41

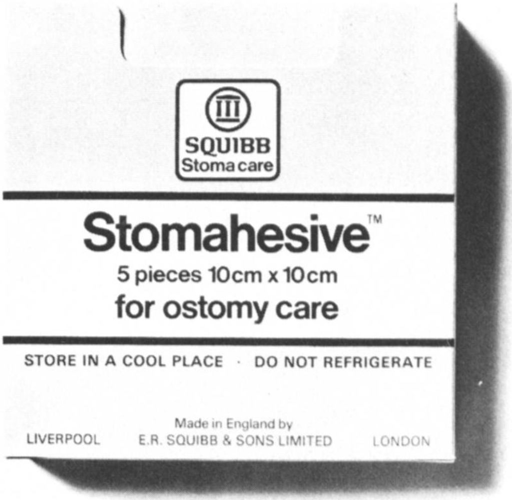
Link

NOVEMBER/DECEMBER 1975 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)

Happy Christmas

the go-between



Sore skin around the stoma can be prevented by using Stomahesive, the Go-Between, from the beginning.

Protective Stomahesive goes between the tender peristomal skin and the appliance reducing risk of leakage and frequency of appliance changes. It fits like a second skin.

Companion products Orabase and Orahesive Powder help to increase security by filling up even those minute spaces through which irritant fluids can attack the skin.

Stomahesive -right from the start.

Stomahesive – boxes of 5 10 cm × 10 cm squares
Orabase – 30 g and 100 g tubes Orahesive – 15 g puffer pack

Stomahesive, Orabase, Orahesive and Plastibase are Squibb registered trademarks.

Full information available on request:
E.R. Squibb and Sons Limited, Regal House, Twickenham TW1 3QT.

SQUIBB

Link No. 41

Association for Spina Bifida & Hydrocephalus (ASBAH)

Patron:
HRH The
Duchess of Gloucester

Chairman:
Mr. 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

Appliance Officer:
Miss F. A. Birkett

Link Editor:
Mrs. Susan Gearing

Contents

page

Editorial

First the good news. The new £5 a week Mobility Allowance will be phased in from January 1976 starting with people aged 15-50 years who are unable to walk, and extending later to cover those from 5-60/65 (pensionable age).

The new allowance is certainly to be welcomed, aiming as it does to assist outdoor mobility in a variety of ways. It does not have to be used in running a vehicle. It can pay for taxis, car hire, holiday transport etc. This flexibility is good news, and so too is the fact that an estimated 100,000 new people will become eligible for the Allowance who have not received help in the past.

Unfortunately the good tidings are marred by the Government's decision to tax the Allowance, despite representations from many organisations. Tax will in effect take 35% off your £5 if you pay at the standard rate.

And for some the £5 is likely to be eaten into even further, for the Government does not intend to give the Mobility Allowance **and** exemption from the present £40 Vehicle Excise Duty.

It seems the unkindest cut of all that the Allowance is to be withdrawn once the disabled person reaches pensionable age. We are told that this is because resources would stretch no further, so let us hope that this will only be temporary, as surely this aid to mobility may well be needed most by these older people.

Provision for regular review of the amount of the Allowance to keep pace with inflation has not been included in the current legislation. Our Association, and others to whom the new provision will mean so much, must seek to ensure that the £5 Allowance will continue to be worth £5.

The much-heralded Mobility Allowance is good news indeed, though there is room to extend its scope and provisions in a number of ways.

FRONT COVER:

The Rood family at their home in Basingstoke.

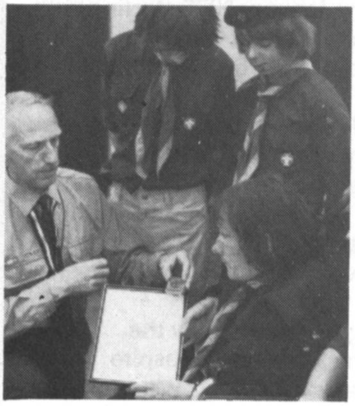
Life for Mrs Maureen Rood this Christmas will be rather hectic as it is for any mother with two young children. There will be extra shopping, Christmas presents to choose, wrap and distribute, Christmas decorations to arrange, parties and so on. Mrs Rood will be doing all her preparations from her wheelchair, for she is confined to the chair with spina bifida.

She copes on her own (with the assistance of husband Peter, of course) with all the housework and with bringing up their two young children, Simon, 3½, and Samantha six months.

We wish the whole family a very happy Christmas.

Photo: Reading Evening Post.

News from all around



Scouting first

Sixteen-year-old Ian Lancaster recently achieved a scouting first in Cambridgeshire. He became the first person in the county to be awarded the Cornwell Badge — signifying great courage, character, endurance and devotion to duty.

Ian, who is spina bifida and completely paralysed from the waist down is a patrol leader and working towards his Chief Scout's award.

Despite his handicap Ian has always managed, with the help of other scouts and scouters, to take part in normal activities.

Ian, who lives in Bar Hill village is pictured (above) receiving his award from the District Commissioner.

