit to Woking playgroup. With her, from left to right, Julie's mother, Mrs. Janice Wells; Mrs. Jill McLaren, playgroup leader; Lady-in-waiting; Mrs. Michael Wigley and ASBAH Trustee Lady Jean Mackenzie. Report and pictures next page.
Photo: Surrey Advertiser

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Editorial

The beginning of a year is a good time to turn optimistically to the months ahead. It is often too easy to become bogged down with daily frustrations and worries and not to appreciate some of the wider developments taking place which may directly affect one's family in the future.

Research projects financed by ASBAH continue and contrary to what some people may think these do produce important results—see Dr. Lorber's article on page 6 on the encouraging advance in the early pre-natal diagnosis of a handicapped baby. This arises from a research project in Edinburgh.

There will be even greater choice this year for families wanting holidays thanks to the generosity of many people in buying holiday caravans and chalets for the use of Local Associations. And there will be further short-stay facilities to relieve some of the pressures on families.

There are also encouraging developments for the spina bifida teenager in the field of vocational assessment (see centre pages).

But it's no use pretending that everything is rosy. That would mean ignoring the very real difficulties encountered by those with spina bifida and their families. It would mean shutting one's eyes to those spina bifida teenagers who are more-or-less housebound and unlikely to experience the outside world, and their anxious and protective parents. It would mean forgetting the many families struggling alone, like those revealed in a recent study by the Department of Health and Social Security, the I.L.E.A. and G.L.C.—"The Need for Community Support". The report showed families struggling more or less on their own to cope with bad housing conditions and other stresses.

ASBAH and the Local Associations play a vital part in reaching out to such families and aware of this need, ASBAH has appointed a Senior Social Worker to develop the social work practice.

ASBAH and the Associations can also help by informing the professionals who meet the families—social workers, health visitors, doctors—on the subject of spina bifida and hydrocephalus. And there is an important role to be played in showing where useful developments can be instituted. A good example was the initiative of Greenwich branch of ASBAH who approached their M.O.H. suggesting that a specialist health visitor for spina bifida children be appointed. They pointed out that this was already being done successfully in another London Borough (Lewisham). Greenwich now has its own health visitor, too!

Dr. J. Lorber writes about the results of "the potato trial"—see page 7.



News from the groups

A Royal visitor

It was a marvellous start to Christmas for ASBAH when the Patron, Her Royal Highness, the Princess Richard of Gloucester, visited the National Office on 13 December and then went on to a playgroup run by a Local Association.

Her Royal Highness was accompanied by Lady-in-waiting, Mrs. Michael Wigley and she was received at the National Office by the Lady Jean Mackenzie, an ASBAH Trustee who presented Mr. R. I. Stubbs, vice-chairman of ASBAH. The chairman, Mr. Zachary is in India. The purpose of the visit was to meet the staff and there was an opportunity to talk over lunch.

This was the Princess's first visit since she became Patron in July and she showed how genuinely interested she is in ASBAH'S work.

After lunch the Princess left for Woking where she met parents and children at the pre-school playgroup run by Hampshire North, West Surrey and South Berkshire Association. The playgroup was started in 1968—one of the first for spina bifida children—and it is held two afternoons a week at the Rhoda McGraw Centre in Board Lane—a modern well-equipped centre.

There are 20 children on the register but due to colds and



Above, Rebecca Owens receives a helping hand from the Princess, accompanied by Mrs. Jill McLaren, playgroup leader.

Right, Princess Richard of Gloucester talks to Mrs. Ruth Moser, volunteer helper. Mrs. McLaren looks on and Caroline Vaughn gets on with the business of the day.

Photos: Surrey Advertiser



sickness some were absent. However, four-year-old Julie Wells was certainly there; she presented the Princess with a posy of flowers.

The Princess stayed for an hour which gave good opportunity for her to see the work at first hand and understand some of the problems. Afterwards everyone said how much they had been encouraged by her support.

In safe hands

Wirral. Trained nurses at Clatterbridge Hospital have offered to baby-sit free-of-charge for children of this Association. It is hoped that many parents will take up the offer. Some parents are naturally reluctant if the baby-sitter is not known to the children, and to overcome this it is hoped that the nurses will be able to meet the children at some of the regular meetings.



News from the groups

New York trip is success

Mr. and Mrs. Brian Neale of Harborne, Birmingham with their son Anthony who has spina bifida, pictured at the start of a buggy ride around Central Park, New York (right).

