

# Link

50

MAY/JUNE 1977 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)



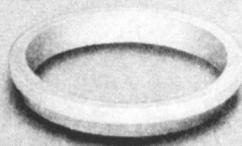
**THE PICTURE WHICH ALMOST TELLS IT ALL.  
FOR THE REST OF THE STORY,  
TURN TO PAGE 4** (Photo by Jack Hickes)

**New Squibb Stoma care product**



# Colostomy Pack

incorporating  
the **New** Squibb Colostomy Pouch Mk.1 with  
Stomahesive and Flange



## + Special Sealing Ring

**The Squibb Colostomy Pack:** a new, easy-to-use  
system of colostomy management ensuring  
freedom from skin problems with extra security  
comfort and convenience

**From Squibb: the people who invented Stomahesive™**

Further information is available on request from  
the Technical Department, E. R. Squibb and Sons Limited  
Regal House Twickenham TW1 3QT

Stomahesive is the registered trade mark of E. R. Squibb and Sons Limited



Link No. 50

Association for Spina Bifida  
& Hydrocephalus (ASBAH)

Patron:  
HRH The  
Duchess of Gloucester

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

Correspondence to ASBAH  
at the National Office:

30 Devonshire Street,  
London W1N 2EB  
Tel: 01-486 6100 or  
01-935 9060

Chief Executive Officer:  
**Miss M. P. Gilbertson**, MCSP

Appeals Secretary:  
**Mrs. Kate White**

Liaison Officer:  
**Mr. H. D. Macfarlane**

Link Editor:  
**Mrs. Susan Gearing**

#### Contents

pages	
4/5	News from all around
6	The Medical treatment of hydrocephalus in babies and children
7	ASBAH working party
8/0	We are Sailing
10/13	Spring Conference (Nottingham)
14	Appeals
16	Carole Smith—Poems and prestige

## Opinion

Thousands of words have been written about the many problems facing parents and handicapped children as the time to leave school draws near and 'Adolescence' has been the general theme of conference upon conference. Platforms have been occupied all over the country by speakers telling of facilities and proclaiming their wares, and an army of 'experts' is available to offer all manner of advice on procedures, organisations, opportunities and whatever-you-will.

To the unthinking all would seem to be under control. The fact is that many young people are particularly vulnerable when they leave school, for nothing like enough time and thought is given to their individual and special problems. Parents blame 'Authority' for lack of understanding and facilities and 'Authority' accuses parents of being possessive and unrealistic. Both are probably right but each must find a way of helping the other if the child is to have any chance of achieving his or her potential in the adult community.

It is not possible to even imagine the difference between an organised and caring special school and the competitive, bewildering adult world, and yet for very many young people that transition is expected to be achieved in a matter of days.

This must inevitably be a most difficult time for parents, for they must continue to be loving and protective but, also, to be able to assess and analyse. Everyone is expected to be realistic.

There is no escaping the fact that personal independence must be the goal if employment, even sheltered employment, is to be a real prospect. This means that personal hygiene is just as important as mobility and that such matters as work tolerance and concentration rate just as highly as the social graces: all are inescapable factors when plans for the future are being considered.

No one is going to change the world overnight so young people must be helped to plan their lives within the framework of our society as it exists today: above all, perhaps, must those plans ensure that everyone is given a chance—a chance to catch up on lost time, a chance to experiment.

If this is to be achieved, local authorities must win time for handicapped young people and must ensure that education authorities and social service departments combine to support the process of growing up, whilst parents must be prepared to play their part by supporting imaginative plans and by untying those symbolic apron strings.

**MR. ROBIN SMITH**  
Director of Queen Elizabeth's Foundation for the Disabled

**SPECIAL SCHOOLS:** Vera Stevenson's article on "The Case for Special Schools" in the last Link attracted a good deal of correspondence. We hope to carry some of this in the July/August issue.



## News from all around

# WHEELCHAIR PARENTS

**WHEN** baby made three for the Seagers of York it was indeed, as Susan Seager puts it, the "perfect seal on our marriage." For John is 33 and has been paralysed from the waist down since he contracted polio at the age of 5, and Susan is confined to a wheelchair through spina bifida, but **Baby Anna is fit and well and at just one year old is beginning to toddle about the place.**

Before she was married Susan was told by a genetic counsellor that there was only a slight chance that she would have a baby with spina bifida and 14 weeks into her pregnancy an amniocentesis test confirmed that all was well. There were no major complications during the

---

### Baby Anna is a dream come true

---

birth and from that moment on the Seagers have never looked back.

