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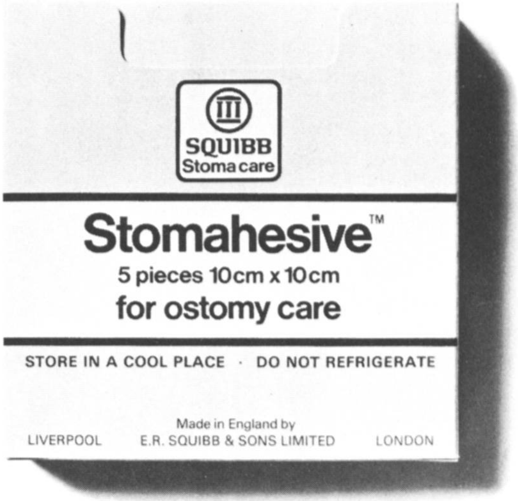
Link

MAY/JUNE 1976 **5p**

Association for Spina Bifida and Hydrocephalus (ASBAH)

Happy birthday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Link No. 44

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

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Appeals Secretary:
Mrs. Kate White

Liaison Officer:
Mr. H. D. Macfarlane

Link Editor:
Mrs. Susan Gearing

Special Birthday Issue Contents.

Also—Special 8 page Birthday Supplement.

Editorial

HAPPY BIRTHDAY

Ten years ago this month (May) the Association for Spina Bifida and Hydrocephalus officially got underway.

It is a mere infant compared with many well-known national charities whose roots go back to Victorian times. But it is no mean feat to start, and firmly to establish a new voluntary organisation serving the whole country. Some charities spring up overnight, and die just as quickly, and it is a tribute to the determination of parents and professionals that ASBAH has continued to grow.

In just ten years its work has served to bring spina bifida in out of the cold, to unite parents and to provide better facilities. These are, however, only early days, and there is a great deal more to be done.

At the ten year mark it is good to pause, and celebrate. But in the midst of self-congratulation there should also be a firm resolve to be bolder and to work even harder for the interests of those with spina bifida and hydrocephalus.

Link is celebrating with a special Tenth Birthday Supplement in the centre of this issue.

PROFESSOR ZACHARY: It is fitting that in this special birthday issue we are able to announce that the Association's Chairman has been honoured with the status of Professor.

HIGHLIGHTS 1966-1976

1966	ASBAH founded.
1967	Harry Secombe launched first appeal.
1968	First five research projects started.
1969	Film, 'What is Spina Bifida?' produced.
1970	Frenchay Unit, Bristol, opened.
1971	Social Workers scheme inaugurated.
1972	First Spring Conference held, at the University of Keele.
1973	HRH the Duchess of Gloucester became Patron.
1974	Ante-natal diagnosis research results.
1975	Five Oaks purchased for short-term-care home.
1976	Tenth Anniversary. Opening of Five Oaks.

News from all around

Duchess visits Sheffield

Sheffield was honoured by a special visit in March from ASBAH's Patron Her Royal Highness the Duchess of Gloucester. She visited Mossbrook School for Spina Bifida Children and in her calm and kindly manner soon endeared herself to staff and children.

After an official reception by the Lord Mayor and Lady Mayoress of Sheffield the Duchess was conducted around the school by the Headmaster, Mr E. Mullin. At first hand she saw the varied work of the medical and physiotherapy departments, and watched some six year olds enjoying a swimming lesson in the heated hydrotherapy pool.

The Duchess also spent some time in the open plan teaching area of the school where the children were busy with their work—including formal school lessons, typing, cooking, needlework, music, etc. She was able to talk with many of the children and staff.

With the headmaster and several members of staff and children of nearby Oakes Park School, the Mossbrook staff and children gathered together in the school hall to thank the Duchess for a brief but memorable visit.

At Luncheon in the Town Hall representatives of local associations were presented to Her Royal Highness who received from the new Mayor the gift of a pearl-handled Sheffield-made pen knife.

The Royal guest then visited the Sheffield Children's Hospital which celebrates it Centenary this year.

The Duchess is presented with a bouquet. Photo: A. F. Tumstill.

She was shown round the Congenital Anomalies Research Unit at the hospital's Thornbury Annex to see the various pieces of research equipment there which have been financed by the Association. The Duchess was also able to talk to staff and to parents and children before her visit came to an end.

New holiday caravan

Swindon and District Association have successfully completed their holiday caravan appeal. The project, which was started just over 12 months ago, has raised over £2,000 in cash, plus numerous items for use in the caravan. Many of the donations were the result of a highly successful postal appeal organised by Mrs Eileen King, an active grandmother of a spina bifida child.

The new caravan, situated near the South Coast just outside Christchurch, is ideally situated for a varied holiday being close to both the sea and the New Forest.