Mr. Neale tells us that the three week trip to New York was a great success.

"Anthony had no ill effects whatever from the trip, and did everything we did which included a fair amount of walking and sightseeing in very hot weather."

Travel insurance for Anthony, arranged through Norwich Union, cost about £10. Fortunately there was no need to make a claim.

After the holiday it was back to studying for Anthony who started his first term at Hereward College of Further Education in Coventry.

Mark of courage

North Hants, S. Berks, and W. Surrey: Sarah Corbey, who is spastic as well as spina bifida has made her parents very proud by being recommended for the Brownie Star of Merit, the Guides highest award for fortitude. Sarah is a pupil at Spraybridge, a special unit attached to Badshot Lea Primary School. Her father, Mr. Geoffrey Corbey writes: "Sarah has great plans for the future and I am sure that if personality and determination have anything to do with it, she will go quite a long way".

First-time success

Lincolnshire: New members can be a good way of bringing new life and new ideas to a Local Association, as Lincolnshire has discovered. A new member, Mrs. J. Saville suggested a money-raising event which this group hadn't attempted—a gymkhana. With a lot of planning and hard work a gymkhana and fete was organised, and raised the magnificent sum of more than £540.



News from here and there

Mayoress sets example

Even with a handicap you can take an active and important part in local life. Mrs. Alexia Pickering, for example, has spina bifida, and is Mayoress of Christchurch, New Zealand. Mrs. Pickering recently toured Britain by herself, and she found time to renew her city's bond of friendship with Christchurch, Hants, by a tour of the town.

Good news for theatregoers

Theatre-goers in the South will be delighted that the Yvonne Arnaud Theatre at Guildford, Surrey, now has a newly installed lift, and special toilet facilities, for the disabled. The lift—a tall, slender glass-fronted column—goes to the top floor circle and club-room of the theatre.

It was opened by famous entertainer, Michael Flanders, who has been campaigning for access to theatres and cinemas for the disabled for 25 years.

Underground: inside information

"A Guide to London's Underground Stations" is a new free booklet published by the Central Council for the Disabled. It has a complete list of London tube stations detailing the number of steps, the type of stairs, the availability of escalators or lifts and whether or not there are any footbridges.



An early warning

No one wishes more than parents that the cause or causes of spina bifida and anencephaly could be found. Unfortunately, we are little further in this than we were 20 years ago. The next best thing would be to detect during early pregnancy whether the baby a mother is carrying is affected by one of these disorders. In this field important advances have been made in the past 2 years

Evidence is being accumulated that a certain normal chemical substance, called alpha-fetoprotein, is present in excessive quantities in the fluid that surrounds the foetus in the womb if the infant has anencephaly or severe forms of spina bifida. Much more information is needed to find out whether milder cases of spina bifida can be detected this way.

A sample of this fluid can be easily obtained at about the 16th to 18th week of pregnancy which is the best time for such a test. This is done under local anaesthetic through the abdominal wall. The procedure, called amniocentesis, is painless and harmless and carries little or no risk of inducing abortion. There is no need to be admitted to hospital for this.

The fluid is then analysed and the result is available within a few days. Termination of the pregnancy can be carried out easily at this early stage if an abnormal result is found. So far many proven instances of anencephaly and spina bifida have been found, and I am not aware that any termination of pregnancy was done on false positive evidence, when the infant was normal.

We do not know yet what proportion of spina bifida babies can be detected by amniocentesis, and research is being conducted in many centres to find this out. The work started in Edinburgh, and a research project there is supported by ASBAH.

This technique, of course, is only used if an expectant mother already has an affected baby or if she has to have amniocentesis for other reasons. It is not likely to be used in those who have not had a previous affected infant or are not at special risk for other reasons.

The antenatal diagnosis of spina bifida and anencephaly by amniocentesis and ultrasound examination

by J. Lorber, M.D., F.R.C.P.

Nevertheless, it is the greatest comfort to those parents who already have had an affected baby and who wish to have other children. They can move confidently on to another pregnancy, knowing that although the odds of another baby having spina bifida or anencephaly again are about 6% to 8%, many at least of the worst affected can now be detected early enough in a pregnancy for it to be terminated without risk. There are now completely new methods of terminating pregnancy at this stage without an operation.