"We haven't had any real difficulties looking after Anna and manage her without help," said Susan.

### Neighbours

They do receive a little help with the household chores from a home help for 1 ½ hours each week and the neighbours often come to take Anna for a walk—"but only because they want to", says Susan.

"Most days I take her myself, strapped on my knee. Now she is trying to

walk we have a truck which she pushes around the house with us in pursuit to rescue her when she ends up in a heap.

"She rides around the house on our knees, without being fastened, quite happily and loves carrying things for us.

"John can do anything for her except bath her. He even changes nappies. The bath has a special lining so it isn't so far down for me to reach.

"I fed Anna myself, weaning her completely at 10 months. It's a heck of a lot cheaper than bottle feeding as well as a lot easier."

John and Susan went to the same school at Welburn Hall near Kirbymoorside and afterwards they met frequently at reunions and fetes. Now they are married John works in Pickering—about 30 miles from their home—as a clerk. They are hoping to move to Pickering fairly soon.

---

### What a draw!

---

Not surprisingly perhaps it was a convenient 7-7 draw when a football team from the Grand Theatre, Wolverhampton played a Bloxwich under-13 side at Aldridge earlier this year. The Theatre team was captained by comedian Don Mclean (centre back row) who was appearing in the pantomime Goldilocks and the Three Bears. MP for Walsall South, Bruce George (3rd on left back row) refereed and was rolled in the mud when the final whistle blew!

The game raised over £50 for the Cannock, Walsall and District ASBAH and a good time was had by all!





## News from all around

### The 'Welli-throw'

It is good to have some news from Northern Ireland — Lurgan and Portadown Association has written to tell *Link* about a very successful 'Welli-Throw' organised by the pupils of Portadown College. The idea was that pupils would be sponsored so many pence for every foot they were able to throw the boot. The 'Welli-Throw' raised the amazing sum of £581.

Due to the unrest in Northern Ireland the Association does not like to organise sales or parties which impose unnecessary travel at night, so the money raised by Portadown College was a particularly welcome boost for the Association's funds.

### Durham Ox helps

Thanks to the landlord and customers of the Durham Ox pub in Beverley, Yorkshire, 13 year old Philip Cooke of the Hull and District Association now has a useful lightweight folding wheelchair. Customers have also nearly raised enough to buy another chair for Jeanette Semple of Withernsea.

### Stop press: Five Oaks

ASBAH's newly acquired home in Yorkshire—Five Oaks—can now meet a much wider need. Its registration has been broadened and in addition to being a short-term care home, it can now take some long-term children, or even be a permanent home.

At ASBAH's Council meeting in February, a special presentation was made to Mary Oughtred who retired at the end of last year. Members of the Executive and others who had worked with Miss Oughtred during her seven years as General Secretary praised the tremendous contribution that she made to the progress of the Association.

### MARY OUGHTRED'S THANK YOU

Little did I dare hope when I came into your midst in December 1969 that you, the Association, could come to show such warmth and affection towards me as you did at my farewell party on 26th February. I appreciate greatly the lovely lizard handbag and the very generous cheque but most of all the kindness you have shown me and the way we have learned to work together in the cause we all hold so dear. I thank you from the bottom of my heart.

With sincerest good wishes to the Association for a future full of progress and to each and everyone of you—I think of you all so often.



### More dress sense

The "Dress Sense" article in the last *Link* did not solve all the problems of dressing the disabled, writes Mrs Susan Gurney of Bexley, Kent.

For her the answer has been to join a pattern-making class at an adult education centre . . . "By the end of the first year I had enough knowledge to make a block to my son's shape . . . Pattern-making reduces the frustration of buying expensive patterns, only to have to alter them. If a mum were unable to go out to work she could also earn money doing valuable and rewarding work for people unable to make their own clothes.

"For me the classes have been a cure for depression where tranquilizers failed . . . because I have confidence in my ability to do something well and have a goal to work to my problems seem easier to live with."



## Health matters

The large majority of babies born with spina bifida have hydrocephalus. This is often not apparent at birth, but can be detected by special X-rays after the injection of air or radio-opaque solutions into the ventricles of the brain. X-rays taken afterwards clearly show the size of the ventricles and their communication with each other.

More recently a technique called computerized axial tomography (CAT) has been developed. With such X-rays the ventricular size can be determined without any injection and is often preferable in older children. Babies, however, need an anaesthetic to keep them still for long enough. This technique gives less complete information because one cannot measure pressure (an all important factor in deciding on treatment) and it does not give an opportunity to examine the cerebrospinal fluid.

