

Link

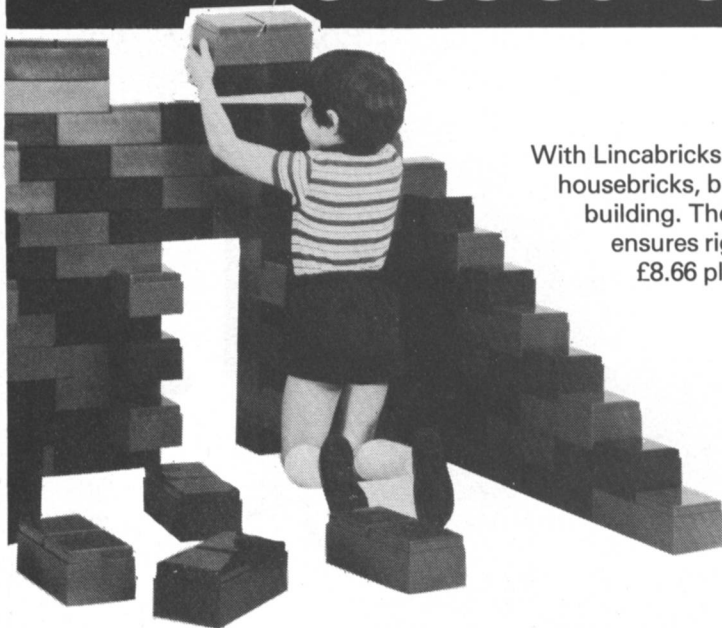
47

NOV/DEC 1976 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)



GALT EARLY STAGES makes sense of play



With Lincabricks—the same size as standard housebricks, but lighter, adds realism to building. The positive interlocking system ensures rigidity. (N0062K) per set of 24, £8.66 plus VAT.

Write for your free copy of Galt Early Stages Catalogue to: James Galt & Co. Ltd., Homes Sales Division, PO Box 10, CHEADLE, Cheshire. 061-428 8511.

Mobility for the disabled



Get out and about.
Range - up to 12 miles.
Just plug in for overnight battery charging.
No licence required.
Climbs kerbs and steep gradients.
Weather equipment and road lighting available.



Send for free folder and demonstration details

Braune of Stroud, Griffin Mill, Thrupp, Stroud, Gloucestershire GL52AZ.

Telephone 045-388 2243.

Name

Address



Link No. 47

**Association for Spina Bifida
& Hydrocephalus (ASBAH)**

Patron:
HRH The
Duchess of Gloucester

Chairman:

Prof. R. B. Zachary, FRCS

Hon. Treasurer:

Mr. E. S. Gower, FICS, FHA

**Correspondence to ASBAH
at the National Office:**

**30 Devonshire Street,
London W1N 2EB**

**Tel: 01-486 6100 or
01-935 9060**

General Secretary:

Miss M. E. Oughtred

Appeals Secretary:

Mrs. Kate White

Liaison Officer:

Mr. H. D. Macfarlane

Link Editor:

Mrs. Susan Gearing

Contents

pages

- 4/5 **News from all around**
- 6/7 **Research Society
Conference (Berne)**
- 8/9 **Annual Report and
Meeting**
- 10 **ASBAH's social work**
- 11/12 **'The disabled as others
see us', by William Bee**
- 13 **Appeals**



The Duchess of Gloucester, accompanied by the Lady Jean Mackenzie, talks to Ailsa Campbell Mackellar (left) and Stephanie Wright who were both staying at Five Oaks for half term. Photo: The Yorkshire Post.

Duchess opens Five Oaks

Tuesday, 26th October, was another Red Letter day in the life of the Association as the day when Five Oaks, Ben Rhydding, was officially opened by our caring and gracious Patron, Her Royal Highness the Duchess of Gloucester.

Over 150 guests representing organisations whose generosity had made the Home possible, together with people who had been concerned in the venture in many ways, including the Architect, Mr. Wycliffe Noble—together with children in residence and staff—welcomed the Duchess, accompanied by the Lord Lieutenant, Brigadier Kenneth Hargreaves and Mrs. Hargreaves and the Lord Mayor and Lady Mayoress of Bradford and the Lady-in-Waiting, Miss Jennifer Thompson.

After luncheon, the Lady Jean Mackenzie presided at the short Opening Ceremony. The Vicar of Ben Rhydding offered a prayer of dedication and Her Royal Highness then spoke of her interest in the Home and how she had followed the progress of purchase and adaptation, and rejoiced to be present officially to declare it open. It had been like planting an acorn and seeing it grow into an oak tree—this time, Five Oaks! Her Royal Highness then unveiled a plaque commemorating the opening. Stephanie Wright, who stayed at the Home in the Summer and was again in residence for half-term, presented the Duchess with a delicate bouquet of flowers, and Professor Zachary expressed thanks to everyone for their support, and especially to the Duchess for her presence and for opening the Home with such sincerity and charm.

The Royal Party then toured the House and met children & staff and studied the special features which had been incorporated to make the house suitable to the special needs of its visitors. This included, among other things, a special bathroom unit designed by the Royal College of Art.



News from all around

Duke (the pony) is a present

Four-year-old Celest Allenby stroking Duke, the pony who was recently given to the Hampshire South Association by customers of the George and Dragon pub at Cosham, Hants.

Spina bifida youngsters in the area are now able to enjoy the pleasure of riding Duke at the Wickham stable. He has already had more than a year's experience working with handicapped children.

Customers of the George and Dragon undertook many different fund-raising schemes to raise £700 for Duke, and £500 towards the completion of the Association's holiday chalet in the New Forest.

Photo: Portsmouth News.

Three Golds for Carol

It has been a very active summer for Carol Smith of Marlow, Bucks—and activity that has brought her real reward in the form of three Gold Medals.

Carol, 17, who has spina bifida and is a member of the Windsor and Maidenhead District Sports Association for the Disabled, won a Gold for table tennis at the Surrey branch games of the British Sports Association for the Disabled (BSAD) at Guildford, and a Gold for the 60 metre wheelchair dash while competing at Stoke Mandeville against members of the British team going to the Toronto National Paraplegic Games. She won yet another Gold Medal—also for the wheelchair dash—at the BSAD National Games. Many congratulations Carol.