'Engineering' progress

North Hants, West Surrey and South Berks Association had an interesting meeting recently about the work of the Engineering Unit at Queen Mary's Hospital, Carshalton.

Mr Bill Bond showed some of the gadgets that his unit had made to help all sorts of handicapped children improve their physical abilities. There was a potty trainer that played a tune every time there was a 'success', and panda whose eyes lit up when spoken to, and the door that dispensed a smarty when opened properly. Some were more complex such as the electric racing car with the adjustable stiffness steering.

News from all around

In the swim

Surrey (NASBAH) have discovered their very own sponsored swimming ace in Trudy-Anne Bush (right). Over the years she has raised more than £783 in this way and her latest effort — swimming a mile in one hour 20 minutes — raised £352 for the NASBAH caravan appeal.

Trudy-Anne has achieved this and much more despite her handicap and the 33 operations she has had to undergo. She is very active in the Guide movement and the picture shows her being presented with the Star of Merit by Mrs Marjorie Hughes, Regional Adviser for London and the South East.

Trudy's swimming prowess, and the magnificent work of her mother, Mrs Mary Bush, described as a 'corner-stone of NASBAH' were given recognition at the Association's annual meeting in March, when ASBAH's General Secretary, Miss Mary Oughtred, presented them with an inscribed salver and writing case and pen respectively.

£200 for bus

Wigan and Chorley Association have presented Wrightington Hospital School with a £200 cheque for their school mini bus fund. The hospital/school treats spina bifida children and one of them, nine-year-old Nicola Eccles presented the cheque to headmaster, Mr Jim Moon.

Conference Report

More people than ever before — over 170 — gathered together for ASBAH's Spring Conference this year, which was held in April at Culham College of Education, Abingdon, Oxfordshire.

As the Conference theme was 'Thirteen to Thirty — The Outlook for Young Members' it was particularly good to see a number of spina bifida adults, teenagers and children there as well as parents, teachers and other professionals.

The Conference got off to a good start with an opening address by Mr. Neil Marten, M.P., whose concern for the disabled is well known and whose thoughtful, as well as lively talk was a great encouragement.

The first half of Saturday morning was devoted to short talks by four experienced people on aspects of growing up: the role of home, school, and assessment centre in finding the right path. Later in the Conference members were given a new insight into what can be done, to give employment to severely disabled people where Management cares.

That there was scope for meaningful life,

Continued on page 7.

JENNIFER HILL WRITES ON COLLEGE, BEING AWAY FROM HOME, AND THE REWARDS OF IT ALL

I believe I am right in saying that only a small percentage of the population go to college or university; if this is true I must consider myself lucky to have been away for a year at Hereward College. This College, in Coventry, is specially designed for physically handicapped young people and the course I was offered comprised 'A' level English, 'O' level History and 'O' level Commerce.

I soon discovered that it was a lot more difficult than I had anticipated. History isn't my strong point anyway, and although I enjoy English Literature I realised that the depth of study at 'A' level was beyond me. I was able to drop History half way through the course and take German. Towards the end of the academic year students who were half way through their courses had interviews concerning their plans for the following year. I jumped at this opportunity to explain that I felt the English course was too heavy going and that I would do better to leave and try to find some kind of employment. I did manage to scrape through 'O' level Commerce which I am sure will prove useful.

For the past six months or so I have been trying to get into the field of French translation, with the help of a translator who lives the other side of Cardiff. This person has given me some very helpful tips, but she has warned me that it may take several years to attain the required standard.

I thoroughly enjoyed my year at Hereward College; as a Christian I am sure God had a purpose in sending me there. There were a few other committed Christians and we formed a Christian Union. The leader of this group was a very severe spastic with a speech impediment. She had terrific determination and has now gone to Sussex University.

Being away from home I missed my parents, in fact I used to phone several times a week. I would probably have phoned every night if I had had enough 10p's but that would have destroyed the object of being away.

Of course, there were a few students who had lived most of their lives in institutions. I think they probably found it easier to adjust to college life than some of us who had left home for the first time.

I feel sure that every physically handicapped person benefits from a time away from home. It broadens their outlook on life and makes them more independent. Also I think it gives them more confidence in approaching people and meeting new situations. Having been away from home I would be happy to do it again.

Although I did not achieve all the qualifications I hoped to, I do not feel this was a wasted year.

An ex-headmistress once wrote to me and quoted this prayer:

> "God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference."