### SHUNT SYSTEMS

The hydrocephalus often becomes rapidly obvious after operation for the spina bifida because this interferes with the balance between cerebrospinal fluid production and absorption. The baby's head will grow more rapidly than normal and other signs of pressure will develop.

For a very long time there was no effective way to treat such hydrocephalus until the invention of shunt systems incorporating a valve or valves. Nevertheless, a small but important proportion of hydrocephalic spina bifida babies grew up with normal intelligence and normal sized heads in the absence of any treatment. These were very lucky. Many of them are now active members of our Association.

There is no doubt that it was the far better control of the hydrocephalus with shunt surgery that led to a dramatic increase in the number of babies treated for spina bifida. Many babies, who would have otherwise died of their hydrocephalus or would have been severely handicapped with brain damage now live and the majority are of normal intelligence and show no other signs of brain damage.

Nevertheless, these successes must be set against the multiple risks of shunt operations;

## *Thoughts on the management of hydrocephalus in babies and children with spina bifida*

By DR JOHN LORBER, MD, FRCP

the blockages, the infections and many others, which lead to a need for repeated operations in most children (and adults) and which often threaten life or the quality of life. Many die of complications from shunt treatment.

A balance must, therefore, be struck. It is evident that in our initial enthusiasm too many infants had shunt operations who did not need them, and among them several suffered unnecessary complications even death.

It is amply obvious that hydrocephalus does not automatically mean a need for an operation. There are many who have mild or moderate hydrocephalus, which is only really progressive in the first months and then becomes arrested, without treatment.

### ISOSORBIDE

Arrest of the hydrocephalus can be achieved in bigger numbers and in safety by the use of a medicine called isosorbide. This drug is very useful in the less severe forms of hydrocephalus. It is given as a medicine by mouth for weeks or months, until a full balance has been achieved between the production and the absorption of cerebrospinal fluid. If isosorbide fails, an operation can always be carried out.

Children who have had no surgical treatment must be watched as carefully for their intellectual development, the size of their head and all other features, as children who have been operated on, to make sure that they come to no harm.

Continued on Page 12

## Mobility: ASBAH WORKING PARTY NEEDS TO HEAR FROM YOU

ASBAH has set up a Working Party to look into the problems of mobility as they affect the members, and then approach Mr Alf Morris, the Minister for the Disabled, with a united voice.

So if you have a particular mobility problem (and also if you have any problems in obtaining adequate Motor Car Insurance cover) please send details to National Office *as soon as possible*. The Working Party hopes to report to the September Executive Committee Meeting of ASBAH.

**TELL YOUR MP.** It is vitally important that you lobby your own MP and let him know how the mobility allowance and the planned withdrawal of the invacar affects *you*. Tell him about any particular mobility problem that you may have.

Your MP is particularly interested in local cases, and these often indicate what the problems are nationally.

Please send copies of the correspondence between you and your MP to ASBAH at National Office by the end of May if possible and certainly no later than the end of June.

## Information

A new organisation has been set up, with effect from April 1, to act as a strong central agency concerned with improving the welfare and status of disabled people. It is called the British Association for Disability and Rehabilitation (BADAR), and is an amalgamation of the Central Council for the Disabled and the British Council for Rehabilitation of the Disabled.

BADAR will have new offices but at present is carrying on at the CCD offices: 34 Eccleston Square, London SW1 1PE (Tel: 01-821 1871).

**Love Matters:** This short booklet introduces the subject of sex in a frank and light-hearted way. It is designed to help the handicapped person and should inspire confidence and encourage the reader to find out more by reading more specialist books or consulting an organisation like SPOD (Sexual Problems of the Disabled).

Love Matters is 10p plus 6½p postage from The Librarian, The Spastics Society, 12 Park Crescent, London W1N 4EQ. (Special price for bulk orders.)

## PARENTS FOR CHILDREN

A new style adoption agency "Parents for Children" has been set up specialising in finding homes for children with physical or mental handicaps, children of mixed race, and children with some kind of problem.

"Parents for Children", set up last year with the help of government funds, believes that there are families who would come forward to give a home to a child with a physical handicap such as spina bifida, if they realised that otherwise he might grow up in care.

Take Mark (right) for example. He was four in February and lives in a residential school. His parents have asked for him to be adopted.

He has very fair hair and pale blue eyes and is small for his age. He does not have the use of his legs, but does "walk" every day during physiotherapy. He gets around well in his trolley. Mark is described as being very happy and warm natured and loves talking to visitors about cars. He is fascinated by all toys with wheels including clocks and watches.