Front Cover

Father Christmas visits a local association Christmas party—a happy scene that will soon be repeated up and down the country this festive season.

Link wishes all its readers a very merry Christmas and a happy New Year.



Sunderland's visits

Sunderland Association has had two interesting outings recently. A visit was arranged to Sheffield Children's Hospital, where they were given an account of the work of the Congenital Anomalies Research Unit. There was also time for an informative question and answer session with Dr Lorber. The other outing, which was entirely different was to HMS Arrow where parents and children were given a film show, a conducted tour of the ship and each child received a small gift to take home. The crew were on hand to help with negotiating the steep stairs. Altogether it was a very enjoyable day with this ship's company who have proved such good friends.



News from all around

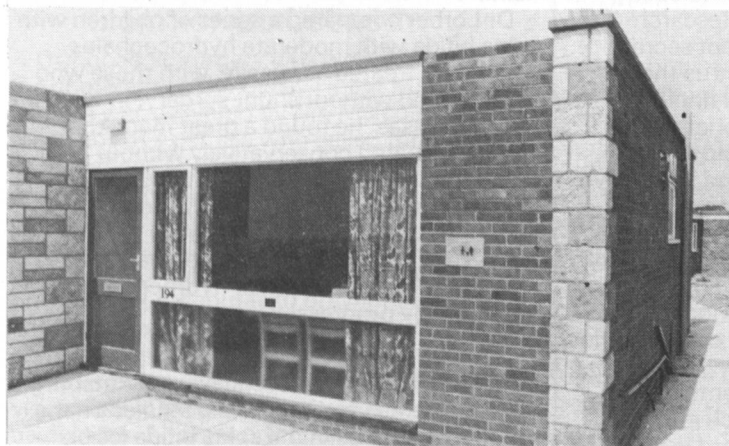


A proud moment for Jackie Page and her friends as she hands over a cheque for £2,500 to Mr Doug Endersby, Chairman of Greenwich Association. The money raised over many months by the Fund which bears her name went towards the new holiday bungalow at Thanet (see story below).

Photo: Kentish Independent.

Bungalow in Kent

Greenwich and District Association now have an attractive, well equipped holiday bungalow thanks to many friends who gave time and money to make it possible. Over £6,000 was raised by the Jackie Page Holiday Home Fund, Greenwich Rotary, Greenwich Association Fund-raising Committee, Greenwich Ladies Circle, Molins Social Club and the RACS Sports Club. In July the first spina bifida family enjoyed a holiday in the bungalow which is ten minutes walk from sandy West Bay on the Thanet coast of Kent and later in the month an outing to the bungalow was arranged for 40 handicapped youngsters and their parents. The Mayor of Greenwich gave the party a good send off and everyone very much enjoyed the day.



Isle of Wight bungalow

The magnificent chalet bungalow (above) at Brambles Chine, Freshwater on the Isle of Wight is owned by the Isle of Wight Association for holidays more-or-less all the year round. The chalet cost £6,000 and this was raised by the Local Association with the generous help of local trades people, local organisations and individuals. The chalet is on the Brambles site which adjoins a sandy

beach and which also boasts an indoor heated pool, games room, bar and shopping facilities. The Isle of Wight Association hopes that families with Spina bifida children all over the country will be able to enjoy holidays in the chalet. It is open all the year except for two short periods in November and February. (For details see advertisement page 15.)

MR ROGER BAYSTON, who has been awarded the Spina Bifida Fellowship reports on

The World of Research

Each year the Society for Research into Hydrocephalus and Spina Bifida (SRHSB) holds a conference to report on recent research in this field. Scores of people come together from many countries of the world to hear the speakers and to discuss the work presented, as well as to meet old friends and colleagues and to "pick their brains" about their current research.

ASBAH is extremely interested in these conferences, to which they, along with other organisations, give financial support. ASBAH is currently supporting several large and costly research projects in this country. Research effort is wasted if the results are kept secret, and a conference such as this gives us the opportunity to publicise any useful findings we have, as well as to hear those of others.

This year the conference was held in Berne, Switzerland, in June. The prolonged heat wave which we experienced in England and Berne was a potential disaster for such a conference—almost the same as torrential rain on the day of a garden party—but the Osthalle of the Bellevue Palace Hotel was an ideal location, it being as spacious and as cool as it could have been in such weather.

The subjects of the papers presented were, as always, very wide. Basic research into the structure of the brain and spinal cord in spina bifida and hydrocephalus was the subject of two papers. The work was carried out in association with Professor Emery of Sheffield, and was reported by his colleagues, Doctors Lendon and Shellshear. Research is not only aimed at finding a cause of hydrocephalus or spina bifida, but more at studying its effects in greater detail so that treatment may be better directed.

SHUNTING DEVICES

Several papers dealt with the effects of shunting devices. Dr Hemmer of Freiburg examined the possibilities of removing shunts from children who appeared not to need them, but in his series this was largely unsuccessful.

The main difficulty was in deciding when a shunt was no longer required, and more research is needed in this area. Dr Kuffer of Berne described the use of drugs to prevent the blocking of shunts due to clotting of the blood. However such drugs have side effects and so these workers did not succeed in reducing the numbers of operations required. Still on the subject of shunts, I was able to report on some experimental work carried out in Sheffield on making the plastic from which shunts are made, resistant to infection. See last issue of "Link".

Dr Lorber compared a series of children with spina bifida with moderate hydrocephalus which was treated surgically, with those who were treated without shunt surgery. In well over 300 cases, he found a great many that could be treated conservatively without operation. The children without shunt were at least as intelligent as those with shunt. They had far fewer operations and fewer died. However, those with shunt often had to have the operation because their hydrocephalus was more rapidly progressive.

NERVE FUNCTION

Dr Reigal and his colleagues from Pittsburgh reported some very interesting studies on the function of nerves in the spina bifida lesion before it was repaired, and suggested that these could be used to determine whether to remove the nerve tissue in the wound or to leave it in place.

PSYCHOLOGICAL STUDIES

Several psychological studies were reported. Mr. Tew from Cardiff studied the effects of admission to hospital and various surgical procedures, and genetic counselling was discussed by Dr. Laurence of Cardiff. He found that in many cases parents were confused or misinterpreted it, and attention needs to be applied to some possible short-comings in the way this is carried out.