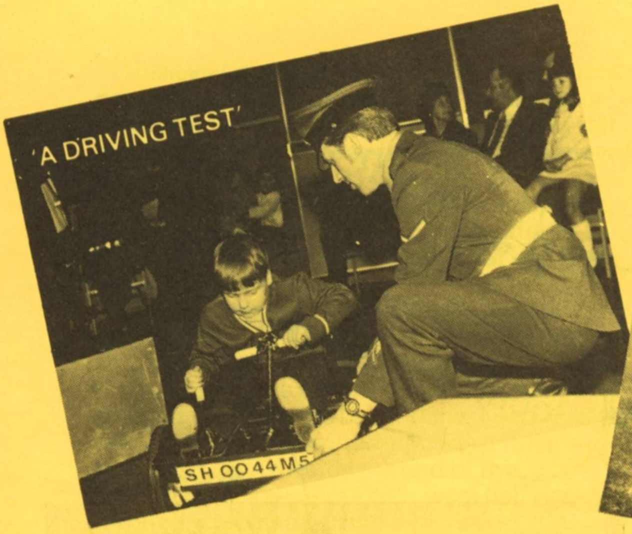
I don't think I can close on a more appropriate note.

Our first ten years

1966-1976

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Link
Souvenir Supplement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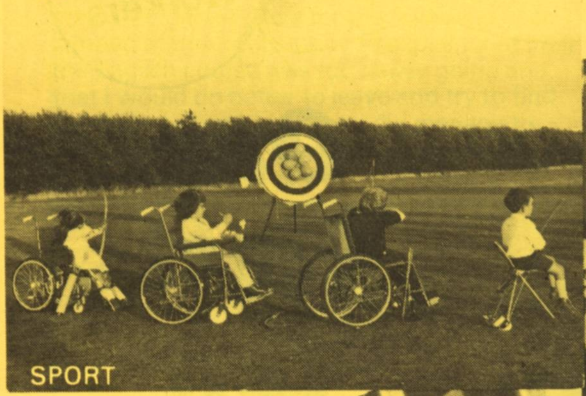
'MAGPIE' APPEAL


SPORT


CHRISTMAS PARTY


MOBILITY


HOLIDAY HOME

A
DECADE
OF
PROGRESS

by Frank Armour who has been involved with the Association since the beginning, and who is also now a member of national staff (the Finance Officer) as well as being the parent of a spina bifida daughter.

The Association for Spina Bifida and Hydrocephalus began its legal existence on April 28, 1966 with the coming together of groups of parents. These groups had formed around the main treatment centres, such as Sheffield, London, Bristol, Glasgow and elsewhere.

The first annual meeting, held in November 1966 under the Chairmanship of Robert Zachary, was attended by delegates (mainly parents) from most parts of the country, and Scotland and Wales.

Within a year the first National Office had been opened in a small attic room alongside Charing Cross Station in London—and within two years an Appeals Organiser and the first full-time General Secretary had been appointed.

The Association's magazine 'Link' appeared at the same time. It has been published continuously throughout the ten year period, and now has a 10,000 circulation. It is a source of up-to-date information and guidance on all subjects relating to spina bifida and hydrocephalus.

The task of informing the general public—and relevant Government departments—about the problems and the needs of those with spina bifida and hydrocephalus was seen from the start as a vital part of the work of the movement. Both the rapidly growing Local Associations and the national body continue to expend a lot of time on this important aspect of public relations and there is no denying that a vast change has in fact taken place in the past ten years in public knowledge and understanding of these two conditions.

The press, television and radio also helped, and celebrities who have played great parts in various ways include Harry Secombe, Wendy Craig, Dora Bryan, Derek Nimmo, Michael Barratt, the 'Magpie' team from Thames Television, Larry Grayson, Arthur Lowe, and Geoffrey Boycott.

Equally effective has been the patient work, and the solid achievements of ASBAH and the Local Associations. ASBAH has always given priority to the needs of these Local Associations, of which over sixty are now affiliated. Each of them was started by the voluntary efforts of parents and other interested people and each is an independent Association 'doing its own thing'. But the resources of the National Association are always at their service.

The achievements of the Local Associations have been varied and numerous, but the Spina Bifida Unit at Frenchay Hospital, Bristol; Tudor House at Liverpool; and the Marchesi Centre at Middlesbrough, represent three high-points of practical endeavour. There have been other particularly valuable achievements such as the three day Conference at Skegness in 1970 organised by the N. East and East Midlands Regional Liaison Committee which attracted so many delegates.