If anyone would like to know more about Mark and other children like him, "Parents for Children", would welcome a phone call or a letter. At the moment it cannot consider applications from families living further than 100 miles from London, as its social workers would be unable to visit frequently either to get to know the family or to offer support later on.

The address is "Parents for Children", 222 Camden High Street, London NW1 8QR. Tel: 01-485 7526/7548.





# WE ARE SAILING

by V. B. HOLMES, R.Y.A. Coach.  
G. H. CRABB, Headmaster,  
Ysgol Erw'r Delyn,  
PENARTH.

However, potential sailors must be able to:

- Swim
- Use hands and arms reasonably well
- Balance while sitting
- Learn at a reasonable rate.

Before dashing off to buy your "MORNING CLOUD" we strongly recommend that you ensure that correct training is available from a qualified Royal Yachting Association Instructor.

The basic problems facing every dinghy sailor is the trim and balance of his boat i.e. moving slightly towards the front or back of the boat (trim) and leaning out over the side (balance). If one has little or no use of the legs, these movements are either difficult or impossible. Most of our handicapped pupils at the South Glamorgan Sailing Centre have sitting balance and we have achieved success by selecting suitably designed boats.

In the early stages of training, Instructors can provide trim and balance in large dinghies such as the "Wayfarer". Once the younger



Parents of handicapped children have to face so many pressures, particularly those concerning medical treatment and suitable educational placement, that the recreational side of a child's life may be overlooked. But as with all children, play and recreation are vital in developing a healthy attitude to life.

Our children may be excluded from many activities enjoyed by physically able children. It is doubly important, therefore, that any recreation or sport in which they can participate should be promoted. Fortunately, sailing is a thrilling and worthwhile sport which does not necessarily depend on the use of legs.

## We have achieved success by selecting suitably designed boats

child has learnt the basic skills of sailing, we use the single-handed "Optimist", as the child sits in the middle of its floor and has only to move from one side to the other in order to maintain balance. For the older, heavier pupil, we use "Aqua Cats" where transfer of weight from one side to the other is facilitated by the trampoline type deck which spans the two hulls.

In conclusion, we are pleased to record a number of successes. The Sailing Centre has produced the first two physically handicapped young people in Great Britain who have qualified for the Royal Yachting Association Elementary Certificate. They had the great honour of being presented with their Certificates by the National Sailing Coach, Mr Bob Bond. Since then six



more young sailors have won their Elementary Certificates and the first two are now up to Intermediate Standard.

*Adrian and Edwina Evans, parents of Huw, the young sailor who was pictured on the cover of the last issue of Link, wrote to say that they hoped others would be encouraged to take up, "this wonderful sport for the handicapped".*

*They added, "May we express our deep gratitude to Mr Crabb, and Mr Holmes (writers of this article) and many others for their initiative, guidance and patience in teaching Huw and others to sail".*

● Above centre—young sailor leaves his wheelchair behind and heads for a teaching session.

● Left—still on dry land the youngsters are given instruction that will stand them in good stead later on.

● Above right—now is the time to put theory to the test; a pupil tackles the job of righting a capsized dinghy.

● Right—alone, afloat and everything shipshape.



## Similar problems from different points of view

**ASBAH's Spring Conference this year again proved to be a refreshing and stimulating weekend for all who attended — over 150 members from local ASBAHs, from national office, as well as professionals and social workers.**

It was particularly good to see so many younger members. In the words of the very able Chairman of the Conference, Mr Raymond Clarke, OBE, JP, Secretary of the Personal Social Services Council, "It is their hopes and ambitions for the future that will need the help and understanding of us all".

The Conference, held in the comfortable surroundings of Clifton College of Education near Nottingham on April 1-3 was on the theme '**Partnership Approach to the Years Ahead — Making the most of Statutory and Voluntary Provision**'. It proved a valuable meeting place for all kinds of people tackling many similar problems from different points of view. Informal discussion plus the opportunity to bear a number of distinguished speakers all contributed to make it a good weekend.

### **Whistle-stop tour**

On Saturday afternoon there was a whistle-stop tour of Portland Training College, Thieves Wood School, and the very impressive West Bridgford Centre for the Physically Handicapped. Meanwhile the under 16's were having a great time being taken out and about by scouts from the 1st Nottingham YMCA and the 88th Nottingham and 69th Nottingham troops.