Dr. Laurence also presented a paper dealing with the reliability of predicting at birth which

babies would be severely handicapped in later life, and which would be relatively mildly affected. The effects of a "selection policy" on parents were reported by Miss Cowie from Carshalton, and an excellent paper by Dr. Guiney described some of the consequences of the introduction of such a policy in Dublin. This led to a discussion of the present state of antenatal diagnosis, and it was hoped that advances in this field would make selection largely unnecessary in the future.

BLADDER FUNCTION

Three papers were presented which described work on bladder function and its control. Two of these, by Dr. Seiferth of Cologne and Dr. de Voogt of Leiden, described the use of some new drugs to improve bladder function in paralysed people. At the moment these benefit only a proportion of such patients because of the different causes of the disability.

ORTHOPAEDIC SURGERY

Orthopaedic surgery was well represented at the conference. The Casey Holter Memorial Lecture was delivered by Mr. Malcolm Menelaus of Australia who called for planning of operations so that several orthopaedic procedures could be done under the same anaesthetic, so reducing discomfort and time spent in hospital. He also made a plea for a more rational approach to such surgery, so that only simple procedures to prevent or correct deformity were carried out on legs which were completely paralysed, whereas those with some useful muscle power should be treated vigorously to preserve or increase their usefulness. Another orthopaedic paper was presented by Dr. Drennan of Connecticut who described his results using a firm plastic corset to prevent the development of excessive spinal deformity. One of the aims of this was to ensure that the normal development of the child was not interrupted or interfered with, so that the "milestones" were reached at the appropriate age. More work and a long-term follow-up would be needed before we were to know how much surgery could be delayed by this.

Next year the conference is to be held in Sheffield; we hope that our reputation as a conference centre will be seen to be well deserved and that the conference itself will be as useful and stimulating as the one in Berne.

NEW £5-A-WEEK CASH BENEFIT FOR DISABLED CHILDREN.

If you have a severely disabled boy or girl aged 11 or over, he or she may qualify for the new £5-a-week Mobility Allowance to help them get out and about.

This is a new benefit for those who are unable (or almost unable) to walk. It is up to you how you use the Mobility Allowance to help your child get about.

You can claim now if your child is aged 11 or over (i.e. if he or she was born before 25.11.65).

Anyone who is aged 15-50 and has not claimed already should do so immediately. Disabled children under 11 will qualify later. So will other age groups.

Fill in the coupon so that we can send you leaflet NI. 211 which includes a claim form and tells you more about the scheme. Or you can ask at your local Social Security office.



MOBILITY ALLOWANCE. CLAIM NOW IF YOUR CHILD IS AGED 11 OR OVER.

Please send me a copy of leaflet NI. 211 about Mobility Allowance.

Name (Mr./Mrs./Miss) _____

Address _____

Postcode _____

Age _____ (Anyone aged 11-50 can claim NOW).

To: Mobility Allowance Unit, DHSS, Norcross, Blackpool, FY5 3TA.

Issued by the Department of Health and Social Security.

MOBC/LI

ASBAH's 1975/76 Annual Report is its tenth and it begins with a brief reflection on the decade. Few families now experience the loneliness and feeling of isolation of the early years, says the report, and resources have been developed to meet specific needs, valuable channels of communication have been opened up and there has been a growing public awareness of, and response to spina bifida and hydrocephalus. The aim for the future must be to maintain the momentum.

It is heartening to note the generosity and goodwill of so many different people from all over the country towards the Association and its work. This help has been particularly notable with regard to fund-raising for the Association's new Short-term care home, Five Oaks which opened this August. To raise the considerable sum needed—about £148,000—was a difficult task and the Appeals Department deserves much praise for the way in which it explained the purpose of the home so that trusts, industry, groups and individuals felt moved to support it so handsomely. Thanks to them the home opened virtually free of debt, but of course, ASBAH will continue to need much help to maintain the home, as well as for the continuation and development of its other work. The calls on its resources are ever increasing.

PUBLICATIONS

The report emphasises the importance ASBAH attaches to its publications programme and notes that two new booklets, "Children with Spina Bifida at School" and "The Care of an Ileal Conduit and Urinary Appliances in Children" have been published and well received.

ASBAH continued to give practical advice on aids and appliances. In addition special mention is made of the work which is being undertaken by the Royal College of Art to develop equipment, which could become standard, to enable young people to deal with their personal hygiene and the work of the Department of Consumer Ergonomics at the University of Technology, Loughborough into mobility equipment suitable for those between the ages

Story of success and continuing challenge

of seven and sixteen. The report says that largely through the Associations' representations delay in the supply of calipers had now been officially recognised as a serious problem although it was still not possible to look forward to an immediate solution.

During the year special attention was paid to the problems facing the school-leaver. The Spring Conference had as its theme, "Thirteen to Thirty" and it highlighted "the need for new initiatives to meet the need of our members for work where this is possible and interesting occupation where it is not."

The Autumn workshop had as its theme, "Communication". It provided an opportunity for groups to consider this in relation to the medical profession, statutory authorities, local organisations and in the field of education.

SOCIAL WORKERS

ASBAH social workers continued their valuable work, complementing the services provided by others. Appointments are always made at the express request of the Local Associations concerned and much of the finance comes from the area involved. Two new appointments were made and others were in prospect. The National Association also gave direct help, including grants, to scores of families during the year.

The wide-ranging research programmes which are of such importance and are financed by the Association continued through the year. (From time to time details of research are included in Link. There is an article on page 6 of this issue on research projects being undertaken in different parts of the world.)

In its conclusion the Report pays tribute to the devotion of the many people up and down the country who gave even more of their time and money to the Association last year. The charitable income for last year was £158,580—a

Continued on page 14

ASBAH's Tenth Annual General Meeting was held on October 2 at the Institute of Child Health in London.

Representatives from Local Associations all over the country heard the Rt Hon Lord Maybray-King, President of the Association, congratulate all concerned with the wonderful achievements of

the last ten years.