It is possible to check on the accuracy of the diagnosis of anencephaly by ultrasonic estimation of the size of the head of the foetus. In anencephaly the head is very small and this is a useful countercheck. Very recently exciting developments have been reported from Australia that this harmless technique may also be applicable to the diagnosis of spina bifida. Ultrasound examination is a rapid, painless procedure and gives immediate results, but at present it is still a research project and is not generally available.

The Potato Trial

Readers may remember all the publicity which was given to the theory that potato blight or something in potatoes might be the cause of spina bifida. It was suggested that if women did not eat potatoes or have any contact with them then as many as 98% of cases of spina bifida could be prevented.

They will also remember that I warned them at the time that there was no real evidence for the theory but that we could easily find out the truth by simple experiment.

As couples who already had a spina bifida child run a considerably greater risk of having another spina bifida or anencephalic baby we could quickly come to a result by observing the outcome of pregnancies in such couples where the mother would go entirely without potatoes as soon as she decided to have another baby and was not having any contraceptive measure. They had to understand that at the present state of knowledge the

risk of having another spina bifida baby was not necessarily less for not eating potatoes.

A good many mothers of spina bifida babies agreed to co-operate in this trial as from the beginning of 1973 and went without potatoes in any form. So far, the results of nine pregnancies are known: six resulted in the birth of normal babies, one was a miscarriage at 18 weeks (but the cause of this miscarriage is not known), and finally, one infant had hydrocephalus with spina bifida and another had anencephaly with spina bifida. So two out of the nine completed pregnancies resulted in an affected baby.

Consequently, one must conclude that spina bifida is not caused by potato blight, and that avoiding potatoes does not protect against spina bifida or anencephaly.

J. Lorber, M.D., F.R.C.P.



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,
46 Tillbrook Road, Regents Park, 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

As more and more teenagers with spina bifida and hydrocephalus come up to school-leaving age, greater attention is being focused on the need for more careful vocational assessment. A handicapped school-leaver needs to be given a better chance of further education, training, and employment at a standard and of a kind to suit him.

Some assessment is carried out by schools or educational psychologists and bodies like the local Careers Advisory Service may help with guidance. There are also a few centres to which doctors may refer school-leavers.

The Wolfson Centre in London is one. Set up by the Institute of Child Health it provides a comprehensive assessment of multi-handicapped children of all ages. Only a small part of its work concerns school-leavers. Assessment usually takes a day but may last a week and there are residential facilities for the young person and his family.

At the Children's Hospital, Sheffield, under the financial sponsorship of ASBAH, Mr. A. P. Lonton is running an assessment service for spina bifida children, some of whom are of school-leaving age.

Such assessments cover physical and learning abilities, social behaviours and intellectual achievement and potential, and may take the form of intelligence and aptitude tests. The work does not usually extend to the subsequent placement of the school-leaver.

But now there is to be a much fuller and more long-term assessment service for school-leavers in Surrey, based on recommendations of a Queen Elizabeth Foundation report, "Handicapped School Leavers". This is an exciting and courageous venture which, if successful, could unlock the door to a brighter future for multi-handicapped young adults.

A unique centre for physically handicapped school-leavers opens this month (January) at Banstead Place in Banstead, Surrey, run by Queen Elizabeth's Foundation for the Disabled.

It is a residential centre which will provide a total assessment of the student's abilities. It will also provide some further education, and be involved in the actual placement of the student—whether for training, further education, sheltered or open employment.

Mr. C. J. Hartley, the Principal said that concern had been mounting in the last few years about the "hotch-potch" inadequate assessment of handicapped school-leavers. Too often young people were "hawked around" from one unsuitable situation to another for several years because not enough care and consideration could be given to their future when they left school.

Banstead Place will take 32 multi-handicapped young people who have just left school, and those who may have left two or three years ago but have not yet settled successfully. Young people will be accepted if it is felt that they are likely to benefit from the programme.

The length of stay will depend on the individual needs and progress of the students, and could be anything from about three months to two years.

Students will be sponsored by their own local

Students,
parents,
teachers,
social
workers,
careers
officers
will
all
play
their
part



Education Authority and application forms would initially be sent in by careers officers. Students would then be asked to visit Banstead, to meet staff and students and generally get the feel of the place.

If the applications were successful they would move in, and initially start on a preliminary course of about four weeks to introduce them to the different aspects of the work at Banstead Place.