Four in a row

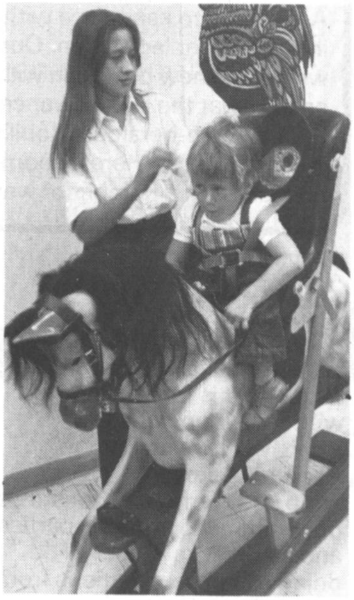
Bournemouth, Christchurch and District Association made it four in a row when they won yet another trophy at Bournemouth Carnival in August. With their float based on the theme, 'Over the Rainbow' they won first prize overall.

Double Dutch

Little Allison Street of Great Wakering, Essex and her cousin Eldreda Smith (right) won first prize in the fancy dress competition at the local fete. Allison (on the left) has spina bifida. The pair of them look pleased — and rightly so — with their success as a rather unusual example of 'Double Dutch'.

Playscheme

Below, one of the youngsters who attended the Red Cross Toy Library Playscheme in Leicester this summer. The playscheme was an extension of the toy library which has been in operation for three years. Among the members of the library are children with spina bifida and hydrocephalus.



Strong support

Remember the editorial in the July/August Link on the question of special broadcasts for the disabled? Well here is strong support for the idea from Southampton.

The Southampton Branch strongly supports the Editorial recommendation that the BBC should include a regular programme for the disabled in its national programmes.

'In the south, Radio Solent gives us an excellent programme each week, but it would be a great help and of great interest to know what goes on in other areas. Incidentally our programme is called "Link" and it is presented by Peter White who is blind.'

Dr Lorber visits New Zealand and Australia

I was very lucky indeed to have been invited to be the principal guest speaker at the first ever National Meeting of the Spina Bifida Associations of Australia in Sydney and of the New Zealand Crippled Children Society in Wellington during August 1975.

The journey to New Zealand, in one hop through California and Tahiti was exhausting, but the friendly reception and the lovely winter sunshine soon dispelled the fatigue. I had a chance to meet and address practically all the spina bifida families at four large meetings held in Auckland and Wellington in the North Island, and Christchurch and Dunedin in the South Island.

The South Island is a little like Switzerland with glorious Alpine scenes. Some parents travelled hundreds of miles to the meetings. Many knew and were appreciative of the work of ASBAH, read our booklets and know Link - but the link is much stronger now after this personal visit.

SPECIAL SCHOOLS

The main topic of my talks was prevention and antenatal diagnosis and the policy of treatment of the new born. There was an overwhelming support for the policy of selective treatment.

I saw many special schools, sheltered workshops and admired the magnificent headquarters of the Crippled Children's Society in Auckland.

The professional part of my New Zealand visit ended in Wellington, where I had the honour to deliver the annual address of the Society in the presence of the Governor General and the Minister for Social Services. The Governor General, Sir Dennis Blundell, gave a reception in Government House after the meeting. Apart from talking I had several television and radio programmes and the Press followed closely my tour, often with accurate reports of what I said.

We in England think that New Zealand and Australia are very near to each other—but the distance is over 1,000 miles and Auckland is as far from Sydney as Athens is from London. As soon as I arrived in Sydney I was met by the New South Wales members of the Society for Crippled Children and the Spina Bifida Association. Even before going to my hotel we visited special schools for physically handicapped children in the beautiful North Shore district of Sydney Harbour.

The next day the Congress began in earnest. It was held in the magnificent new Town Hall of Bankstown, a suburb of Sydney, through the courtesy of the Mayor. We had a splendid official dinner in his office and then came the Inaugural Meeting in the Auditorium which had well over 500 seats and was full. After Sir John Kerr, the Governor General of Australia and Dr. Keys Smith of Melbourne I gave my Guest Oration. The main theme of this was the need for full information on all aspects of spina bifida for parents and for all people working with spina bifida.

BIG INTEREST

A few sessions were reserved for parents only and one for professional personnel, but an important feature of each session was the question time. Parents were not shy to ask or contribute! There was such an interest that I held an extra unofficial informal session with the parents, with no holds barred. In my closing speech I dealt with 'Realistic Goals in the Management of the Child with Spina Bifida'. The last day finished with the Grand Finale of 'Starquest' in Her Majesty's Theatre.

The Spina Bifida Association also organised many social programmes after the Meeting: a trip in a specially hired boat in Sydney Harbour, a visit to the magnificent new Opera House to hear Tosca and the adjacent Concert Hall for a symphony concert.

After Sydney I went to Hobart in Tasmania where one Saturday morning I believe I saw all the spina bifida children in the Island (which is bigger than Scotland!), then to Melbourne and Perth. Everywhere I was received with great friendliness.

I was glad to have the chance to convey the official Greetings of our Association to our friends in Australia, which they warmly reciprocated.

JOHN LORBER

Growing up with spina bifida

by GORDON CARTER
of Cambridge

'SCHOOL WAS HARDEST PART'

Although only seventeen, I think that the hardest part of my life has been my schooling, because I never went to a day school and the two schools that I attended were both a long way from home.

The first school was situated in the North Riding of Yorkshire. It was a school for physically disabled pupils. It was there that I learnt how to dress myself, an activity which I then found fairly difficult. Shoes were a big problem for me, as I cannot bend my knees, especially as we were turfed off our beds on to the hard wooden floors to dress. I find it quite difficult even now, to put shoes on while sitting on the floor.

There were constant disagreements between the school, my parents and my medical team. After four years in 1967, I was withdrawn from there and sent to another school for physically disabled pupils. The difference between them was that the Yorkshire school was co-educational while the other was for boys only. I preferred the latter for that reason, but of course I was only very young when I was in Yorkshire.