Time was allocated to group discussions — perhaps not enough time — as for many members these discussions proved one of the most valuable parts of the weekend. A lot of useful ideas were generated and the individual

group representatives communicated the feelings of their groups to the rest of the conference clearly and concisely.

Many groups felt that there was a real need for greatly increased after school and further education provision particularly because so many spina bifida youngsters are approaching school leaving. One group suggested that the Association might start its own workshop, giving suitable occupation and employment at realistic wages to young adults with spina bifida and hydrocephalus. Work experience in the final year of school was also considered to be important, for employers as well as for the pupils.

### **Clear policy**

A call was made for ASBAH at national level to formulate a clear policy for the future of the Association. One group agreed with the suggestion that groups of parents should visit and make worthwhile contacts with local employers, but stressed that this must be done well, probably with the help of specialists such as careers advisers.

Co-operation with statutory organisations, was considered to be essential and something for which the local associations should be prepared to take the initiative, but one group did wonder how seriously some local Social Service Departments really took the work of 'amateurs' — the voluntary bodies like ASBAH — and whether co-operation on their part might be mainly out of economic necessity.

### **Friendly, relaxed**

These and other findings should give much food for thought.

---

The general atmosphere of the weekend was very friendly and relaxed and much credit for this must go to the Chairman Mr Raymond Clarke, and to the Hostess the Lady Jean Mackenzie. Nor must one forget the man who bears the main responsibility for organising it all, Mr H. D. Marfarlane, 'Mac', ASBAH's Liaison Officer.

# TO THE YEARS AHEAD

## Cooperation must lead to joint action

Mr Robin Smith, Director of Queen Elizabeth's Foundation for the Disabled, Surrey, tackled the theme of the conference — the partnership between statutory and voluntary organisations.

He made a plea for greater co-operation between statutory and voluntary bodies, and by co-operation he meant not only a getting together to exchange ideas, but also to formulate policies and take real action together.

The feeling of some association members at the Conference was that co-operation with the local authorities usually led to confrontation. One member said her local authority would co-operate to a degree but not when it came to financial matters; another member spoke of some authorities refusal to consider any kind of partnership.

Mr Smith said. "We have heard talk of the need to plan for the best use of resources, but how many Directors of Social Services, when planning, take into account *all* the resources in the area—including those provided by the voluntary bodies? It certainly doesn't happen in Surrey.

"I think its monstrous, and it means there is a lack of co-ordination of effort, and a waste of money somewhere.

"It is important that we co-operate, not for the sake of our own organisations which don't matter a damn, but for the sake of the people we are there to help . . .

As for the voluntary bodies, Mr Smith said, "I have felt it almost immoral the way we have been going around in the last ten years, holding out our hands to the local authorities and saying 'What are *you* going to do' . . . I hope the present lack of money will make us really examine our priorities and where the need really is . . ."

## Plea to be allowed to go it alone

"Give us the chance to be independent" — that seemed to be the general call from the young adults with spina bifida who during the Conference had a session of their own where they aired their views, and hopes.

The Lady Jean Mackenzie chaired the discussion and later reported to the Conference;

"We came to the conclusion that what everyone wanted was the opportunity to 'have a bash' themselves. It was thought that the best way would be by using Five Oaks in groups of 12. Different age groups would have a week where everyone was given a chance to look after themselves in all ways . . . They also thought they would like to find two or three flats, preferably on the ground floor, and see if they could manage there themselves. Everyone thought they would like to see how far they could be totally independent."

The group also asked to be given ideas about the kind of things that might interest them and which they could do in their own locality for occupation or employment. They wondered if courses at Five Oaks could be arranged in subjects such as carpentry, pottery, marquetry, dressmaking, clock repairs, cookery . . .

It was felt that parents could do a great deal to help their children be independent. One young girl described her mother as "absolutely marvellous—when I asked her to get out of the kitchen and leave me to it, she did".

The formation of local groups of young adults with spina bifida was thought to be a good idea—the groups having representation on the ordinary local associations, and eventually on national ASBAH, too.

"Some of these ideas are certainly ambitious" said Lady Jean, "but I feel we should do all we can to help."

## Some advice on lobbying by an MP

In his opening speech to the Conference, Mr Kenneth Clarke, MP for Rushcliffe, Nottingham, pointed out that although politicians were acutely aware of the needs of the disabled, their desire to help had had to be tempered in view of the deep economic depression.

"We must consider what is really essential and make a more searching task of priorities . . . We are not short of sheer goodwill and goodwill can be turned into voluntary effort which could put a lot into the social services. We have to develop the strongest possible partnership between professionals and the thousands of people with ordinary goodwill."