Mr. Hartley said that the full involvement of the student, his parents, teachers, social workers and careers officers would be vitally important

PLANNING FOR THE FUTURE



BANSTEAD PLACE

throughout. For this reason it is likely that the students will come from the South East of England, so that easy contact can be maintained.

After the four week introductory course, an individual programme will be worked out for each student.

"This will be formulated with full understanding on the part of the student and his family, and in close co-operation with the local authority and relevant government department" explained Mr. Hartley.

It will be an inter-disciplinary programme,

assessing the student's social behaviour, educational abilities, his psychological make-up and physical capabilities.

The carefully selected team at Banstead Place include teachers, a medical social worker, physiotherapist, occupational therapist, speech therapist, technical officer, recreation officer, as well as social workers, and medical and domestic staff.

But students won't be cloistered at Banstead Place. They will go out into the community as much possible, whether for further education—at Ewell Technical College or other appropriate educational facilities in the neighbourhood—for trial working periods in local factories and other work situations, or for social and recreational activities.

Mr. Hartley and his staff have already managed to build up a good relationship with the local community, and he said he was very pleased at the response from individuals and organisations.

The programme for each student will be constantly reviewed and adjusted, as he progresses to the point at which a decision can be made about his future.

Mr. Hartley said: "We at Banstead Place will be totally involved with the placement, and already we have made good contacts with as many relevant organisations as we can—those concerned with the training, further education and employment of the physically handicapped.

"They welcome the opportunity of receiving physically handicapped young people who have been properly assessed, and who will therefore be more than likely to fit in well to their organisation."

Banstead Place, a beautiful Queen Anne House with modern additions, was until last summer a Medical Rehabilitation Centre run by the Queen Elizabeth Foundation.

Mr. Hartley said that although Banstead Place will mainly serve the South East, he was hopeful that if it proved worthwhile the work could be carried out at other similar centres to cover the whole country.

For further information on the work at Banstead Place write to Mr. C. J. Hartley, Principal, Banstead Place, Park Road, Banstead, Surrey, SM7 3EE. Tel.: Burgh Heath 56222, or 51756.



Letters

Baby bouncers: good or bad?

In a recent article in Link, Ann Grimley, MCSP, SRP, speaks of the use of a baby bouncer in treatment. Yet, only a few weeks ago on radio, a doctor stated that the use of baby bouncers could cause permanent brain damage to babies and should never be used, even on healthy children. Your comments, please.

**Mr. D. C. Bywater,
Gloucester.**

Editor's note: This isn't an easy one to answer, because there is a difference of opinion amongst the medical profession on the question of the value of baby bouncers. But if used sensibly and in moderation they are unlikely to cause any damage.

Miss Felicity Birkett, ASBAH's Appliance Officer, does not advise parents to go out of their way to buy a baby bouncer. If you want to borrow one from a friend to try it out on your child, all well and good. But many children do not like them at all.

If used for short periods of about 20 minutes, they can provide some exercise for the child, and put him in the upright position.

Don't leave the child for long periods (over half an hour). Don't use for a severely hydrocephalic or spina bifida child. Miss Birkett wouldn't advise using a bouncer for a child under one year.

Use and abuse of chalets

Many Associations now own holiday accommodation and a great number of Association members are able to have reasonably priced holidays with few or no problems, so please may I make a request to treat this accommodation as you would a 5-star hotel. If our accommodation is anything to go by it is being sadly neglected by those who use it.

There are no chambermaids to do the cleaning, we each have to do it for the next family, and yet we have people moving in to stale rotten food,

Holidays are just around the corner! Don't forget to book up and make plans for your summer holidays as early as possible. If you want advice or help for whatever kind of holiday contact Mr. H. D. Macfarlane, ASBAH's Liaison Officer at the National Office.

Several families went abroad last year and took advantage of ASBAH's contact with an insurance company in arranging foreign travel insurance.

ASBAH has been so glad to hear that families got on well, and that fortunately no one had to make a claim. This should help very much with further applications for cover.

unflushed toilets, unswept floors, and although we have rubber sheets for all beds, one of the mattresses has been wet so many times it has gone mildewed.

People neglect to hand in the chalet keys at the office on leaving, consequently the next user cannot get in so the site management have to break in, replace the lock, and then we have a bill—so unnecessary. Sometimes people go out and lock the chalet leaving the key inside—another lock, another bill.

Please treat the accommodation as you would the Ritz or Hilton . . . all we want is for everyone to have a good time.