Other important developments in the decade have been the appointment of specialist field social workers in certain areas, the production of informative booklets and films for the guidance of parents, 'patients' and professionals, the development of an advisory service on appliances and

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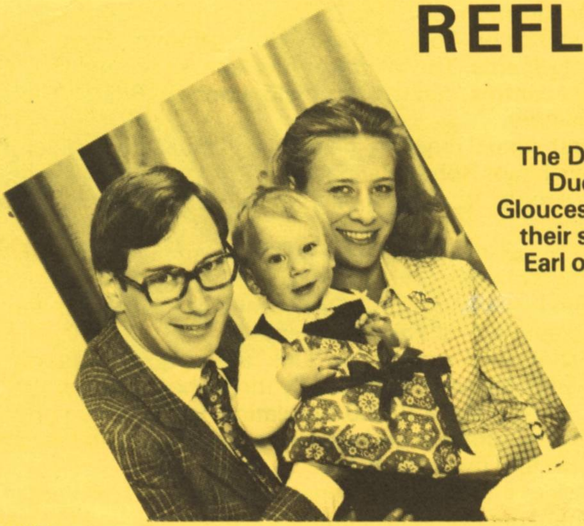
REFLECTIONS ON OU



The Duke and Duchess of Gloucester with their son, The Earl of Ulster.

B

KENSINGTON PALACE
LONDON W8 4PU

May, 1976

It gives me great pleasure to extend my warmest congratulations to the Association on its tenth Anniversary.

From my personal experience as Patron for the last three years, I know what strength and encouragement the Association gives to its members, and how much good has resulted from the wider public awareness of the nature of Spina Bifida and Hydrocephalus.

I would like to send to the Association and to every member, my very best wishes for the years ahead.

Professor R. B. Zachary, FRCS, Chairman of ASBAH writes:

The Association started because it was needed. Ten years ago spina bifida was being treated in a number of centres in the country, not only by operation on the back but also with the valve for hydrocephalus, orthopaedic treatment for the legs and medical and surgical treatment of the urinary system.

Although the doctors in charge would plan the treatment in advance, the parents were all too often in the dark.

To overcome this lack of knowledge parents were called together in various parts of the country, e.g. in Sheffield on a Saturday afternoon, for a talk outlining the principle problems of spina bifida and hydrocephalus and the aims of treatment.

It was obvious that a similar need existed throughout the country. Representatives from London and Manchester visited Sheffield and decided to form a National Association.

The first aim, therefore, was the spread of knowledge of the condition, not only to parents but to the public at large and especially to the medical, nursing, teaching and welfare professions. In addition the special requirements of these children were made known to the authorities.

As the children grew up, so it became clear that the educational opportunities were very limited, that families were in urgent need of help and advice in the field of welfare, that appliances were poorly designed and slow to be supplied, that

R BIRTHDAY

young people were finishing their limited schooling with no chance of employment, that some parents could never have relief from their burden for a holiday, that many children hated school holidays because they were confined to the house.

What a variety of problems arose to be tackled by this young Association, and the Association has grown in stature to meet the challenge.

Full-time staff have been appointed, so that the fields of welfare, of appliances, of education and of publications are now covered.

Although expert advisers have joined in this work the Association has remained a "grassroots" organisation with its Council of Representatives from each of the 60 affiliated local associations.

How little of this work could have been done without the vigorous and successful activity of the appeals department which has enabled us to achieve such highlights as the Research Fellowship Fund and purchase of the short term care home.

The support we have in our appeals and in our everyday work from a number of important and influential people has encouraged the public to help us generously. One need only mention the particular and personal involvement of our President Lord Maybray-King over many years.

We are extremely fortunate to have as our Patron HRH the Duchess of Gloucester whose interest and real concern for our people is so apparent. What an inspiration to make the second decade even better!

The RT. Hon. Lord Maybray-King, President of ASBAH, writes:

When ASBAH was founded ten years ago spina bifida and hydrocephalus, although scourges of infant life, were unknown to the general public, and infant mortality among these children was very high.

Professor Zachary (and we congratulate him this year on his Professorship) led a group who founded ASBAH and it is to his vision and devotion that many owe a great deal.

One of the great tasks was to inform the public of these special children and their special needs. Year by year we steadily succeed in this field. Fraternal organisations like the Independent Order of Foresters and the Loyal Order of Moose, schools, kindly folk, have contributed gifts to ASBAH.

Local Associations have been formed and are growing in number. Here parents can share experiences and difficulties.

The special needs of handicapped children, special equipment, special apparatus are gradually being investigated and provided. The spina bifida child is now helped to one of life's greatest gifts—mobility. Side by side with this, research into causes and treatment continues to develop, and now in the tenth year, one of the dreams approaches reality—a home where children can stay for short periods.

The first ten years have been years, first of venture, and then of achievement. All this has been made possible by the magnificent voluntary efforts of skilled medical and surgical men and women, by splendid work in the local branches, and by a small but devoted band of administrators at headquarters, led by the General Secretary, Miss Mary Oughtred.

I congratulate ASBAH on its first decade, and look forward eagerly to triumphs in the second ten years.

Sir George Haynes, CBE, a Vice-President of ASBAH writes:

I consider that ASBAH has made a quite outstanding contribution to the welfare of the disabled.