1968 and 1969 went by without any problems but in 1970, my feet started to blister, and as any spina bifida sufferer should know, these can lay one up in bed for as much as nine months. The first trouble I had was a callous on the sole of my left foot, and although I did not have to go to bed with it, I had to wait nine weeks before I could stand.

Since then, blisters have arisen now and again, making life very difficult for people concerned with looking after me, what with lifting, transportation etc. I remember when I had a sore on my behind, and I was laid up for months. If ever any spina bifida reader comes across this problem of a sore behind, and has to lie in bed until it is healed, remember one thing — be patient!

Fortunately, I am reasonably mobile and can find a way round most problems such as rough ground and steps. However, I am now mostly confined to a wheelchair, due to my foot trouble, whereas previously I used to walk up to two miles a day.

'I HAVE PLENTY OF HOBBIES'

During my seventeen years, I have found plenty of hobbies and interests to occupy me.

My main hobby is ornithology. This I started about five years ago and since then I have learnt to recognise many species of bird, both by observation and with the aid of books. One of my secondary hobbies is rock collecting, and that includes fossils, minerals and very rare gems. I used to collect stamps but I found it rather tedious sticking them in an album, especially when I decided to change my presentation. I do hope to start again sometime.

I have a mild interest in space travel and followed all the Apollo space flights, and then, coming down to earth again, I have a fascination for warships, of the post-World War II era, and I try and follow all the naval news.

'WE REBUILD SCOUT TROOP'

In September 1968, I joined the Scouts, and worked my way through the Scout Badge, and the Scout Standard, and nearly finished my Advanced Scout Standard. When I first joined there were twenty-two in the troop, but because of bad leadership, they all eventually left, except me. A former helper then took charge and together we gradually got together a new bunch. It also gave me promotion.

When the new troop numbered about ten people, a patrol was formed and I was made the Patrol Leader. Once the troop got to eighteen people, two patrols were formed and I was promoted to Senior Patrol Leader, and was more or less in charge of the whole troop. In July 1974 I left the troop and in September, unofficially became a Venture Scout. At the moment my Scouting has come to a halt, but when I start work I hope to find a Venture Unit to join.

Lastly, on the subject of hobbies and interests, I like photography and travelling. I have travelled to many places in England, Wales and Southern Scotland, and also toured the Loire Valley in France, in 1972.

Finally I will write about my prospects for the future. I hope to go to a village called Papworth Everrard where there are several industries for the disabled. They include light engineering (components), heavy engineering (coach building etc.), printing, leatherwork, and possibly others that I have not been told about. There is also accommodation, in the form of hostels which have dining rooms, T.V. rooms and bed-sitting rooms. If and when I am accepted I will be able to travel about in my invalid three-wheeler.

'ONE OF THE LUCKY ONES'

For many disabled people a job is a very difficult thing to find, because the person concerned has to consider, depending on their disability, where they can live. The problem is that there are too few places for disabled people to go, whether it is to school or to work, and I consider myself lucky that there is a possible place for me at Papworth, near Cambridge.

New pension available

Preparations for the introduction of a **Non-Contributory Invalidity Pension** are now complete, and the first group will come into benefit on **20th November, 1975**. To summarise its provisions, the benefit will be £7.90 a week, payable to severely disabled men and single women over the age of 16 who have been incapable of work for 28 weeks and who, through not having worked, have not been able to build up a sufficient contribution record entitling them to the more usual contributory benefit. It is tax-free and will **not** be means-tested. Married women living with their husbands will not be eligible at this stage: a housewives' version of the NCIP will be introduced as soon as possible afterwards.

The DHSS will be contacting those on supplementary benefit who are likely to qualify for the NCIP. If you do **not** hear from the DHSS but think you might qualify, get in touch with your local social security office. Ask them for a leaflet NI 210, which explains the conditions for the non-contributory invalidity pension in simple terms and includes a form on which to make a claim.

TENTH ANNIVERSARY CELEBRATION

To mark this milestone in the Association's history, a gathering is to be held at the Stoke Mandeville Stadium (near Aylesbury), Bucks. on Saturday, 15th May, 1976. We hope all the officers of the Association will come, and that EVERY Local Association will be represented.

Details will be sent to each Association shortly, but meanwhile earmark this date, book a coach perhaps, and make this a MUST for 1976.

Overnight accommodation can be arranged for those with long journeys who would like to stay (dormitory style à la paraolympiads!).

Spring Conference 'Thirteen to Thirty'

The Association's Spring Conference has become an annual event to which members all over the country and friends concerned with the care and welfare of members look forward.

In 1976 the Conference is to be held at Culham College of Education, Abingdon, Oxfordshire from 9-11 April, and the theme will be 'Thirteen to Thirty'. Culham is about eight miles from Oxford and so very centrally situated, and we look forward to a good response.

As last year, it will be possible to accommodate children. We also hope that teenage members will enrol for the Conference.

Programmes and forms of application will be ready in a few weeks' time.

SERIOUS BUSINESS OF BUYING TOYS

Toys, toys, toys. Large and small, bright, shiny toys are temptingly displayed in advertisements and on a thousand and one shelves in practically every shop we pass.

Each Christmas the pressures are on us to spend even more on these desirable commodities. We are made to feel that each toy will bring lasting happiness and hours and hours of amusement.