**June Davies, Hon. Sec.,
Staffordshire ASBAH.**

Editor's note: I think Staffordshire have been particularly unlucky. Most Associations seem very happy with their holiday tenants.

Spring Conference

5-7 April, 1974. York University.

ASBAH hopes to see Local Associations well represented at this year's Conference which will feature everything to do with the physical side of living—homes, houses, adaptations, etc.

It will give great scope for hearing both from professional people and from families with ideas that really work, and there will be plenty of opportunity for discussion.

The opening speaker will be Dr. G. G. Browning, Regional Consultant in Physical Medicine who is coming to us from Glasgow. We will also be welcoming as another speaker, Mr. H. Thacker, at present Director of Social Services for Leicester. And there will be a Symposium of members of Local Associations with useful experience to share.

Due to generally increased costs and VAT the Conference fee has had to be raised this year to £10, but we think you will consider this good value for money.

Detailed programmes from National Office.



Family page

Mr. Danny Elliott, Chairman of South Hants Local Association, writes about a successful trip aboard

The good ship "Sparkle"

One August morning a small party of children, young adults and parents from the South Hants Association set out for Birdham yacht basin in Chichester, bound for the handsome catamaran "Sparkle".

She is provided for the use of handicapped people by SPARKS—"Sportsmen Pledged to Aid Research into Crippling Diseases". She is an excellent 45ft vessel, specially designed with large flat decks and can take 10 wheelchairs. She is very stable with a powerful engine and two large lugsails for easy sailing. Handicapped passengers can participate in the sailing of "Sparkle" and thus begin to learn how to sail.

We were able to park our minibus right against the gangway down to the jetty where "Sparkle" lay. Skipper John Turnbull and his "mate" greeted us, and the gangplank was lowered. This was two iron rails which could be adjusted to wheel track width or foot width—simple but efficient.

Once on board it was time to cast off. The skipper hauled in the gangplank, closed the rails around the side and started the engine. The mooring lines were slipped and "Sparkle" moved out into the channel.

It took only a few minutes to reach the lock between the basin and the outer channel of Chichester harbour. "Sparkle" moved in behind the five boats



already waiting inside the lock. After the gates were closed and the sluices opened, the water flooded in the boats in the lock rose to the level of the outside channel.

The little fleet moved out, and soon the skipper opened the throttle and we felt the benefit of the powerful engine. The morning was really ideal—bright and sunny—and everyone settled down to quietly enjoy the long run down the channel into Emsworth Harbour and then out into the Solent.

Out into open waters, the skipper eased back on the throttle and left the wheel. "Sparkle" is fitted with an auto direction self-steering gear allowing the crew absolute freedom. The skipper unashed the sails and hoisted them with help from 10-year-old Danny and Richard (21) in their wheelchairs.

The skipper cut the engine and all was quiet, and he brought out fishing rods and

hand lines.

At first we thought the fish had gone home, and then young Michael yelled out and started hauling in the line, fumbling with the unfamiliar equipment. Seconds later a flapping splashy mackerel lay in the bucket. Then came another and another and in all 11 fish were caught before we re-entered Emsworth Harbour.

On the way up to the lock the skipper lowered the sails and hustled along under power to keep in front of the tide. This time inside the lock the boats were lowered to the level of the basin, and people lining the banks waved to us. The whole atmosphere was one of enjoyment, and the children were sad when their sail was over.



Danny Elliott and Richard Jewel of the S. Hants Association on board "Sparkle".

Where will "Sparkle" be this year? See next page.



Appeals and publicity

By the time you read this Christmas will have come and gone and I hope for you all that it brought happiness and some degree of contentment. Let us hope that 1974 will be a brighter year in every respect than 1973.

A welcome visit

One Friday morning, when the newspapers were full of gloom and it was cold and raining, and the photocopier had gone wrong, and so on into my office walked a family of father, mother and two boys with a cheque for £225 for ASBAH funds. They had raised this by organising a sponsored swim on the RAF station in Germany where father is stationed. They were home on leave but stopped off on their way to Plymouth to hand over the cheque. I felt ashamed of myself for having been depressed! This splendid effort, undertaken by four swimmers, arose quite spontaneously from

father having seen a medical film about spina bifida four years ago, and he had remembered.

Radio Appeal

So far, 1,000 people have replied to Larry Grayson's Radio Appeal for the provision of Short Stay Care, and the total received is more than £2,500. We were very touched by some of the gifts, obviously representing considerable sacrifice. Many letters came from old age pensioners.