Ten years ago the public was largely unaware of the nature of spina bifida and hydrocephalus; of its severity and the extent of the suffering it caused. It was a handicap known to relatively few.

This lack of social awareness and hence of social concern has been transformed. This is due, in large measure to the work of the Association and the activity of the growing number of local associations. There is now far more understanding of the nature of these severe handicaps.

The support of many authorities and voluntary organisations has been secured and cooperation is steadily increasing. Severe handicaps tend to isolate and separate those who suffer from them, but the larger community with deeper understanding is opening its mind to the opportunities for personal service.

There is a balance and perspective about the Association's activities which I find impressive. In the difficult times ahead, when financial resources remain very restricted, this quality in its work will be a source of strength.

WE NO LONGER HAVE TO EXPLAIN

Alan and Margaret Twyford (above) are married spina bifidas. They were adults when ASBAH was launched 10 years ago and they have played an active part in the life and growth of the Association. Here are their thoughts on the past decade.

Incidentally 'Link' can claim to have introduced Alan and Margaret.

He wrote to her about an article she had had published in 'Link' and some time after they arranged to meet.

My wife and I, aged thirty and both born with spina bifida, grew up at a time when there was no ASBAH. As we see it, the main achievement of the Association is the support given to parents and spina bifida adults through the many Local Associations, ASBAH publications (especially 'Link'), and through the annual conferences.

When we began work spina bifida was far less known and we had to explain to others what it is. Now, generally, our colleagues and friends have a good idea of what is involved, without our needing to explain. We are convinced this has resulted from greater coverage given to spina bifida in "the media" partly thanks to ASBAH's efforts.

We are encouraged to learn how much more readily "ordinary" schools at least at the primary level, are prepared to accept children with spina bifida. We both attended 'special' schools and feel this was best for *us*, but we recognise that for many of the present generation 'Ordinary' schools may be best.

Everyone should realise, that we *must* look to the future, when the children are adults, and hopefully, independent. Much support will be required by those who are now growing up. In this respect ASBAH can provide the necessary impetus, aided by others, to ensure that young people obtain necessary training and counselling.

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special equipment and toys, and on education and employment. The annual Spring Conferences, and the appointment of a Liaison Officer have also done much to link and improve relationships between the National and Local Associations and professionals.

The raising of large sums for medical and other forms of research has also been most important.

Now ASBAH looks forward to the next stage of its development, which must surely include a closer involvement with and concern for further education and employment prospects and the provision of occupation centres; with housing and accommodation for the handicapped; with the closer integration of the handicapped person into the life of the community and the activities of the Associations; and with the co-ordination of efforts for all disabled people.

These and other tasks, such as the running of the short-term care home due to open shortly at Ilkley in Yorkshire, will call for yet more injections of energy, expertise and money if they are to be successfully achieved, and if the Association is to have real impact in providing a life worth living for those with whom it is concerned.

The SHASBAH trolley story

Many children have reason to thank South Hants and the Southampton Local Associations for the useful SHASBAH Trolley.

The trolley was designed by Mr K. Charrett and the first trolleys were built in a blacksmith's shop in Fareham by members of the South Hants Association, more than 12 years ago.

Later the Southampton Association, led by Mr Frank Mortimer, took over production of the trolleys. Something like 2,000 trolleys have been produced.

BRISTOL SHARE TENTH BIRTHDAY YEAR

Bristol Local Association shares this 10th birthday year with the National Association and Link feels it appropriate to show the work which has been done over the decade in the West Country. It illustrates so well the invaluable service that a flourishing local association can give.

Saturday, 19 March 1966 was, to parents of spina bifida and hydrocephalic children in the Bristol, Gloucestershire, Wiltshire and Somerset area, the beginning of our Association, which has helped us all in one way or another.

During the first year, with an evergrowing membership, we held a garden party and a Christmas party for the children, had parents' evenings and raised over £600 for the adaptation of a kidney x-ray machine at a local hospital.

The next project was to buy and adapt our first caravan which was sited in Dorset and used as a cheap, or free, holiday home for our members.

In 1969, we became affiliated to the National Association and have "grown up" with them. First of all Swindon, and then Gloucestershire, branched off on their own with our initial help and now both North Wilts and Taunton have formed their own sub-groups.

Our biggest project was the provision of the Spina Bifida Unit at Frenchay Hospital, the first of its kind in the country, and we are now financing an extension of the unit, to give more space to the doctors and appliance fitters.

We have also purchased a mini-bus.

The present Secretary, Ray Mabbutt the Treasurer, Gordon Egan, and the Assistant Secretary, Avis Mabbutt, were on the original steering committee back in 1966. The membership has continued to increase, and many parents who have lost their children during these ten years are amongst our most interested members.