This year more than ever before it is wise to stop and really think about the toys you are going to spend your hard earned money on. Don't overlook the good-old faithfuls which can somehow seem rather boring compared with the new, 'magical' 1975 Christmas stock. Plasticine, crayons, paints, Lego, and puzzles can give hours of play.

A simple way of seeking out 'good' toys is to stick with the well-known toy firms such as Fisher Price and Galt Toys. You should find a good selection of both locally. Or you could shop in the comfort of your own home. There are several mail order catalogues available now offering what are usually described as 'educational' toys.

The range of toys made by Paul and Marjorie Abbatt — pioneers of educational toys — is even more irresistible than ever this year and all are offered through their mail order service. (address below).

The Educational Supply Association Ltd — ESA — offer a splendid mail order service and they have a catalogue of toys which has a special play value for handicapped children: 'Play and Extra Specials'.

A newcomer to the field of educational toys is the Early Learning Centre, which started in April 1974 and already has 15,000 member families. This enterprising firm has a panel of teachers and playgroup people who have tried and tested a lot of toys and have chosen to market those they consider to be good value for money. They have a catalogue of about 200 items.

Each month members of the Centre receive the month's selection — a toy, puzzle, book etc. chosen for a specific age group (in the age range 0 — 7 years) and costing about £1.30. There is a newsletter, too, as part of this Play and Learn Programme. You don't pay to join, but membership commences when you buy the Month's Selection, and you can opt out when you like.

Whatever toys you — or Father Christmas — give to your child this year I hope they will make his or her Christmas a really happy one.

SUSAN GEARING

The addresses for the mail order catalogues are: Paul & Marjorie Abbatt Toys, 74 Wigmore St, London W1. Catalogue 15p. ESA Ltd, Pinnacles, PO Box 22, Harlow, Essex. 'Play and Extra Specials' is free. Early Learning Centre , 173 Kings Road, Reading RG1 4EX.

Living

Film in demand

The film 'Riding towards Freedom' which was shown at the Spring Conference in Manchester has attracted much attention and many people have asked for details.

The hiring charge is £3.30p and it is available from Town and Country Productions Ltd, 21 Cheyne Row, London SW3 (Tel: 01-352 7950). Please give a month's notice if possible.

and Learning–Together

Prospect Hall, a new college built at Selly Oak, Birmingham is the first short-term residential adult education college in the United Kingdom specifically designed to accommodate both the physically handicapped and able-bodied. It aims to provide a wide range of short courses (about 9-12 days on average) for students of 16 and over.

Unfortunately due to financial pressures the main courses will not begin until 1976. But Prospect Hall has already played host to some students, for in the Summer two courses were organised there by PHAB (Physically Handicapped and Able-Bodied).

Donna Smith, a spina bifida in her mid-twenties was on one of these courses and has written her impression of the college.

An introduction to pottery — just one of the crafts which will be taught at Prospect Hall. The aim is to introduce students to subjects and hobbies which they will be able to develop after the course. Note the potter's wheel is at a suitable height for students in wheelchairs.

It's a brand new, ultra-modern college situated four miles from the centre of Birmingham and is part of the Selly Oak Colleges complex. It offers courses covering subjects from arts, crafts and hobbies of various kinds to specialised subjects including gardening and horticulture, religion, literature, sociology, current affairs, and freelance journalism.

The underlying aim of Prospect Hall is to encourage both the physically handicapped and able-bodied to become interested in new subjects and hobbies.

The whole College is geared to the physically handicapped and their various needs so that they may be as independent as possible during their stay. The study bedrooms in particular are spacious with ample room for students in wheelchairs. The able-bodied use exactly the same type of rooms and also feel comfortable and at ease when occupying them.

When Prospect Hall is in full swing there will be care staff on duty to help the handicapped, and also qualified nurses, although it is intended that able-bodied students will help, as it is only through mutual help that each person learns the meaning of the words 'give and take'.

I was fortunate enough to be invited to the second of two PHAB courses that were held at the College in August. Students came from the U.K., France and Germany. The subject for study for the week was Shakespeare and Stratford Country.

With the help of our three really excellent tutors we studied either Shakespearian drama (my choice), Elizabethan music or Elizabethan Theatre. The last group, amongst other things, made a painted cloth back-drop for our concert on the last evening of the week. We performed some of our week's work to an audience of friends, and we all enjoyed ourselves, I think!

The course gave the participants, particularly the physically handicapped, 'opportunity not pity' — the old and established motto of the PHAB organisation.

ANNUAL MEETING

The Challenge

Despite the problems of inflation — and the heavy rain outside — delegates to ASBAH's Annual Meeting in London in September were given no chance to be gloomy. The atmosphere was one of optimism and challenge for the future.

The President, The Rt. Hon. Lord Maybray-King opened the Meeting, with a flourish and congratulated ASBAH on its work.

The important service provided by the Field Social Workers was praised by ASBAH's Chairman, Mr R. B. Zachary, who said, 'the need for them is now without question.' But he pointed out that this work was severely limited by lack of money. However where Local Associations could carry the main financial burden the National Association could continue to give valuable assistance through its Senior Social Worker.

Mr Zachary made special mention of Five Oaks, which is to be ASBAH's new short-term care home and the need for a further £60,000 for alterations, furnishings and equipment.

Before moving the adoption of the Report, Mr Zachary said, 'Next year will be the tenth birthday of our Association and we are determined to make it a year to remember.