Referring again to the concern which politicians regardless of party felt for the needs of the disabled community, Mr Clarke stressed the importance of lobbying individual Members of Parliament (and particularly the members of the All Party Disablement Committee). He advised approaching them about one particular aspect of need rather than on all fronts.

---

### Management of Hydrocephalus Continued from Page 6

In my clinic in the last six years about half the spina bifida children needed shunt operations. Previously about a third of our children with moderate hydrocephalus had no treatment of any kind. On long-term follow-up for up to 16 years, they show no sign that they have suffered in any way. In fact, their intelligence as a group is about 10 points higher than the group which had operations—and they were saved all the risks, the repeated revisions and the anxiety that must be ever present if a child has a shunt.

All this does not mean that shunt treatment is not essential in children with more severe or more rapidly progressive hydrocephalus. For these, operations and early operation, still gives the best chance of satisfactory development.

## ASBAH must grow with the people it serves

Mr D. F. Ellison Nash, FRCS, Senior Surgeon at St Bartholomew's Hospital, London, and known to so many ASBAH families, gave a "realistic appraisal" of the task of ASBAH—an Association which "seeks to make the quality of life worth surviving for".

He said that it must move on to being "an employment adviser and a marriage counsellor . . ." "I am not suggesting that we turn our attention away completely from the newborn and from the problem of the would-be toddler and the primary school, but that a much greater and more sustained effort must be made to assess the adult problem and to join wholeheartedly with those other pressure groups which by their efforts can improve the standard of living for the severely disabled . . ."

"The incidence of spina bifida has fallen, the birth rate continues to fall and we are facing a major problem with the 1950-1970 survivors as they move into adult life . . ."

Mr Nash raised the particular problems of the 14-15 year olds, many of whom are only of a social maturity of about 11 or 12 with regard to responsibility for self-care. Because of their physical maturity it was difficult to keep them to aged 18 or 19 in schools with a significantly younger group, and he spoke of the need for some kind of extended education unit like the one at Hinwick started by the Shaftesbury Society. "It is a sort of sixth form where a greater degree of independence can be allowed without letting go on the close personal and nursing supervision . . ." We have in the past failed this particular age group badly. The bright ones have been OK with further education perhaps, either home-based or in a residential unit, and of course, numbers of them have gone on to university successfully. If they are not up to that standard intellectually there is very little left for them, and I am sorry to say that some of the training institutions simply

# TO THE YEARS AHEAD



A moment of relaxation at this year's Conference.

don't provide adequate medical and nursing supervision."

Speaking about the importance of mobility he expressed his alarm at the withdrawal of the invacar (which because it is a 3-wheeler can be driven from the age of 16) which makes it impossible for school leavers to learn to drive and to be immediately mobile so that they can obtain work . . . "You must join the other pressure groups and try and put right the wrong that has arisen from those who pressurised the DHSS to abolish the trike in favour of a 4-wheeler . . . which will be beyond the grasp of the young school-leaver."

Turning to the question of follow-up, Mr Nash made the point that there is a lack of medical follow-up once patients have left school, and perhaps moved to a different district. They are transferred to an adult hospital, see a different orthopaedic surgeon and there are no combined special clinics, because the numbers of young adults with spina bifida in most areas are not sufficient.

"The most difficult aspect of this follow-up is the management of the urinary tract and here I believe the Association can help by winking out consultants in the various specialities who are prepared to take a specific interest in this age group . . .

"I have been fortunate in having the necessary follow-up out-patient facilities at a major hospital and it has given me great pleasure to have the privilege of caring for those I knew as babies now that they are employed, many of them married with children of their own"

## Teenagers say they need guidance on sex

**Many of the young people with spina bifida and hydrocephalus interviewed by a psychologist admitted to worrying about sex, and a quarter of them said that their worries were sufficient to interfere with their concentration and their daily living.**

Dr S. Dorner, Ph.D, from the Department of Psychological Medicine, Gt Ormond Street Hospital, spoke to the conference about his findings based on a study of 46 young people with spina bifida, aged 13-19.

An interest in sex was common amongst all the over 16's, and 80% said they wanted a relationship. Six said they were having a relationship and this was not related to the degree of handicap, as three of the six were very seriously handicapped.

One of the big worries for the boys was how to tell a girl that they had a urinary diversion and a penal bag, and the other main concern was would they be potent and be able to have actual sexual activity.

Girls, on the other hand, were mainly concerned with marriage and having a family, and what the risks were of the baby being affected. Only one girl had a reasonably accurate understanding of the risks, but Dr Dorner pointed out that this survey was two years old and he felt the picture may have changed.