The Committee is very aware of the problems we shall face as our children come up to teenage and school-leaving years and appreciate this is now a main concern.

Our very best wishes to ASBAH as we share this 10th birthday year.

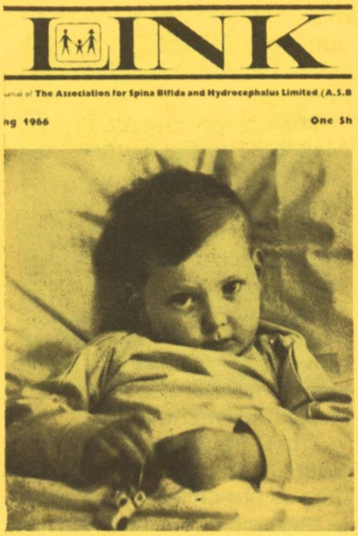
Sheila Egan, Bristol Association.

The first Honorary General Secretary of ASBAH, Mr T. L. Williams writes:

'I think it was autumn 1964 when Mr Duncan Forrest suggested that I might like to assist with the formation of a spina bifida association in the south.

How well attended were those early meetings! One could sense the emotion and the determination to do everything possible for our children. Much of the work was just hard graft, but it was done with an eye to the future.

It was a natural progression to link up with fellow travellers in Sheffield and other places to develop a national organisation. It was very rewarding to have worked with such a dedicated group of people.'



LINK

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

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Above, Peter Whitehead, aged 3, as he appeared on the cover of the first 'Link'.

Right, Peter, today a pupil at Coney Hill school Hayes, Kent.

TEN YEARS ON FOR PETER, SARAH AND JOANNA

'Link is ten years old this issue. The first 'Link' as we know it, came out in the Spring of 1966, having developed from a simple but effective duplicated newsletter. Young Peter Whitehead, then 3 years, was the cover star of the first issue. Now, ten years on, Peter has written about himself.

Here, too, is a short article about two spina bifida youngsters.

'I am Peter Whitehead and I am in the book again after ten years.

Now I am at Coney Hill School. It is a boarding school and I'm very happy, but I would love to be at home more often with my family.

I can walk on my feet with calipers and crutches which sometimes break and I have to use my wheelchair.

I have got a good family especially my Mum and I have a lot of interests like basketry, woodwork, cookery and flower arrangement. Recently I won a prize in the Shaftesbury Society Annual Eisteddfod and also a second class certificate in the National Christian Educational Council Scripture examination.

I have a lot of friends at school and at home. Most of my friends at home are my brother's friends.

One day I hope to be able to work a Telex Machine. At school I am learning to type'.

Ten-year-old Sarah Godfrey, and friend.

Here are just two—fairly typical—spina bifida youngsters.

The first, Sarah Godfrey, is ten this year (in November) and she and her parents are actively involved with the Bristol Association. Her life has been interrupted by numerous hospital stays—for 17 operations altogether. She has also had to fight meningitis and septicaemia. There have been times when her parents thought she would never pull through, but Sarah today is a lively child enjoying life to the full. Two of her great hobbies are brownies and swimming.

Joanna Toubkin, II, of Tonbridge, Kent is physically much more restricted, particularly at the moment as she is in a Milwaukee brace after a spinal fusion operation just before last Christmas. The Toubkins are members of Kent Association, but unfortunately few activities are held in their part of the country. Joanna is a pupil at Chailey Heritage, Sussex, but goes home every other weekend and her parents are having to extend the house on the ground floor to make it suitable for Joanna.

Appeals and publicity

Just the ticket !

I think it is generally agreed that in a changing world the approach to fund raising has to change too, because more and more people are finding outright gifts to charity are beyond their means. They still want to support good causes though, and are very ready to buy Christmas and greeting cards, for example, and other necessities where the profit goes to the charity of their choice.

Another market which has been successfully tapped is the regular weekly lottery and I am setting out details of a new venture sponsored by The Central Council for The Disabled because it may be of interest to your Local Association as a source of regular income.

An organisation called SUPPORT has been set up to be responsible for the prizes, printing, postage and administrative overheads involved in promoting a weekly lottery. Other charities are invited to become affiliates and to sell the tickets. Each ticket costs 10p and each week there will be £1,000 in cash prizes. All tickets sold by participating groups will yield a net weekly income @ 45% of the total sales, payable quarterly. Thus:

Weekly sales of tickets @ 10p each	Net weekly income @ 45%	Total net income projected for one year
	£	£
100	4.50	234
500	22.50	1,170
1,000	45.00	2,340

and so on!