Professor R. B. Zachary, ASBAH's Chairman presented the Annual Report and Statement of Accounts and Mrs F. D. Coggan, wife of the Archbishop of Canterbury and one of ASBAH's Vice-Presidents, in moving the Adoption of the Report, spoke of the need for special

sympathy, understanding and encouragement for parents.

Apart from the business of the day, there was opportunity over lunch and tea for members to get together, and the highlight of the day was the address by the Rt Hon David Ennals, the Secretary of State at the Department of Health and Social Security.

David Ennals speaks about help for the disabled

It was fitting that at ASBAH's 10th Annual Meeting the members were able to hear from 'the man at the helm' — the Rt Hon David Ennals, MP, Secretary of State at the Department of Health and Social Security.

Mr Ennals said how pleased he was to have been asked to speak and 'to meet the people who are involved with the Association, and to sense the atmosphere of a body which has done so much for the people with whom it is concerned.'

He said there would always be a real need for organisations like ASBAH. 'Its social work service is of immense value in complementing the work of health and social service personnel, helping the families through the emotional and psychological difficulties which they face.

'I have spent more of my time being involved with voluntary organisations than I have being a Member of Parliament. I do, therefore, know something of the tremendous commitment and dedication which is required from those who sustain the work at a local level . . .

'Disabled children and young people need financial help to mobility, and encouragement.

'The area of cash provision for disabled children and young people is one in which there has been in recent years very substantial progress . . .

'The Attendance Allowance was the first recognition of the problems that families with disabled children may experience. Its introduction meant that for the first time a

tax-free, non-means-tested cash allowance was available to families. (The Allowance at the higher rate rises to £12.20 a week from this month (November) and rises to £8.15 a week for the lower rate). Mr Ennals said that 4,600 adults and children with spina bifida and hydrocephalus were receiving the Attendance Allowance by the end of June 1976.

NEW BENEFITS

Three other new cash benefits introduced by the Government should also fill a gap in statutory provision for the disabled and their families — the Non-Contributory Invalidity Pension, the Invalid Care Allowance and the Mobility Allowance.

The Non-Contributory Invalidity Pension, which rises to £9.20 this month gives benefit as of right to disabled people of 16 and over, who are unable to work and have not been able to establish a contribution record.

The Invalid Care Allowance provides help for those people — other than housewives — who have had to give up work to care for a disabled person.

'Until a few years ago, payments of this kind were thought impossible. Even now the Allowance has no exact parallel in any country in the world'. Mr Ennals expressed his concern at the large number of people who were still unaware that they were entitled to the

Continued on page 14

Mr Peter Poole who was appointed ASBAH's Social Work Adviser three years ago, writes about this increasingly important service to families:

How our team of social workers sets out to help

● STOP PRESS

ASBAH's new Aids and Appliances Officer is to be Miss Jill Vernon who will take up her duties on January 1, 1977.

Miss Vernon, who holds a degree in Ergonomics, is at present working on the research project at Loughborough investigating improved mobility equipment for the 8-15 year olds. This means that Miss Vernon is currently concerned with studying the day to day lives of young people with spina bifida and hydrocephalus, and ASBAH looks forward to welcoming her in the New Year.

Local Authority social workers often feel unable to give all the help and support they would like to give to our families. This is rarely the fault of the Authority; the demands made upon the limited number of social workers is considerable since they each have to deal with such a vast range of problems. These include mental health, fostering, child care, the elderly, the homeless, as well as many kinds of physical handicap too numerous to mention here. This means that few of the local authority social workers have either time or opportunity to study spina bifida and hydrocephalus, and learn of the many complex and confusing problems which affect our children.

It was for this reason that ASBAH set up a social work service for its members. This was done only where there was a clear demand for this kind of help from a local association.

Most people will have heard about the growing team of social workers who serve members in many counties across the country. Generally speaking the work which is done does not attract a great deal of attention or make the headlines in the local paper. We tend much more to hear about the 'troublespots', the crises, the breakdown of families with unbearable problems. Of course, when a difficulty is met or a problem solved, it is no longer newsworthy and we feel all is well.

Our workers try to visit all the families in the area where they are appointed and also to get to know a great deal about the services and facilities in the area. With this knowledge, the workers can often see problems before they become really acute and can act as 'trouble-shooters'. This help is particularly valuable in the case of a newborn handicapped child where, as most of you will know only too well, the worry and strain imposed on the family at this time can be particularly distressing.

We have found it helpful for each of our social workers to spend time in studying the medical aspects of spina bifida and hydrocephalus and then to build on to this knowledge the experience of the many parents who have already coped successfully with these problems. All of the staff are trained and meet together regularly to share the knowledge they acquire and to consider how to make the best use of the resources available.

In this way, we hope to provide not only much better support for those in need but also a friendly, knowledgeable person who can share your worries in complete confidence, offering advice and understanding which is sometimes difficult to find elsewhere.

Link hopes to be able to carry further articles about aspects of the Association's social work.

"I have been interested to read the articles by spina bifida girls and boys of my own age in Link recently and wonder if you would like to make use of the enclosed 'script'.

"I represented my school — Aberconwy Comprehensive —

with two other sixth-formers in a speech-making contest organised by the local Rotary Club, and our team came second. I kept pretty closely to the script, imagining myself as an after-dinner speaker, and after initial nerves quite

enjoyed the experience!"

William Bee,
Penmaenmawr, Gwynedd

Editor's Note: Due to pressure on space the script has been edited, and we carry it below:

'THE DISABLED AS OTHERS SEE US'

Social attitudes to the disabled today vary greatly from person to person. The two extremes, both based on inadequate knowledge of the subject, are the "kill at birth" concept on one side, and excessive pity on the other. Both are wrong in my opinion, mainly because they appear to be based on false assumptions about the disabled.

The idea of killing the congenitally malformed at birth seems to assume that they will either not be happy in life or that it will cost too much to keep them alive. As for not being happy, that is absurd, I am extremely happy, and most of the disabled children I know are of similar disposition, even those rejected by their parents. Even the mentally handicapped are happy.