Mr D. M. Bryant (North Hampshire, West Surrey & S. Berks Assn) seconding the adoption of the Report referred to the Association's latest publication (Children with Spina Bifida at School) which gives guidance and help to teachers as, 'an object lesson in fulfilling what must be one of the Association's main aims — spreading accurate knowledge and help.'

After the formal business, Lord Maybray-King welcomed the guest speaker, Mr Geoffrey Gilbertson, Chairman of the National Advisory Council on the Employment of Disabled People.

Mr Gilbertson, himself confined to a wheelchair gave a broad outline of the Council's work to develop, within the Department of Employment, services and policies for the disabled.

While recognising that Government had an important role to play he spoke of the importance of striking the right balance between central control and the work of local organisations.

'Whatever happens, we must not lose the enthusiasm and commitment, and the practical skill of the hundreds of people who give a large part of their lives to caring for disabled people'.

Mr Gilbertson said he realised the concern felt about the future of the quota scheme and sheltered employment and said that the Government hoped to announce its proposals before the end of the year.

He added that sheltered employment was the most difficult area of all, because of the problem of getting a complete, nationwide service. He called upon ASBAH, through the Local Associations, to help by letting his Council know of the employment opportunities locally.

Dr Upadhyaya: 'John Holter of India'

A special guest at ASBAH's Annual Meeting was Dr Upadhyaya, a distinguished surgeon from India.

The Chairman, Mr Zachary, welcomed Dr Upadhyaya who is Professor of Paediatric Surgery in Delhi.

Mr Zachary told the meeting of Dr Upadhyaya's great achievement in producing an Indian valve for the treatment of hydrocephalus at a price which most Indians can afford. He had been aware of the lack of treatment for those with spina bifida and hydrocephalus in India and was concerned that the valves almost all came from America and were too expensive for a country like India.

He determined to develop an Indian valve. It was developed in a small room by hand, and soon five or six new patients with hydrocephalus were going there each week.

'The need is there' said Mr Zachary 'and now these valves are being produced commercially; the cost is approximately one-tenth of the cost of the valves which are at present being used. This contribution which Dr Upadhyaya has made has been recognised this year by an award of the Medical Council of India for this outstanding work. Dr Upadhyaya may well be called the John Holter of India.'

ANNUAL REPORT

Work goes on

ASBAH's Ninth Annual Report emphasises the difficult task facing the Association in the present economic situation.

It points out that the Association needs to expand and grow with the people and families it exists to serve. But 'in spite of increased support from the public, the falling purchasing power of each pound threatens the most carefully laid plans'.

Nevertheless, the Association through careful planning and thrift, is determined not to fail in its service to members.

The Annual Report, published in September, shows the wide scope of work undertaken by the Association during the year.

Generally the Association sets out to complement existing services and to assist in cases where its special experience of spina bifida and hydrocephalus could be of help.

The importance which ASBAH attaches to the problems facing school-leavers and young adults was highlighted during the year by the appointment of an Education, Training and Employment Officer, Mr P M Johnston-Smith who has already extended the Association's knowledge and influence in this important field.

In the field of appliances and equipment the Association through its Appliance Officer continued not only to give valuable advice, but also to stimulate research and development of special items. But the Report sounds a disquieting note over the slow and inefficient provision and repair of calipers in many parts of the country.

'We are told that the reason is principally lack of staff skilled in the craft — especially the leatherwork. Can no incentives be made available, so that workers may train and continue to work in this vital and, it could be thought, satisfying service?'

The battle against inflation is well illustrated in the Report. The Appeal team raised £100,000 compared with £73,000 in 1973/4 for specific areas of work and for the maintenance of services. It was a magnificent effort, but was £10,000 less than the Association needed.

Nevertheless the Association was heartened by the response from its supporters.

The Report praised the work of the Local Associations — '.. they are an integral part of the Association. The feelings of interdependence and unity are deepening with the years . . . '.

*** Copies of the Association's Annual Report for 1974/75 can be obtained from National Office.**

RESEARCH

The Association and the Spina Bifida Trust are currently sponsoring the following research projects:

Chemical analysis of amniotic fluid in relation to ante-natal diagnosis. Dr. D. J. H. Brock — Edinburgh. (3 years 1973-76)	£6,852.
Work on the Effects of Genetic Counselling. Dr. M. Laurence — South Wales. (1 year 1974-76)	£2,000.
Study of Brain Tissue Damage in Hydrocephalus. Dr. R. Weller — Southampton. (3 years 1974-77)	£1,100.
Investigation of Shunt Colonisation. Mr. R. Bayston — Sheffield. (2 years 1974-76)	£9,659.
Ultra Structural Study of Developing Spinal Cord. Dr. A. J. Barson — Manchester. (3 years 1972-75)	£3,866.
Support of research projects in pathological, orthopaedic and urological aspects of spina bifida. Prof. J. Emery — Sheffield. (3 years 1974-77)	£6,650.
Investigation into Mobility Requirements of Children with Spina Bifida. Prof. N. S. Kirk — Loughborough. (1 year 1975-76)	£10,000.
Development of Sanitary Equipment for Spina Bifida Subjects. Prof. L. B. Archer — Royal College of Art, London. (1 year 1975-76)	£2,950.
Design and Development of Hand-propelled Go-Kart. Mr. Eric Booth — Queen Mary College, London. (1 year 1974-75)	£3,000.
Educational Psychologist. Dr. J. Lorber — Sheffield. (3 years 1973-76)	£11,966.

Aids and equipment

The Scamp – new car comes onto the market

A new hand-propelled vehicle, The Scamp, has just come onto the market and for this we have to thank Vauxhall Motors.