There are only two stipulations: participating groups must guarantee a minimum weekly sale of 100 tickets and, to comply with the Lotteries Act, must become members of the constitution of SUPPORT. This entails a membership fee of £1 per annum, but for Associations affiliated to ASBAH we would take out membership as a National Association which would cover the legal requirement for our affiliates.

The benefits are the provision of a regular income with no financial outlay, administrative and paper work is kept to a minimum and your circle of volunteers and helpers will widen.

If you think you could find a salesman for the tickets—like the foreman in a largish factory say—get in touch with your Association Secretary and see what can be done to start a scheme in your area. I have full information which can be supplied to secretaries on request.

Please, do help our appeal for Green Shield stamps to buy furnishings for Five Oaks. We open this summer and need so many things! If every family could produce one full book by scrounging from neighbours and friends it would be marvellous.

Best of luck

KATE WHITE

Conference Report

continued from page 5

even without employment, was underlined in a very positive way by Mr. Ron Travers of the Cheshire Foundation and the last session brought together much of the earlier thinking through a talk on relationships within the family, with friends and with the opposite sex.

The Conference owes a great debt of gratitude to Dr. Esther Simpson, Senior Principal Medical Officer of the Department of Health and Social Security, who chaired the Conference so sympathetically and skilfully and who drew the two days' work together in a very able closing address.

Lady Jean Mackenzie, now so well known to all who attend the Association's Spring Conferences, once more delighted everyone with her availability, charm and concern for everyone's welfare. Her leadership of five successive conferences speaks volumes of her dedication to the Association and its work.

In response to requests from earlier conferences, more time was devoted to discussion groups and this was widely welcomed.

Unfortunately the Conference took place at about the time Link went to press and therefore only this short report can appear in this number. However a full Conference round-up will appear in the next issue.

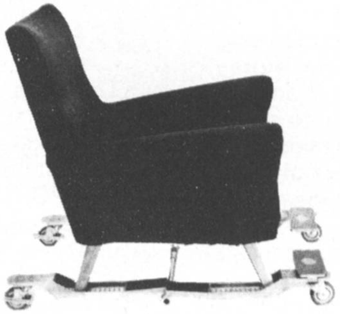
Aids and equipment

FELICITY BIRKETT

Making a chair mobile

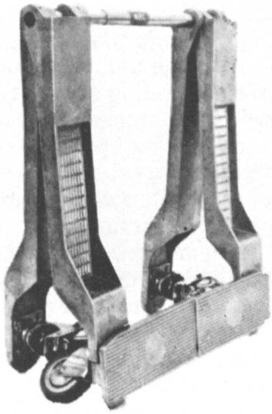
The Mini-roller (right) is a useful gadget for converting an ordinary chair—dining room or lounge type—into a wheelchair. It is a mobile chassis with four small wheels, the two back wheels having brakes.

The carrier folds in half and will then fit into a car boot or store away in a cupboard. It is narrower than a wheelchair and could therefore be used where the doors are not wide enough to allow a wheelchair to pass, thus eliminating having to carry a person. It could also be used upstairs in a house to save having to carry a wheelchair up and down stairs.



MINI-ROLLER—fitted to a chair.

The Mini-roller is available from Medical Supply Association, 77 Baker Street, London W1 and costs £19.50.



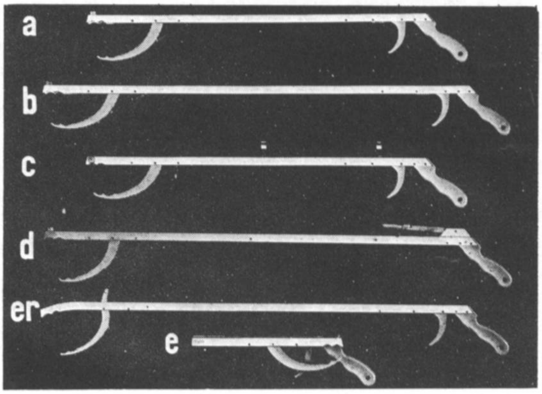
MINI-ROLLER—folded and ready for stowing.

Pick-up sticks

If you are confined to a wheelchair, walk in long leg calipers or have stiff hips, dropping something on the floor can be a disaster simply because you cannot reach the floor with your hand. A pick-up stick can help you to retrieve all manner of small objects from the floor and also to reach for books etc. from high shelves.

Some are straight sticks varying in length from 18ins. to 48ins., with a pick up device at one end; this device consists of jaws which open to about 2½ins. The handle mechanism works on a trigger, lever or squeeze principle and many have magnets on the end for picking up pins, needles etc. The lightweight ones are 4-8ozs. in weight and the heavy duty ones 16-22ozs; the prices range from 60p-£6.50.