Any argument based on the quality of life seems to assume that modern civilisation has achieved something near to perfection — that I doubt but I am not here to speak on modern society. However, it is clear that any assumption that the quality of life of the disabled will not be high because they cannot do some of the things you can do, is on dodgy ground. Maybe the disabled can't play football with other people, but football from a wheelchair is a considerably more skilful game anyway. Maybe I can't run a four-minute mile, but few can, and how many here can do 450 yards in a wheelchair in 4 minutes, 15 seconds? (That may not sound very impressive but may I suggest you try it). Children will always find something to do and the same applies to the disabled. They are able to adapt or invent their own amusements to fit within their limitations.

What's more, it is always possible to find a game in which to compete on even terms, such as chess (I can't find anyone to beat me in Aberconwy but that's because of the low standard of competition!).

What's more, it is often the case that a family gains from having a disabled person in their midst, growing closer together as a unit.

As for costing too much to keep them alive, surely it is money well spent if the disabled have a beneficial effect on society. Anyway, I'm sure it has cost considerably less to keep me ticking over than if one of you were to go home having had a brandy too many and smash up a poor pedestrian with your car.

It is often said on the matter of money that the disabled are always on the scrounge. However, in the national press a few months ago it was reported that the disabled of Cumbria had collected money themselves to take them to attend a conference of the disabled in Iran. What's more, when they got there they intended to donate a minibus to the disabled of that oil rich nation! (I only hope the Shah gave them their petrol.)

Maybe the disabled take a lot from charity, but they will also collect for a charity to help the poor of society. Witness the advertisement in the national press for Dr Barnardo's showing the boy in a wheelchair who had done a sponsored swim for them. I myself have donated several pounds from my carol singing efforts! Therefore it is clear that although the disabled take money from charity they're equally prepared to put it back where possible.

Continued on page 12

Making the best use of the Mobility Allowance

In his speech at the Annual General Meeting, Mr. Ennals referred to the importance of ensuring that the Mobility Allowance about to be available to children between 11-14 should be used 'for the child's best interest'.

This may seem very obvious, but in these days when budgets are strained it will be all too easy for the £5 a week to go into the family kitty to help with expenses, including running the family car and all that means to the disabled child and his family.

It does seem worth suggesting, however, that each new recipient should pause and consider—

- This is my son's/daughter's grant; what is the best (new) mobility help for him/her?
- Should I discuss the possibilities with him/her?
- What possibilities are there?

- (a) Saving the allowance, invested at today's high rates, it will grow, so that (1) it could buy a powered wheelchair; (2) be a nestegg towards a vehicle at 16:
- (b) In a few months only there would be enough for a new hand-propelled tricycle of suitable size, where this is appropriate:
- (c) Should at least part of the allowance be reserved for a special outing of my youngster's own choice—or for a new play once a month? (E.g., using car hire, where a family has not got a car.)

These are only a few ideas. For some people there may be a limited choice—but the thought is there.

Continued from page 11.

'The disabled as others see us'

Excessive pity for the disabled is wrong. Too much pity will either create the attitude that there is something seriously wrong with you, which leads to self pity which is a serious problem if it occurs in a disabled person, or anyone else for that matter; or it will lead to excessive dependence on other people for something they should be able to do themselves. From my experience, at a school for the handicapped, I know that if children spend as little as a week with relatives who spoil them, they need to be taught even how to tie their shoelaces again.

I think the most common attitude towards the disabled is just plain curiosity. I always have to put up with stares from children, and adults who try to pretend they're not looking.

Children are usually not too bad, however. After the first week of a new school year they generally accept me for what I am, just part of the furniture in fact. Adults, on the other hand, with their subtle glances from the corner of their eyes, are far more embarrassing, and I often wish they would have a good stare and get it over with. As it is, when I go for a swim I attract considerable attention as I perambulate along the promenade, and when I stop and actually undress and go for a swim the stares get ridiculous.

To sum up, the disabled need to be treated as normal people if humanly possible. Do not pity them: stare at them as little as possible; and make every attempt to keep them alive, no matter what the cost.



Appeals and publicity

People who made Five Oaks possible

You will have read elsewhere in this issue about the opening of Five Oaks: I should like to think that all the genuine goodwill shown by the many people who donated the £146,000 needed to set up this Home will "rub off" on all the children who go there and help to make sure that they enjoy their stay.

The money was raised in widely different ways—one bearded gentleman shaved off half his beard and half his moustache and went round like that for three days in response to a challenge from friends at his "local" and collected the bets he won for Five Oaks. A little boy in New Zealand who lost a foot in an accident when he was five sent us postage stamps from his precious collection. The cast of the TV programme "The Angels" collected halfpence to a total of nearly £15.

We value every gift, large or small, but special acknowledgement must be made of the tremendous debt we owe to the Independent Order of Foresters, who "adopted" ASBAH for the four years from September 1972 to August 1976, and raised the magnificent sum of about £21,500 for Five Oaks, plus gifts in kind, as well as giving practical help to many of our local associations and to the Scottish Spina Bifida Association.

Does anybody know any similar organisation looking for an Association to adopt for the next four years?

You will remember the two children on our poster putting their best foot forward. Copies of this photograph are available for any leaflets or literature which local associations are producing.



Young Joanne Crane makes sure that brother Andrew (left) and friend Ian James don't have it all their own way, in a game of football in the garden of her home in Birmingham. Photo: Sunday Mercury.

KNITTING NEEDLES AT THE READY

International Voluntary Service, which helps the deprived and needy in the UK and all over the world, is launching a sponsored knit to raise funds for their many projects and invites other charities to join in for the benefit of their own funds also, by retaining 25% of the total sponsorship money that they raise.

If anyone is interested please write to me. And if anyone is interested in having our own ASBAH National Sponsorship or similar activity in which all Local Associations would take part and retain say 50% of the total sponsorship, leaving ASBAH 50% for the cost of running the scheme and a little to help national funds, please write to me and we will see what we can dream up.

Finally, although at the time of writing it's hard to believe that Christmas is so near, I send you all the traditional wish—a very merry Christmas and a happy New Year.

Kate White

David Ennals speaks about help for the disabled

Allowance and who, as a result, had not claimed it.

He described the Mobility Allowance as 'a major breakthrough in the field of outdoor mobility, bringing help for the first time to disabled children and other disabled people who could not drive'. He was aware of the concern among the disabled about the planned phasing out, over five years, of the invalid trike, which had been decided on because it would not meet international standards of safety (see Link editorial Sept/Oct issue).