Any ideas?

We are always casting around for new ideas on how to raise money, and if any Link readers come up with a brainwave I shall

be grateful to hear about it. I find that people in general are sympathetic when approached, but the means of getting to them are not always easy. I would like to think up special approaches to specific groups of people like fishermen, gardeners, cricketers, carpenters, candlestick makers, and so on. Any ideas?

One day workshops

Ideas were on the menu when we held a Workshop at Devonshire Street House at the end of October. Representatives from 36 Local Associations attended, and we had a good talk about publicity and fund-raising.

The Workshop itself was voted a good idea and there was a request for further meetings on other subjects of concern,

Kate White

"Sparkle"

The catamaran "Sparkle" will operate from these resorts in 1974.

Kingston-on-Thames. May 1-31 (not Sats. and Suns.). Apply to: Capt. G. E. Welch, Central Council for the Disabled, 34 Eccleston Sq., London SW1.

Poole. June 12-30, Sept. 4-30 (not Mons. and Tues.). R. W. Davies-Taylor, 4 Marina Drive, Lilliput, Poole, Hants.

Chichester. July 6-Aug. 15 (not Sats. and Suns.). A. H. James, Social Services Dept., Wren House, County Hall, Chichester, Sx.

Newhaven. Aug. 19-30 (not Sats. and Suns.). K. E. Godley, East Sussex Assoc. for the Disabled, St. Wilfrid's, 143 High St., Lewes, Sx.

Sparkle can take 10 people in wheelchairs, 3 ambulant and two able-bodied. Individuals can join up with a group. No physically handicapped children under 9. Trips are free, but donations to the SPARKS fund are welcome.

Senior Social Worker

MEET MR PETER POOLE, who has joined ASBAH as Senior Social Worker in order to develop the social work practice among families with spina bifida and hydrocephalic children.

Mr Poole has more than 20 years' experience of nursing, welfare and social work, and holds a Certificate in Community Care and a Certificate in Social Work from London University. In recent years he has been particularly involved in work with the physically handicapped as a social worker with the Royal Borough of Kensington and Chelsea.

Mr Poole, who is married with two children, lives in New Malden, Surrey.

He will be concerned with some cases himself, and will be co-operating in an advisory capacity with the social workers serving various Local Associations. He welcomes the opportunity of meeting Local Associations and in discussing the value of social work and its development.

Graduate Anne Walker tells how she managed to combine a career with a happy family life after the birth of her spina bifida son

"I've forgotten how to brood"

There was one thing I was determined about when Colin was born—that I wouldn't let a spina bifida child interfere with my life!

This didn't mean that I wouldn't do everything humanly possible to help him; but that I wouldn't let his handicap force me into oblivion.

Easier said than done, though. Guilt and doubts, the daily drudgery and hopeless despair were my constant companions. Could I ever love this child—he that had replaced my beautiful little girl who had died the year before?

Here was I with a degree in electrical engineering, progressing well with my sport, gliding, but seeing ahead only blackness and despair and the loss of everything I had striven for.

Caravan home

Three years ago when Colin was 18 months and Philip, his brother, 4 years, we lived in Leeds in a little semi-detached. Then my husband changed his job and took one in East Anglia, leaving me behind with all the settling up and selling the house etc. I soon put the furniture into store, got a caravan, hooked it up behind the car and set off with Philip and Colin for the wilds of East Anglia.

Little did I know that the van was to be our home for the next 4½ months of the winter of 1970/1. It was only 15ft long and we placed it on a "transit" site. Still, we managed, and eventually found our dream home.

For the following year I was content to home-make, get Colin settled into the routine of playgroup and hospital etc. and tackle the house wiring (my job!) and our vast garden.

But I still had time to brood. I saw my career slipping away as technology outstripped my knowledge.

After a particularly bad bout of depression I decided to get a "mother's help" or nanny for the children, then find a job.

I advertised for about a month and eventually a girl called Sandra came to live with us. She only came from the next village!

Sandra now happily looks after Colin, and he's very fond of her. The two of them take a hospital car once a week for physiotherapy and Colin goes



The Walker family of Bury St. Edmunds. From left to right, Colin, Mr. Walker, Philip and Mrs. Anne Walker. Photo: Bury Free Press.

with a neighbour to the handicapped children's playgroup.