Some two years ago the Student Training Department of Vauxhall Motors were approached by Mrs Herbert, the Headmistress at the Lady Zia Wernher School in Luton and asked if they could make a vehicle for the spina bifida children at her school.

After consultations with the school staff, including physiotherapists, and many trials with the children, the students produced a prototype hand-propelled vehicle. This first model was presented to the school in October 1973. Newer and better versions were then developed, until it was felt that the vehicle was good enough to be manufactured.

It was seen by the Appliance Committee of ASBAH who encouraged Vauxhall Motors to find a company to manufacture it. After much discussion, the design rights were given to Demeur Precision Ltd. To help reduce costs, standard parts have been used and many firms have given assistance, including Vauxhall themselves, Miles Redfern, and Raleigh Industries.

The Scamp is 36″ long and 21½″ wide, and weighs 25 lbs. The body slopes at the front so that the children can hitch themselves backwards onto it from the floor. It is propelled by backward and forward motion of the levers and steered by sideways movement of the levers.

The seating support has purposely been kept to a minimum to enable those with bulky calipers to sit comfortably. For those needing more support it is quite simple for a handyman to attach a padded cut-out plastic washing-up bowl or similar seat.

It looks very smart with its black moulded plastic body and red hubbed wheels, and we hope it will bring pleasure to many children. It should be suitable for children between about four and nine years.

The Scamp is available from:

Demeur Precision Ltd
17/19 Taylor Street,
Luton, Beds.
Tel: Luton 21488.

Price: £37.75 plus VAT. Post and packaging are extra. VAT will not be charged if the order is accompanied by a certificate signed by a doctor.

The 'odd shoe service' run by Queen Elizabeth Foundation for the Disabled (and mentioned in the July/August Link) has a new address. Orders and shoes should now go to the Queen Elizabeth's Foundation, Leatherhead, Surrey.

Health matters

Sweet and simple

JOHN RILEY considers a range of deodorants

Choosing a deodorant is of paramount importance, like finding the right appliance. Many firms boast of odour-proof bags but as yet I haven't found one that fully justifies the boast.

There are some very good deodorants about today and I think the best idea is to try one or two to find out which suits you. Not only is a deodorant beneficial to the wearer but also to the people with whom one comes into contact Undeodorised urine, as you know, can be very offensive.

During my post-operative days I knew nothing of deodorants, but I soon took the hint when my relatives started wearing gas masks. Exaggeration of course, but not too far from the truth.

Now that deodorants are available on prescription there is no reason why you should not shop around to find a suitable one. Here then are my comments on some that I have tried over the past three years:

Satts 'No-Roma'.

I am using this one now and I find it very good for permanent and disposable type bags. Unlike other deodorants mentioned here 'No-Roma' does not have a smell to it.

J. G. Franklin 'Ostomy Plus'.

This proved very effective for all the appliances I have tried. There are separate, scented deodorants for men and women which is rather novel, and they are easy to carry in purse or pocket. I think the container could be made a little larger as the contents of the bottle do not last very long.

Simpla Sasco 'Dor'.

This is also very effective for all types of appliances, but I think that the scent is too strong.

Downs Surgical: 'Chironair'.

This deodorant, on the contrary, is not strong enough, and I had to use large quantities to get rid of odour. Also I found the container a little bulky for the pocket.

This article is based on my own experiences and what suits me may not necessarily suit others. However, I should be very interested to receive any comments and to hear your views.

Editor's note: Please write to John Riley, 52 Hay Green Lane, Bourneville, Birmingham 30 1UN. John, who is a spina bifida with a urinary diversion, is Ileal Conduit Secretary for the Midlands.

● Felicity Birkett, ASBAH's Appliance Officer comments: 'There are also two other products on the market which I would recommend you to try:— Hibitaine, and Nilodor, Both can be obtained from chemists.

Appeals and publicity

'What have you asked Father Christmas for?'

● **Mark Dawson and Lorraine Sharp of Highfurlong School, Blackpool, photographed by Mr Barron Woods, a husband of one of the staff.**

And we wish you all a very happy Christmas and hope the New Year will be brighter in every way.

SUPPORTERS KEEP UP THE GOOD WORK

Quite a lot of decisions have to be made virtually in the dark: Will people buy Christmas cards, or won't they? Will annual subscribers be able to afford to send their subscription this year, or won't they?

We in the Appeals Department seem to be using up a lot of faith these days because we have to plan so far ahead. I hope life is more simple for fund-raisers in your area.

Our annual subscribers are one of our standbys, and this year, realising how difficult it is even for able-bodied people to manage in these inflationary days and therefore how much more difficult for those with handicap, they have been very generous. And so have many others. We are most grateful.

By the time you read this we shall have collected up the Geoffrey Boycott sponsorship money but at the time of writing I am unable to say what the total will be. But we do congratulate Geoffrey on scoring 1,915 runs and we thank him for his great interest and kind concern. We hope he will be able to be present at the opening of our short term care home 'Five Oaks' for which he has batted so magnificently.

The next item on our programme is the carol concert in Trafalgar Square on Tuesday 16 December at 5pm. We have been privileged to obtain the Band of the Grenadier Guards, who are giving their services free, and to lead the singing we have the Scouts and Guides Choir from Bexley Heath.

Plans are going forward for the Midwinter Ball on 21 January at the Dorchester and for the Gala Performance at the Palladium on 29 February. The kindness and readiness to help that so many people are showing to us is really very encouraging and I feel sure it helps parents to know that there is so much goodwill.