'What about those people who are too young to have a tricycle and now won't be able to get one? Very young drivers have been particularly likely to be involved in accidents. When the Allowance is paid from the age of five years it should mean increased family support, so that help with a vehicle at 16 may be possible.

When the trike did eventually go the Government would look into alternative ways of meeting the needs of trike users and other vehicle scheme beneficiaries, and see what other vehicles were available.

ACCOMMODATION

Mr Ennals spoke of his Department's work in the field of accommodation for the disabled—particularly in providing house adaptations, and on employment he announced that the Employment Service Agency was trying to draw employers' attention to the needs of the disabled.

Great importance was also attached to social integration—one of the main developments of the past ten years or more—which should lead to a greater awareness and more genuine understanding by the public of the abilities and potentialities of the disabled.

'Arrangements are also needed for the medical needs of spina bifida adolescents too old for care in a children's hospital. Representatives of your organisation met officials in my Department in June of last year to discuss these problems.' Regional Medical Officers were asked to identify all the spina bifida children reaching adolescence and

several multi-disciplinary out-patients clinics were set up to assess the continuing needs of these people. Health authorities saw this as a real challenge and a number of them have already taken the first steps to ensure continuity of care and to minimise the difficulties that parents and their children may face when the age of 16 is reached.

'I wish to add my own personal commitment and I pledge that I will take a continuing interest in this'.

Mr Ennals kindly undertook to answer questions and the first concerned the number of people whose attendance allowance had been reduced to the lower rate at the three-yearly review. It was demonstrated to Mr Ennals that this was not a problem confined to any one area and he promised to investigate if details were sent to him through ASBAH's General Secretary. (*This is an opportunity of which we should avail ourselves*).

Vice-Chairman of ASBAH's Executive Committee, Mr R. I. Stubbs proposed the vote of thanks to Mr Ennals and said it was good to know that there was someone who was sympathetic to our needs 'at the helm'.

Continued from page 8.

Story of success and continuing challenge

51% increase over the previous year, and even a cursory glance at the accounts will show that the money is being put to very good use.

The Report ends: 'We have many friends both in government departments and among the voluntary organisations, and we believe that much work in the future to provide for the welfare of our young adults needs to be arranged co-operatively in order that they may not become an isolated group . . . New schemes will be needed and at the same time the personal service to individuals which goes almost unnoticed, except in the hearts of those involved, must be continued and strengthened . . . '.



ASBAH booklets . . . leaflets . . . posters

- Your Child with Spina Bifida*, by J. Lorber, MD, FRCP 20p
Your Child with Hydrocephalus by J. Lorber, MD, FRCP 15p
The Nursery Years, by S. Haskell, M.A., Ph.D., and M. E. Paull, Dip. Ph.H. . . 15p
Children with Spina Bifida at School. Ed. P. Henderson CB, MD, DPH . . . 30p
The Care of an Ileal Conduit and Urinary Appliances by
 E. Durham Smith, MD, MS, FRACS, FACS and others 15p
Clothing for the Spina Bifida Child by Barbara Webster, SRN, RSCN . . . 15p
 A new book on equipment and aids will be available shortly.

Information leaflets 100 for £1.30
 All available from ASBAH, 30 Devonshire Street, London W1N 2EB. (Special rates available to Local Associations.)

Scottish Spina Bifida Association booklets.

- The Spina Bifida Baby* . . . being revised.
Growing Up with Spina Bifida . . . 20p. both by O. R. Nettles, MCSP, ONC.
 Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh, EH4 2BW (at special rates for bulk orders).

Fund raising and publicity material

- Posters** **Car Stickers** 5p each.
 Best Foot Forward 20 x 30in. — 10p each. **Cards for Notice Boards** 10 for 10p.
 Best Foot Forward 15 x 10in. — 10 for 40p. **Flag Day Emblems** 1,000 for 70p.
 For local publicity 15 x 10in. — 10 for 40p. **Plastic Lapel Badges** £2.10 for 100.
All available from Appeals Dept. — postage extra. Full list on request.

Spina bifida badges. 25p each, postage extra. (for one badge enclose s.a.e.). Bulk orders particularly welcome. Available from: Mr K. McKenzie, Salisbury & District ASBAH, 111 East Gomeldon Rd, Gomeldon, Salisbury SP4 6LZ.

Films about spina bifida and hydrocephalus

- What is Spina Bifida?** Black/white. 16mm. 25 mins.
A New Lease of Life. Colour. 8mm. 25 mins.
Like Ordinary Children. Colour. 16mm. 30 mins.
Growing Together. Colour. 16mm. 40 mins.

All may be hired from Concord Films Council, Nacton, Ipswich, Suffolk.

The Mansfield Association film **"What shall we do tomorrow?"** Colour, 16mm. 22 mins, may be hired direct from Mrs Freeman (see p.16.)

Holiday accommodation for spina bifida families

Camber Sands, nr. Rye, Sussex. New well-equipped 6-berth chalet near the sea. Apply: Mr S. Evans, 1 Coniston Gardens, Wembley, Middx. 01-904 7840.

Christchurch, Dorset, Hoburn Farm. 6/8-berth caravan, 1 mile from sea, near New Forest. Further details: G. R. Large, 89 Duchess Way, Queensfield, Swindon.

Easington, Withernsea. 7-berth caravan on well-equipped site by sandy beach. Details: Mr A. Clark, 3 Leys Close, Carleton, Skipton, N. Yorks, BD23 3EW.

Golden Sands, Voryd, Rhyl, N. Wales. 8-berth caravan, mains water, electricity, gas, shower and T.V. Every facility on site, right by the sea. Enquiries to Mr. Adams, 58 Strathedan Road, Bradeley, Stoke-on-Trent.

Great Yarmouth. Caister Beach Caravan Camp — 6-berth caravan. Details: Mrs E. N. Barefoot, 23 Marlborough Road, Southall, Middx. Tel. 01-574 5067.

Haggerston Castle (5 miles south of Berwick-on-Tweed): 8-berth caravan. Details: Mrs Connolly, 103 Raby Rd, Oxclose, Washington, Tyne and Wear.