I found an extremely interesting job three days a week in Newmarket, 20 miles away. The work is very absorbing and deals with microcircuits. I'm afraid I never mentioned Colin's handicap to my employers. I was too afraid that I wouldn't get the job. (Actually Colin is the healthiest child I know and I've never had a day off due to his being ill.)

A helping hand

Big brother, Philip, is remarkable with his kindness to Colin, and is a great source of strength to me. He helps with jobs like laying the table, washing up etc. and comes and comforts me if I get depressed.

Colin will be going to the local school, soon, in his wheelchair, and Sandra will, of course, be staying. Her role is very important. One of her jobs will be to change Colin at school at lunch-time.

From the day Sandra came to us I've never been happier and Colin never more loved.

Sandra loves her work too, I'm assured, and we do everything we can to make her life interesting. I've now forgotten how to brood. We tackle Colin's problems with enthusiasm. **Continued**



Aids and equipment

Miss Felicity Birkett joined ASBAH at headquarters in September as Appliance Officer, to succeed Mrs. Olwen Nettles.

Miss Birkett is already known to some readers of Link because of her work as Superintendent Physiotherapist at Tadworth Court, the country branch of Great Ormond Street Hospital. She was there for four years working with children in the spina bifida unit, and before that was at Great Ormond Street itself for two years.

Miss Birkett will be travelling around meeting local groups and keeping them in touch with equipment and appliances and will be writing in Link.

If you have any problems or useful ideas, please write to Miss Birkett at the National Office.

Continued

Oh—and I never gave up gliding. We take Philip and Colin to the airfield with us, come rain or shine.

So my message is: "Get help. Work to pay for it, and see if you can get the Attendance Allowance".

There are girls like Sandra who would like to care for children like Colin. But do they get the chance? We need an employment agency. We need to get careers teachers to suggest being a nanny as a worthwhile job, especially for a handicapped child.

You have to be really determined, but remember it is possible to get back your life and sanity.

Anne Walker,

Kanga Pants

The Springwood Cellulose Co. Ltd., who manufacture Kanga Incontinence Pants, are now marketing a side-opening version. The great advantage of these is that they can be changed without removing calipers. By using Velcro fasteners of two different widths, 2 inches of adjustment is available at each side. But be sure to fasten the Velcro before washing the pants, otherwise you will find them sticking to the rest of the washing. They are available from Home Nursing Supplies Ltd., P.O. Box W4, Westbury, Wilts., in sizes ranging from 18 in. waist to 60 in. hip. They are rather expensive at £1.80 a pair for the smallest size, but they should wear well provided they are not boiled. Please write to me for any further information.

Sweet smelling change!

If you have odour problems with nappies, pants, urinary appliances or diversion bags you may be interested to know that there are two good "odour control liquids" on the market.

- (1) Nilodor which is available from Nilodor Co., Daniel Street, Oldham, Lancs.
- (2) Chironair from Down Bros. and Mayer Phelps Limited, Church Path, Mitcham, Surrey.

Both retail at 0.30-0.35 p for a 4-oz. bottle.

You can put a few drops into a diversion bag or other urinary appliance before fitting it or add a few drops to the water when rinsing nappies and pants to give a "sweet smelling change".

Safety bath mats

Mothercare market safety bath mats in two sizes, viz. 17in by 10in at 40p and 22in by 14in at 70p. These are made in soft rubber with a non-slip textured surface and have specially designed suckers on the underside to adhere to the bath. They can be used on any slippery surface such as the car seat or a kitchen chair. They serve two purposes. (1) They prevent your child slipping, and (2) they prevent calipers scratching the furniture—especially useful when visiting friends.

Cot bumpers

These are a good safety precaution; tied on to the inside of the cot bars, they prevent your child sticking his legs out through the bars, in which position he could break his leg, especially if he has just come out of plaster. The bumpers are made of foam covered with a waterproof, easily cleaned material. They cost £1.55 each from Mothercare. Two will surround the whole cot.