The Helping Hand Co. of Church Road, Sandhurst, Kent make a variety of sticks one of which folds and is thus easy to carry. The British Red Cross Society, 9 Grosvenor Crescent, London S.W. 1 and Homecraft Supplies, 27 Trinity Road, London S.W. 17, both market a selection of pick-up sticks.



The full 'Helping Hand' range is now as follows (a) Featherwieght model, (b) Longreach model, (c) Limpet model, (d) Retainer model, (er) Easy reacher, (e) The Folding model.

The Department of Health and Social Security have appointed a new agency for the Piedro Boots. The Agency will keep a large stock of boots from child size 3 to adult size 8½ in three widths and we hope that the long delivery delays previously experienced will be eliminated.

INVALID CARE ALLOWANCE.

Someone staying at home to care for a severely disabled relative could be entitled to £7.90 a week from 5th July.

Someone who cannot do a full-time paid job because they look after a severely disabled relative, can now claim £7.90 a week Invalid Care Allowance, provided that their relative is receiving an attendance allowance.

Invalid Care Allowance is simple to claim because the disabled relative does not have to undergo any further medical examination.

Invalid Care Allowance is not means-tested and entitlement does not depend on any national insurance contributions having been paid. In fact, those who get the allowance will be credited with contributions to protect their rights to other benefits. This means it is worth claiming even as a replacement for any supplementary benefit which is being paid for looking after a disabled relative.

Who qualifies.

Anyone except a married woman can claim if they are:

* engaged full time (35 hours a week or more) looking after a relative who is getting attendance allowance or constant attendance allowance.
* aged 16-60 (women) or 16-65 (men).
* not earning more than £6 a week.
* not in full-time education.

Issued by the Department of Health and Social Security.

Who could get more.

In addition to the £7.90 a week personal allowance, £4.90 a week may be payable for a wife or housekeeper, £6.50 a week for a first or only child and £5.00 a week for each other child.

How to find out more.

Many thousands of copies of leaflet NI 212, which contains fuller details of Invalid Care Allowance and a claim form, have been sent out already.

If you know someone who hasn't received a copy yet, please tell them to ask at a DHSS office or use the coupon below–and claim the allowance without delay.

Please send me leaflet NI 212 about the new Invalid Care Allowance.

Name: ____________________
(Mr/Mrs/Miss)

Full Address: ____________________

____

____

Please post this coupon to DHSS Leaflets Unit, Block 4, Government Buildings,
Honeypot Lane, Stanmore,
Middlesex HA7 1AY.

IC/L/1.

'Link' presents the second part of an edited version of, 'Sex and the Handicapped,' a paper which was first given to a meeting of the Spina Bifida Association of Victoria, Australia, by Prof. R. A. MacMahon of the Department of Paediatrics, Montash University School of Medicine.

Sex and the Handicapped

If a spina bifida patient marries, can they have children, will the children be affected, and will they be able to care for the children?

Carter and Evans (England), studied a series of spina bifida patients born before 1954 to estimate the risk of neural tube malformation in the children of such patients who survive to adult life. This is, of course, a very select group who survived and married before much of the modern therapy, such as the hydrocephalus shunt was readily available.

The 215 patients who were traced have had between them 104 children, two of whom have a neural tube malformation. Thirty-eight of the patients have much of their reproductive life before them still, so this is still an incomplete survey.

The results of this study combined with two other studies give an estimate of risk to off-spring of patients of either sex of about 3%.

It is of interest to note that 14% of the male survivors have had children, while 55% of the female survivors have had children. This tends to confirm the information from spinal injured patients that male fertility is greatly impaired, while female fertility is little impaired.

The proportion of children affected (3%) of these patients, means that the risk of a spina bifida patient having a spina bifida child is about the same risk as that of the able-bodied parents of a spina bifida child having another spina bifida child. The important point to note about this present series is that the risk to children of male patients is at least as high as the risk to children of female patients.

The problems of the severely handicapped mother in caring for children would be a major factor to consider, but the final question of whether to have children must be a personal one. Mothers have coped with this very problem, undoubtedly with much support.

ASBAH booklets . . . leaflets . . . posters

Your Child with Spina Bifida, 3rd Ed., 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	15p
Clothing for the Spina Bifida Child by Barbara Webster, SRN, RSCN	15p
Equipment & Aids to Mobility by O. R. Nettles, MCSP, ONC.	25p
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
Best Foot Forward 20 x 30in. — 10p each.
Best Foot Forward 15 x 10in. — 10 for 40p.
For local publicity 15 x 10in. — 10 for 40p.

Car Stickers 5p each.
Cards for Notice Boards 10 for 10p.
Flag Day Emblems 1,000 for 70p.
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 Wear.

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.

Prestatyn: The two caravans usually advertised are fully booked for this year.

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 Dickins Way, Horsham, Sx, 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: 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.

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