Isle of Wight. Brambles Chine, Yarmouth. 6-berth luxury chalet-bungalow, adjoining beach. Available all year. Car an advantage. Details: Mrs S. Gully, Little Orchard, Eddington Road, St. Helens, I.W. Tel. Bembridge 2141.

Looe. Millendreath Holiday Village. Two bungalows. Details: Mr Keith Jackson, 202 Exeter Street, Plymouth, and Mrs Cook, 19 Winslade Road, Harestock, Winchester.

Mablethorpe. Two well-equipped self-contained chalets, 6-berth, at Golden Sands Estates. Details: Mr K. Hall, 17 Walhouse St, Cannock, Staffs.

New Forest. Well-equipped 6-berth chalet. Easy reach of Bournemouth, Beaulieu etc. Swimming pool, paddling pool, restaurant and playground on site. Details: Mrs A. Rae, 16 Clifton Road, Lee-on-Solent, Hants. Tel. Lee-on-Solent 550242.

Selsey. New well-appointed, self-contained 16ft. x 30ft. six-berth mobile home. For details send s.a.e. to Mr R. V. Taylor, 3 Dickens Way, Horsham, Sx, RH13 6BQ.

Skegness: Specially designed, well-equipped bungalow, sleeping 8. Situated at Chapel St Leonard's, nr. Skegness, on pleasant site near safe beach. Details: Mrs J. Brook, 11 Standforth Rd, Dalton, Huddersfield HD5 9HD. Tel: Hudd. 21776.

Winterton-on-Sea, nr. Great Yarmouth — new well-equipped 6-berth chalet. Indoor swimming pool, shop, and play areas. Details: Mr R. Morris, 127 The Pastures, Downley, High Wycombe, Bucks. Tel: H. Wycombe 32184.

Withernsea. Equipped 6-berth chalet on a pleasant site. Apply to Mrs P. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax: Tel: 0422-56402.

AFFILIATED ASSOCIATIONS – Hon Secretaries

BEDFORD AND DISTRICT

Mr. S. Odell,
9 Beauchamp Rd, Wootton,
Beds MK43 9E2.

BOLTON AND BURY

Mrs. B. Grosvenor, 12 St. Peter's Rd,
Bury, Lancs, BL9 9RB.

BOURNEMOUTH

CHRISTCHURCH & DISTRICT

Mr. R. A. Frake, 11 Scott Close,
Wallisdown.

BRISTOL

Mr. R. W. Mabbutt, 20 Bramble Drive,
Stoke Bishop, Bristol.

BROMLEY & DISTRICT

Mrs. J. Moore, 102 Westwood Park,
London SE23 3QH.

BUCKINGHAMSHIRE

Mrs. L. E. Tilly, 2 St. John's Drive,
Windsor, Berks.

BURNLEY

Mr. M. Lane,
5 Creswick Ave, Burnley, Lancs.

CALDERDALE

Mr. A. L. Crowther,
42 Marlton Rd, Northoram, Halifax.

CHESTER & DISTRICT

Mrs. K. Jones,
19 Beech Hey Lane, Willaston, Wirral.

DARLINGTON AND DISTRICT

Mrs. M. Crawford,
53 Linden Terrace, Copley,
Bishop Auckland, Co. Durham.

DERBY

Mrs. O. Baker,
16 Marston Close, Littleover.

DEVON AND CORNWALL

Mr. J. Carter,
5 Culme Rd, Mannamead, Plymouth.

DON AND DEARNE

Mr. T. J. Murphy,
43 Cutts-Ave, Wath-on-Deerne, Yorks.

DUDLEY & WOLVERHAMPTON

G. M. Norman,
231 Coalway Rd, Merry Hill,
Wolverhampton.

EAST ANGLIAN

Mrs. M. Drewry,
1 Fieldsteads, New Rd, Impington,
Cambridge.

ESSEX

Mr. V. Williams,
122 Rothbury Ave, Rainham.

GLOUCESTERSHIRE NORTH

Mrs. J. Hall,
Old School House, Church Rd,
Caenross, Stroud.

GREENWICH

Mrs. A. Pearson,
80 Brinklow Crescent, Woolwich, SE18.

HAMPSHIRE NORTH,

W. SURREY & S. BERKS.

Mrs. Selby,
The Old Police Station, Leapale Road,
Guildford.

HAMPSHIRE SOUTH

Mrs. P. J. Jewell,
19 Stockheath Lane, Havant, Hants PO9 3BU

HERTS AND SOUTH BEDS.

Mrs. S. M. McGavin,
3 Netherfield Rd, Harpenden.

HUDDERSFIELD

Mrs. J. Brook,
11 Standforth Rd, Dalton, Huddersfield,
W. Yorks.

HULL & DISTRICT

Mrs. G. D. Brown,
233 Cranbrook Ave, Hull HU6 7TX.

JERSEY (Channel Islands)

Mrs. U. Emmanuel, Le Lavandou,
Gorey Village, Jersey, C.I.

KENT

Mr. M. J. Apps
33 Beresford Rd, Gillingham.

LEEDS AND BRADFORD

Mr. G. Baxter,
38 Hoyle Court Rd, Baildon, Yorks.

LEICESTERSHIRE

Mr. P. Cusack,
31 Lime Grove, Kirby Muxloe.

LEIGH & DISTRICT

Mr. T. Power,
3 Taunton Drive, West Leigh, Lancs.

LINCOLN, GAINSBOROUGH

& MID Lincs.

Mrs. P. Keyse,
Pinfold, Chapel Lane, North Scarle,
Lincoln.

LINCOLNSHIRE N.E.

& S. HUMBERSIDE

Mr. T. Chapman,
32 Glenfield Rd,
Grimsby, S. Humberside.

LINCOLNSHIRE SOUTH

Mrs. P. Mason,
2 Mayfair Gardens, Boston.

LIVERPOOL

Mr. P. A. Glennon,
Tudor House, Wood Lane, Netherley,
Liverpool L27 4YA.

LONDON, CENTRAL & NORTH

Mrs. J. Mason,
65 Belmont Lane, Stanmore,
Middx.

LONDON N. EAST

Miss D. Baxter,
8 Keith Ave, Wickford, Essex.