Felicity Birkett

ASBAH publications and publicity

<i>Your Child with Spina Bifida</i> by Dr. J. Lorber, MD, FRCP	15p*
<i>Your Child with Hydrocephalus</i> by Dr. J. Lorber, MD, FRCP	15p*
<i>Equipment & Aids to Mobility</i> by O. R. Nettles, MCSP, ONC. A folder of four booklets	complete set 25p*
<i>Clothing for the Spina Bifida Child</i> by Barbara Webster, SRN, RSCN	15p*
General information leaflets	100 for £1
Laflet for young people	100 for £1

Scottish Spina Bifida Association booklets

<i>The Spina Bifida Baby</i> by O. R. Nettles, MCSP, ONC	10p
<i>Growing Up with Spina Bifida</i> by O. R. Nettles, MCSP, ONC	20p

All available from: ASBAH, Devonshire Street House, 30 Devonshire Street, London W1N 2EB. (*Special rates available to Local Associations.) Bulk orders of Scottish Association booklets to: The Scottish Spina Bifida Assn., 7 South East Circus Place, Edinburgh EH3 6TJ (at special rates).

Postage on all items is extra outside the UK.

Films

The first four films may be hired from Concord Films Council, Nacton, Ipswich, Suffolk. Enquiries about purchasing these four to ASBAH.

What is Spina Bifida? Black/white, 16 mm, 25 minutes. Shows the early treatment of a baby born with spina bifida and hydrocephalus, and the involvement of parents. Hire: £2.

A New Lease of Life. Colour, 8 mm, 25 minutes. This film, made by a parent, shows by a series of animated drawings the nature of the spinal lesions and refers to treatment. Hire: £2.

Like Ordinary Children. Colour, 16 mm, 30 minutes. Two teenage girls describe their disability and their feelings about integration into society. The attitude of girls from a local school to those with handicaps is also shown. Hire: £4.

Growing Together. Colour, 16 mm, sound, 40 minutes. This film is about education and the choices of day school available to spina bifida children. Discussion topics to accompany this film are being prepared. Hire: £4.

What Shall We Do Tomorrow? Colour, 16 mm, 22 minutes. It deals with the problems and achievements of spina bifida youngsters, with comments from parents and teachers. It shows, too, some local money-raising events. The film was made for Mansfield & Worksop Local Association. Enquiries to: The Secretary, Mrs. E. Freeman, 23 Melbourne Street, Mansfield Woodhouse, Notts. Tel.: Mansfield 26860. Hire: £3 plus carriage and compensation.

Posters. Double Crown, 5p each, "Future Bright", 10 for 20p.
Flag Day emblems. 1,000 for 50p.
Cards for notice boards. 10 for 10p.
Car stickers. 5p each. Postage extra.
Fund-raising items. Price list/details on request.

Local Association offers

Badges. Silver and green enamel with pin fastening. Replica of the Spina Bifida emblem. Bulk orders are welcomed particularly. Price: 22p per badge. Postage extra. (For a single badge please enclose s.a.e.) Apply to: Mr. K. McKenzie, Badges Secretary, Salisbury & District ASBAH, 111 East Gomeldon Road, Gomeldon, Salisbury SP4 6LZ.

Badges for children. Good quality 1½in diam. SB symbol and the words, "Spina Bifida Children" in black on green background. Price: 25 badges for 75p; 50 for £1.40; 100 for £2.65, including postage. Cheques and postal orders crossed and payable to "SASBAH". Send with order to: Mrs. I. Olditch, High Lea, Turners Green Lane, Wadhurst, Sussex.

Ties. Heavy weave washable terylene with SB symbol on dark blue or dark green. Sold by N. Hants, S. Berks and W. Surrey ASBAH. Price: £1 each. Cash with order to Mr. B. High, 10 Woodruff Ave., Burpham, Guildford, Surrey. Please state colour choice.

Inter-association holiday opportunities

Camber Sands, nr. Rye, Sussex. New, well-equipped chalet, in pleasant situation near the sea available for families with spina bifida members. Sleeps six. Please apply to Mr. S. Evans, 1 Coniston Gardens, Wembley, Middx. 01-904 7840.

Cleethorpes. Three-bedroom bungalow to accommodate 6-8 persons at Humberston Fitties, nr. Cleethorpes, Lincs. Further information from Mrs. W. Steele, 59 Louth Road, Holton-le-Clay, Grimsby.

Great Yarmouth. Self-contained 6-berth caravan at Caister Beach Caravan Camp, nr. Gt. Yarmouth. Details from Mrs. N. E. Barefoot, 23 Marlborough Road, Southall, Middx. 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 at 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, Lincs. Apply to Mr. Ken Hall, 17 Walhouse Street, Cannock, Staffs.

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

New Forest. Well-equipped chalet, sleeping six people. 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, Horsham, Sx.

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