The teenagers felt unable to talk to their parents about sex, but admitted that they would like help in this whole area. Dr Dorner said he thought professionals like himself also needed guidance in trying to find the best way of offering advice.



## Appeals and publicity

### Glenda Jackson heads appeal

You will be pleased to know that the actress Glenda Jackson has very kindly agreed to head our Christmas Appeal—it may seem odd to be talking about Christmas cards when we are not yet into Summer but there is nothing like being prepared!

### Golfing aid

We are asking all golf clubs to help us. September has been named "Play for ASBAH Month" and we hope that clubs will give us some or all of the entry fees for the medal tournaments arranged in September.

### Design a Jubilee card

Talking of competitions, here is your invitation to join ASBAH in a tribute to Her Majesty the Queen for her Silver Jubilee.

We are offering prizes in three age groups for the best design for a Jubilee Greeting Card. Entrance fee 10p with stamped addressed envelope, please, from me. The three best designs in each age group will be taken to Buckingham Palace and the winners will receive the following prizes: 1 prize £25.00, 2nd prize £20.00, 3rd prize £10.00 in each of the age groups 4-6 years, 7-11 years, 12-16 years.



The Dorchester Ball held recently was a great success and here is a photograph of Debbie Tingey presenting our Duchess with a bouquet.

### The collectors Kit

I have already mentioned to Secretaries, that we now have an arrangement with Angal, the Fundraising specialists, that flag day equipment will be held by them and supplied to Local Associations direct. I thought you would like to see this photograph (left).

It shows the new COLLECTORS KIT which is in a distinctive green and white. The kit not only provides an efficient and convenient means of dispensing emblems (400 included) and collecting donations but also lends an appropriate authority to collectors on flagdays, house-to-house collections and other public events. It is hoped that groups will equip themselves with these new collecting aids as soon as possible: prices can only go up and the more Angal can despatch in the current year the lower the cost overall to ASBAH.

Price 87p per kit (minimum 10 kits). All items available separately: polyboxes, PVC labels and wallets as well as the expendable reseal labels and emblems. Angal's address is: 48a Holmbush Road, London SW15 3LE. Tel: 01-788 5464.





**READ  
ALL  
ABOUT  
IT**



## ASBAH booklets . . . leaflets . . . posters

- Your Child with Spina Bifida*, by J. Lorber, MD, FRCP . . . . . 20p  
*Your Child with Hydrocephalus* by J. Lorber, MD, FRCP . . . . . 15p  
*The Nursery Years*, by S. Haskell, M.A., Ph.D., and M. E. Paull, Dip. Ph.H. . . . . 15p  
*Children with Spina Bifida at School*. Ed. P. Henderson CB, MD, DPH . . . . . 30p  
*The Care of an Ileal Conduit and Urinary Appliances* by  
 E. Durham Smith, MD, MS, FRACS, FACS and others . . . . . 15p  
*Clothing for the Spina Bifida Child* by Barbara Webster, SRN, RSCN . . . . . 15p  
*Aids and Equipment* . . . . . 60p  
 Information leaflets . . . . . 100 for £1.30  
 All available from ASBAH, 30 Devonshire Street, London W1N 2EB. (Special rates available to Local Associations.) Please note that postage is extra. Allow a minimum of 9p per booklet.

### 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.  
**Plastic Lapel Badges** £2.10 for 100.  
**All available from Appeals Dept.** — postage extra. Full list on request.  
 Flag Day equipment from Angal, 48a Holmbush Road, London SW15 3LE. (01-788 5464)  
**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 Road, Gomeldon, Salisbury SP4 6LZ.

## Holiday accommodation for spina bifida families

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

**Christchurch, Dorset, Hoburn Farm.** 6/8-berth caravan, 1 mile from sea, near New Forest club house. Details: Mrs D. Collier, 359 Cricklade Rd, Swindon, Wilts.

**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. Details: 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 Shepherd, 115 Holborn Rd, Sunderland. Tel. Sunderland 283568.

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

**Looe.** Millendreath Holiday Village. Three bungalows. Details: Mr Keith Jackson, 202 Exeter Street, Plymouth. Mrs C. Bugden, 27 The Grove, Sholing, Southampton. Tel. Southampton 444921, and Mr C. Matthews, 11 Kingsbere Ave., Wallisdown, Bournemouth. Tel. Bournemouth 53850.