One of London's largest colleges — the Imperial College — has promised to run its Rag season in aid of ASBAH and we hope for a sizeable contribution from their efforts — which they wish to be divided between the short term care home and our research programme. As an experiment we have produced a 'uniform' for their collectors, which may be of interest to flag-day organisers in local areas. It is a tabard, made by joining two spina bifida plastic carrier bags at the shoulders, cutting out a hole for the neck and fastening the bottom corners with tape or string. Quite effective — and a help if it is raining!

Do not forget ASBAH's month next May when we hope to put the message across to a wider public. If we all concentrate our efforts on making this a really sizzling month of activity it must bring us valuable publicity.

Kate White

ASBAH publications and publicity

Your Child with Spina Bifida, 3rd Ed., by J. Lorber, MD, FRCP . . . 20p
Your Child with Hydrocephalus by J. Lorber, MD, FRCP 15p
Equipment & Aids to Mobility by O. R. Nettles, MCSP, ONC. A folder of four booklets . . . . complete set 25p
Clothing for the Spina Bifida Child by Barbara Webster, SRN, RSCN. . . 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
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).

Posters. Double Crown, 5p each, 'Best Foot Forward'—separate posters for General Appeal, and local publicity events, 10 for 40p.

Flag Day emblems. 1,000 for 70p.

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 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 SB4 6LZ.

Special offer

Children's badges with S B symbol and the words "Spina Bifida Children" in black on green. Special reduction to clear—2p each. Cheques and postal orders 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 £1.10p plus postage, while stocks last. Reductions for bulk orders. Cash with order to Mr. B. High, 10 Woodruff Ave., Burpham, Guildford, Surrey. Please state colour.

BOOKS

Two new books for young people have recently been published to give an insight into the lives of physically handicapped children.

Mark's Wheelchair Adventures by Camilla Jessel (Methuen £1.95).

This is a story with many black and white photographs of a handicapped boy Mark. He has spina bifida and moves with his family to a housing estate, and the story shows how he is soon able to share in the activities of the children in the neighbourhood. Easy reading, and suitable for children from about eight, it does however paint a rather idealistic picture of the life of a handicapped child.

Rachel by Elizabeth Fanshawe (Bodley Head £1.45).

Primarily a picture book for young children, it tells the story of young Rachel in her wheelchair who goes to an ordinary school and does ordinary everyday things like any other child. The coloured drawings are beautiful and the whole book is sympathetically and cleverly written. It is unfortunately rather expensive as a little book for a young child.

The Editor.

Inter-association holiday opportunities

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

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

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

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.

Prestatyn: 2 six-berth luxury caravans, running hot and cold water, flush toilets, televisions, gas fires. £12.50 per week. No vacs. August. Apply: Mrs. E. Taplin, Colonial House, 63, Corporation Street, Manchester M4 3DT.

Selsey. New well-appointed, self-contained 16ft. x 30ft. 6-berth mobile for families with spina bifida members. Sited at Selsey, Sussex. For full details please send s.a.e. to Mr. R. V. Taylor, 3 Dickins Way, Horsham, Sussex, RH13 6BQ.

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: High Wycombe 32184.

ADVERTISEMENTS FOR 1976

Link is revising the complete list of advertisements on this page for 1976 starting with the next issue. This includes advertisements under 'Local Association offers' and 'Inter-Association holiday opportunities'. We are starting afresh, so existing entries will only go in if you ask or send in your details. All copy to Link Editor at National Office by December 1st.

AFFILIATED ASSOCIATIONS – Hon Secretaries

BEDFORD AND DISTRICT
Mr. S. Odell,
9 Beauchamp Road,
Wootton, Beds MK43 9E2.

BOLTON AND BURY
Mrs. B. Grosvenor,
12 St. Peter's Road,
Bury, Lancs, BL9 9RB.

BOURNEMOUTH, CHRISTCHURCH & DISTRICT
Mr. D. D. Lanning,
1 Blythe Close,
Christchurch, Dorset.

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
Mrs. M. Robinson,
266 Colne Road,
Slouth, Earby.

CALDERDALE
Mr. A. L. Crowther,
42 Marldon Road,
Northowram, Halifax.

DARLINGTON AND DISTRICT
Mrs. M. Crawford,
53 Linden Terrace, Copley,
Bishop Aukland, Co. Durham.

DERBY
Mrs. P. E. Broadgate,
11 Old Lane,
Darley Abbey, Derby.

DEVON AND CORNWALL
Mr. J. Carter,
5 Culme Road,
Mannamead, Plymouth.

DON AND DEARNE
Mr. T. J. Murphy,
43 Cutts-Avenue,
Wath-On-Dearne, Yorks.

EAST ANGLIAN
Mrs. P. Symonds,
28 Leys Road, Cambridge.

ESSEX
Mr. J. T. Saunders,
2 The Ruskins, Rayne,
Braintree, Essex.

GLOUCESTERSHIRE
Mrs. B. Symonds,
9 Collum End Rise,
Leckhampton, Cheltenham,

GREENWICH
Mrs. J. Goldsmith,
194 Dacre Park,
Lewisham SE13 5SH.

HAMPSHIRE NORTH, W. SURREY & S. BERKS.
Mrs. Selby,
The Old Police Station,
Leapale Road, Guildford.

HAMPSHIRE SOUTH
Mr. C. Bowen,
7 Brocklands, Havant.