LONDON N. WEST

Mr. L. R. Mower,
59 Betham Rd, Greenford,
Middx.

LONDON SOUTH

Mrs. C. Byrne,
Flat 1, 10 Wexford Rd, London SW12.

MANCHESTER AND DISTRICT

Mrs. E. Taplin,
Colonial House, 63 Corporation Street,
Manchester M4 3DT.

MANCHESTER CENTRAL

Mrs. J. Whiting,
33 Weston Ave, Manchester, M10 0QP.

MANSFIELD, WORKSOP AND

DISTRICTS

Mrs. E. Freeman,
23 Melbourne Street,
Mansfield Woodhouse, Notts.

NORTH EAST

(Northumberland)

Mrs. E. Grant,
27 Redwell Rd, Prudhoe, Northumberland.

NORTHAMPTONSHIRE

Mrs. A. Hardy,
28 Eastbourne Ave, Corby, Northants.

NOTTINGHAM & DISTRICT

Mrs. S. E. Plant,
305 Foxhill Rd, Carlton, Nottingham.

OXFORDSHIRE

Mrs. M. Staddon,
11 Stansfield Close,
Headington, Oxford OX3 8TH.

PONTEFRAC T CASTLEFORD

& DISTRICT

Mrs. N. Robinson,
4 Sandal Rise, Thorpe, Audlin,
Pontefrac WFB 3EX.

PRESTON

Mrs. B. H. Waring,
6 Demming Close, Lea, Preston, Lancs.

ST. HELEN'S & DISTRICT

Mrs. N. Maddocks,
324 Warrington Rd, Rainhill,
Prescot L35 9JA.

SALISBURY AND DISTRICT

Mrs. J. Renshaw,
195 Gainsborough Close,
Salisbury SP2 4HB.

SHEFFIELD

Mr. T. Robinson,
4 Longford Close, Bradway,
Sheffield S17 4LH.

SOUTHAMPTON & DISTRICT

Mrs. P. M. Trim,
Abetta, The Drove,
Southampton SO4 1XB.

STAFFORDSHIRE

Mr. J. Davies,
8 Oakhill Ave, Stoke-on-Trent ST4 5JN.

STAINES, HOUNSLOW AND

DISTRICT

Mrs. S. Karmios,
36 Melbourne Avenue,
West Ealing W13 9BT.

STOCKPORT

Mrs. S. Silver,
1 Brookside Ave, Offerton, Stockport.

SUNDERLAND

Mr. W. D. Easton,
4 Irene Ave, Grangetown, Sunderland.

SURREY (NASBAH)

Mrs. D. M. Driscoll,
26 Limes Ave, Waddon, Croydon, Surrey.

SUSSEX

Mrs. M. White,
Averys, Ruspur, Horsham, Sussex.

SWINDON AND DISTRICT

Mrs. J. Trembling,
3 Church Place, Swindon, Wilts.

TRAFFORD AND Salford

Mrs. J. Gray,
9 Whitegates Close,
Timperley WA15 7PG.

WARRINGTON & DISTRICT

Mr. S. J. Charlton,
36 Park Ave, Latchford, Warrington.

WARWICKSHIRE

Mr. R. W. Chawner,
18 Finch Drive, Sutton Coldfield,
Warwickshire.

WESSEX

Mrs. J. Wheller,
5 Wyke Road, Weymouth.

WIGAN AND CHORLEY

Mr. J. A. Hughes,
20 Kennedy Close, Standish, Nr. Wigan,
Lancs.

WIRRAL

Mrs. S. Keeler,
7 Church Road, Upton, Wirral L49 6JX.

WORCESTERSHIRE

Mr. M. Davis,
Lower Field, Wynnatts Way, Abberley.

YORKSHIRE NORTH

Miss F. M. Seward,
45 The Paddock, York YO2 6AW.

NORTHERN IRELAND

BELFAST & DISTRICT

Mr. E. B. C. Green,
169 Warren Gardens, Lisburn, Co. Antrim.

SCOTTISH ASSOCIATION

Mrs. G. McIntyre,
General Secretary,
190 Queensferry Rd, Edinburgh EH4 2BW.

MID WALES & BORDER

COUNTIES

Mrs. D. Brayne,
5 Woodcote Way, Monkmoor,
Shrewsbury, Salop.

NORTH WALES

Mrs. M. Messham,
47 Cherry Tree Rd, Bradley, Wrexham.

SOUTH WALES

Mrs. D. Cox,
28 Cromwell Rd, Bulwark,
Chepstow NP6 5AD.

OTHER LOCAL ASSOCIATIONS

Blackpool & Fylde

Mr. L. F. Sharpe,
1 Broadfield Ave, Poulton-Le-Fylde.

Cannock and Walsall

Mr. C. Bird,
2 Lime Grove, Rushall, Walsall, WS4 1JS.

Cheshire South

Mr. J. Bill,
4 Taxmere Close, Sandbach, Cheshire.

Chesterfield

Mrs. K. M. Tomlinson,
56 Brooke Drive, Brimington Common,
Chesterfield.

Consett & District

Mrs. M. Holmes,
30 Watling Street, Leadgate, Co. Durham.

Isle of Wight

Mr. D. J. S. Sprake,
Springfield, Town Lane, Chale Green,
Ventnor.

Lunesdale (Lancaster)

Miss P. Crook,
Brannanlor, Ball Lane, Caton, Lancaster.

Rochdale

Mrs. Ann Lawton,
55 Wimpole Street, Shaw Rd. Estate,
Oldham.

Somerses

Mr. N. H. Smith,
Zermatt, Church Hill, High Littleton, Avon

Spennorth (Yorks.)

Mrs. H. Lodge,
38 George Street, Cleckheaton, Yorks.

Teesside

Mr. J. Gray,
Marches Centre, Tollesby Rd,
Middlesbrough.

NORTHERN IRELAND

Mrs. E. Kenny,
The Bungalow, Teesham, Ballymena.

Lurgan & Portadown

Mr. P. A. Smyth,
Marymount, North Circular Road,
Lurgan, Co. Armagh.

Mid-Ulster

Mr. J. R. Stafford,
26 Killymerron Park, Dungannon, Co. Tyrone