**Mablethorpe.** Two well-equipped self-contained chalets, 6-berth, at Golden Sands Estates. Details: Mr B. Guest, 57 Bloxwich Lane, Leamore, Walsall, Staffs.

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

**Prestatyn.** 2 luxury 6-berth caravans at Bourne Leisure Site. £22 per week. Due to demand one week bookings only. Vacancies for May, Sept., Oct. only. Bookings to: E. Taplin, Colonial House, 63 Corporation Street, Manchester M4 3DT.

**Selsey.** Well-appointed, self-contained 16ftx30ft 6-berth mobile home. For details send s.a.e. to: Mr R. V. Taylor, 3 Dickins Way, Horsham, Sx RH13 6BQ.

Well-equipped specially designed mobile home. 7-berth plus cot. Details: (please send sae to): Mrs L. Thomson, 154 Stafford Rd, Caterham, Surrey.

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

**Winterton-on-Sea, nr. Great Yarmouth.** New well-equipped 6-berth chalet. Indoor swimming pool, shop, and play areas. Details: Mr R. Morris. Tel. H. Wycombe 32184.

**Withernsea.** Well-equipped 6-berth chalet at Golden Sands Chalet Park. Shop, licensed club, play areas, amusements on site. Details: Mrs F. D. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel. 0422 56402.

# Poems and prestige worth more than any money

Thirty-three-year-old Carole Smith of Swansea has been writing poems since she was six, but it was only recently that she plucked up enough courage to have some of them published. Her eight-page book, "My World Through Four Eyes" has now been sent as far afield as Hong Kong, Australia and Africa. It has even earned Carole a small profit on the publishing costs, but as she says, "the prestige is worth more to me than any money".

As a child Carole was unable to attend normal school but she did have a dedicated teacher who visited her home every morning and devoted parents and family who, "encouraged me to take an active part in everyday life."

In doing just this Carole has witnessed a real change in attitudes to the disabled. "Everything seems to be more out in the open these days and people are prepared to accept disabled people more easily."

Carole was taught at home until she was 15 and then she helped out in her parents' grocery shop. The shop was sold when she was 17 and with the end of her role in the shop went a lot of her sense of purpose.

"I started to feel bored and useless. I had never seriously thought of taking a job outside the home as I thought I couldn't really cope with travelling by bus. I am rather forgetful about small things like numbers on buses.

"I began to suffer from insomnia and various vague aches and pains and as a result began taking sleeping tablets. I really felt like a physical wreck and I knew I was hell to live with . . ."

The doctors eventually made her snap out of it with the blunt advice that there was nothing

## REBIRTH.

Out of darkness, warmth and comfort  
There came cold and damp,  
Hands reached out lovingly to hold me  
But I yelled, like hell I yelled,  
Even the soft white birth towel  
That they wrapped me in  
Could not stop my tears.  
So I'd returned  
I told them all that I was coming back,  
I knew I was though I'd no wish to be,  
So here I was aged dot, back in square one  
Where I'd no wish to be.

physically wrong—all that was needed was the right job in society.

Her first job was at the local Woolworth's cafeteria. "It was only washing up but it meant the opening up of a whole new life for me," she said. "It took all my courage to leave the shelter of home and to go to work on my own for the first time, but I was determined not to fail."

After two years Carole moved to a job at the hotel in their village. "I am still washing up and loving every moment of it. It is so nice to be mixing with different people every day."

Confident of her place in society Carole went on to develop the confidence to publish her poems, and she is now working on "volume 2".

**If you would like a copy of Carole's poems, send 25p and a large envelope to: Miss Carole Smith, 5 Southgate Road, Pennard, Swansea, Glamorgan.**

---

## LOCAL ASSOCIATIONS

**There are over 80 local Associations all over Britain. If you would like the address of your nearest Association please refer to the last issue of *Link* (back page) or contact National Office. Changes since last issue:**

**BEDFORD & DISTRICT:** Mrs J. Clifton, 55 Gainsborough Rise, Bedford.

**LEEDS AND BRADFORD:** Mrs J. Lupton, 41 Brooklands Crescent, Yeadon, Leeds.

**LURGAN & PORTADOWN:** Mr B. Byrne, 148 Newry Road, Banbridge, Co. Down.

**MID-ULSTER:** Mrs V. McKenzie, 11 Woodland Drive, Cooksdown, Co. Tyrone.

**SOUTH YORKSHIRE (formerly Don and Dearne):** Mr T. J. Murphy, 43 Cutts Avenue, Wath-on-Deerne, Yorks.

**A full list will appear in the next *Link*.**