HERTS AND SOUTH BEDS.
Mrs. S. M. McGavin,
21 Claygate Avenue,
Harpenden, Herts.

HUDDERSFIELD
Mrs. C. Carter,
32 Winget Avenue,
Cowlersley, Huddersfield.

HULL & DISTRICT
Mrs. G. D. Brown,
233 Cranbrook Avenue,
Hull HU6 7TX.

JERSEY (Channel Islands)
Mrs. U. Emmanuel,
Le Lavandou,
Gorey Village, Jersey, C.I.

KENT
Mrs. P. Fearn,
120 Mill Street, E. Malling.

LEEDS AND BRADFORD
Mr. G. Baxter,
38 Hoyle Court Road,
Baildon, Yorks.

LEICESTERSHIRE
Mr. P. Cusack,
39, Kings Walk,
Leicester. F.E.

LEIGH & DISTRICT
Mr. T. Power,
3 Taunton Drive,
West Leigh, Lancs.

LINCOLN AND DISTRICT
Mrs. P. Keyse,
Pinfold, Chapel Lane,
North Scarle, Lincoln.

LINCOLNSHIRE
Mrs. Blakey,
7 Shetland Way,
Immingham,
S. Humberside.

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

LONDON
Mr. J. Barefoot,
23 Marlborough Road,
Southall, UB2 5LW.

Barnet area
Mrs. V. A. Brooker,
6 Merrivale, Southgate,
London N14 4SH.

Ealing area
Mr. L. R. Mower,
59 Betham Road,
Greenford, Middx.

North East (Forest) Area
Miss. D. Baxter,
8 Keith Avenue,
Wickford, Essex.

LONDON SOUTH
Mrs. C. Byrne,
Flat 1, 10 Wexford Road,
London, S.W.12.

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

MANSFIELD, WORKSOP AND DISTRICTS
Mrs. E. Freeman,
23 Melbourne Street,
Mansfield Woodhouse, Notts.

NORTH EAST (Northumberland)
Mrs. E. Grant,
27 Redwell Road, Prudhoe,
Northumberland.

NORTHAMPTONSHIRE
Mrs. Aldwinkle,
38 Robin Lane,
Wellingborough.

NOTTINGHAM & DISTRICT
Mrs. S. E. Plant,
305 Foxhill Road,
Carlton, Nottingham.

PONTEFRACT, CASTLEFORD & DISTRICT
Mrs. N. Robinson,
4 Sandal Rise,
Thorpe, Audlin,
Pontefract WF8 3EX.

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

ST. HELEN'S & DISTRICT
Mrs. N. Maddocks,
324 Warrington Road,
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,
Blackfield,
Southampton SO4 1XB.

STAFFORDHIRE
Mrs. J. Davies,
8 Oakhill Avenue,
Oakhill,
Stoke-on-Trent ST4 5JN.

STAINES, HOUNSLOW AND DISTRICT
c/o Mr. J. C. Edwards,
12 Sunmead Road,
Sunbury on Thames, Middx.

STOCKPORT
Mrs. S. Silver,
1 Brookside Avenue,
Offerton, Stockport.

SUNDERLAND
Mr. W. D. Easton,
4 Irene Avenue, Grangetown.
Sunderland.

SURREY (NASBAH)
Mrs. D. M. Driscoll,
26 Limes Avenue, Waddon,
Croydon, Surrey.

SUSSEX
Mrs. M. White,
Averys, Rusper,
Horsham, Sussex.

SWINDON AND DISTRICT
Mrs. J. Trembling,
3 Church Place,
Swindon, Wilts.

TRAFFORD
Mrs. A Bough,
9 Overdale, Crescent,
Flixton, Urmston.

WARRINGTON & DISTRICT
Mr. S. J. Charlton,
36 Park Avenue,
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.

WORCESTERSHIRE
Mrs. M. Davis,
Lower Field,
Wynniatts 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 Road,
Edinburgh EH4 2BW.

MID WALES & BORDER COUNTIES
Mrs. D. Brayne,
5 Woodcote Way,
Monkmoor, Shrewsbury, Salop.

NORTH WALES
Mrs. M. Messham,
47 Cherry Tree Road,
Bradley, Wrexham.

SOUTH WALES
Mrs. D. Cox,
28 Cromwell Road, Bulwark,
Chepstow NP6 5AD.

OTHER LOCAL ASSOCIATIONS

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

Cannock & Walsall
Mrs. W. Evans,
19 Drake Road,
Bloxwich, WS3 3LR.

Chester & District
Mrs. K. Jones,
19 Beech Hey Lane,
Willaston, Wirral.

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.

Dudley & Wolverhampton
Mr. B. Attwood,
1 Autumn Drive,
Lower Gornal, Dudley.

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

Lunesdale (Lancaster)
Miss P. Crook,
Brananlor, Ball Lane,
Caton, Lancaster.

Rochdale
Mrs. Ann Lawton,
55 Wimpole Street,
Shaw Road Estate,
Oldham, Lancs.

Spenborough (Yorks.)
Mrs. H. Lodge,
38 George Street,
Cleckheaton, Yorks.

Teesside
Mr. J. Gray,
Marchesi Centre,
Tollesby Road, Middlesbrough.

NORTHERN IRELAND
Ballymena
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.

EIRE
Irish Assoc. For SB & H
Joseph Plunkett Power
Ballymun.
Dublin II

Printed by David Green (Printers) Ltd, Kettering, Northamptonshire