

Link

SEPT/OCT 1976 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)



Cover story
See page 10

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.





Link No. 45

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

Patron:
HRH The
Duchess of Gloucester

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

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

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

General Secretary:
Miss M. E. Oughtred

Appeals Secretary:
Mrs. Kate White

Liaison Officer:
Mr. H. D. Macfarlane

Link Editor:
Mrs. Susan Gearing

Contents

page	
4/5/6	News from all around
7	Duke of Edinburgh Award Scheme
8/9	Relationships
10	Book Review. Five Oaks is open!
11	Aids and Equipment: (Rubber Ramps)
13	Research Fellow appointed
14	Appeals and Publicity

Editorial

The government's decision to phase out the invalid tricycle (invacar) has caused widespread alarm among those who rely upon this vehicle for mobility. Some of the fears are exaggerated and David Ennals, Secretary of State for Social Services followed his first statement on 23 July with a second four days later in an effort to put matters into perspective.

The invacar is going to have to go because while it is considered that it meets acceptable safety standards at the moment, it is unlikely to be able to be adapted to meet the tougher international standards which will apply in Britain in years to come.

But Mr Ennals emphasises they are not withdrawing existing invacars from those who wish to keep them; new tricycles already on order and those produced as part of final order still to be placed will be used as replacements for existing users; maintenance standards will be improved and the tricycle fleet should be kept going for at least five years.

When it is no longer possible to keep the tricycles on the road Mr Ennals promises, "We will assess the extent of the need for specialised vehicles for the remaining vehicle scheme beneficiaries and see what alternative vehicles and electrically powered wheelchairs are available on home and world markets."

There is also a plus. In future owners will not face the prospect of losing the tricycle if they lose their job. Also tricycle owners who do switch to the mobility allowance will not be subject to the present age limit for payment.

Thus Mr Ennals offers reassurance for those with tricycles who wish to keep them. And that is good news.

However, it appears that for future generations of disabled an invacar or a new alternative vehicle, meeting higher safety standards and made available on the same basis as the tricycle, will not be available. The disabled will still be able to get to work however. The £5 Mobility allowance, reviewed annually, is a useful contribution towards travel costs, and those who incur substantial expenses which they cannot afford in getting to work can turn to the Employment Services Agency for help.

But the invacar was more than just a means of getting to work. It was access to 24-hour mobility and independence, it could be driven at the age of 16, was compact and relatively easy to drive, and it was therefore particularly important to the congenitally disabled. It was on these grounds that ASBAH urged the retention of the invacar in its written evidence to the Sharp Committee on the question of mobility, although it called for a completely new design which would be much safer and hopefully include room for a passenger.

Continued on page 9.



News from all around

This time it is good news from all around. From all over England and from Northern Ireland comes news that spina bifidas, both young and adult, are making the most of life. So much so that some of them and their parents have written to share their enjoyment and enthusiasm with readers of Link.

New home for Colin and Marina

Colin and Marina McLean have every reason to be happy. They were married last October and have now moved into a new home in the Croydon area.

But there is also somebody else who has a well-earned share in this happiness and that is Colin's mother Ethel who lives in Thornton Heath, and was one of the founder members of NASBAH (Surrey). Colin is spina bifida; Marina is able bodied and Mrs McLean told Link, "He made me a very happy mother when he married an able bodied girl, and so I thought you might like to hear about my son."

Colin is now 33 years old. He wears calipers on both legs and walks with sticks, but from an early age it was clear he intended to live a full life. He joined a cub pack at the age of nine and went to camp. Mrs McLean went too.

When he first left school he worked in a nursery garden. For the past 12 years, however, he has worked in an office, and it was there he met Marina.

Colin's main hobby is table tennis and he has competed in three marathons—the last one lasted for 32 hours and raised money for the Eldon Phab Club. Colin is Chairman of the club. He also runs four teams in the Croydon Table Tennis League and three in the Croydon Business Houses League. He swims and will "have a go" at cricket.

David discovers the River Thames

It was a day full of events for 11-year-old David Statham of Woking when he went on a trip with the Staines, Hounslow Association up the Thames on the boat Sparkle.

First there were the locks to negotiate. "This was the first time I had ever gone through a lock and it was quite exciting. When we were through the lock the river was quite busy and all



Colin and Marina McLean (see New home for . . .) Photo: The Advertiser, Croydon.

of a sudden a motor boat came quite near us."

Next came the, "Cadet-type sailors having races in rowing boats. We watched two of the rowing boats race. No VII won."

And then another lock—"This one was much smaller and couldn't fit in so many boats, but we managed to get in the first time we tried. It took five minutes for the water to get up to the level on the other side of the lock. A man turned a wheel and the two gates of the lock opened and off we went."

A pause for lunch, a stop to feed the ducks, a spell on dry land when David won two wheelchair races and then, if anything, the return trip was even more exciting.

"We saw the same cadets, but one boat had overturned. We left them struggling and



News from all around

continued down river a bit and saw two boys who had overturned their yacht. About two miles further on a police boat went after a speed boat.

"When we got off the boat our Mums and Dads were there to greet us and take us home after a nice boiling hot day on the Thames."

To London to see the sights

London can be an exciting place, especially if you happen to be 15 years old. Teenager Carole Dean from Southport and her schoolfriends will long remember their visit.

"We were met by Alf, who was to be our driver, and taken to the Spastic Assessment Centre in Fitzroy Square. After getting settled into the hostel we went downstairs, met Alf, and went to the British Museum. After that we went sight-seeing and came home to bed.

Every minute of the trip was filled to overflowing. "We went to Buckingham Palace to see the Changing of the Guard, but it rained so we went to the Royal Mews and saw the Queen's horses and coaches."

Then to the Houses of Parliament where, "we were shown around by Lord Maybray-King and when we came outside he pushed me a little way along the pavement; quite expertly, I thought."

The group went to see "Jesus Christ Superstar", visited the Tower of London and spent the morning of the day of their return shopping in Oxford Street. "All in all we had a great time."

Pauline wants to hear from you

Twenty-two year old Pauline Brennan from Northern Ireland leads a busy life but she intends to make time to keep in touch with other spina bifidas.

She wrote, "I have spina bifida but I can do everything for myself. I live a normal life and even have a job working in a factory."

Pauline added she was very impressed by the work being done on behalf of spina bifidas and would "like any spina bifida to write to me as I would love to hear more."

Pauline's address is 36 Drummdaconnor Road, Crossgar, Downpatrick, Co. Down, Northern Ireland.

LEE IN THE SADDLE

The young man (right) is Lee Edwards one of the Humberside Disabled Horse Riding Group. He is trying out a saddle given by Blue Peter.

Other members of the group, including Philip, son of Mrs G. D. Brown, secretary of the Hull and District Association, gave a riding demonstration for HRH Princess Anne in December. They were well rewarded when the Princess presented them with a rosette in the green and white of ASBAH.

Still in sporting vein, 15 of the Association's children took part in the Humberside Disabled Sports Day. They won 18 medals.



Lee Edwards with Dr June Alexander, founder of the Humberside Disabled Horse Riding Group and Mrs E. Holditch, secretary.



News from all around

Germany and beautiful buildings

Two other spina bifidas have ventured into Europe for their holidays. Alistair Gordon, 11, from York went to Bamberg in Germany and Carole Armour, 21, of Horsham went to Bordeaux with the Winged Fellowship.

Alistair stayed with the Franks family and both they and Germany made a profound impression.

Alistair reports, "I must say that it was the first time I had been abroad and also the first time I had been in a plane. I thought it was very exciting when the plane was above the clouds."

The Franks took Alistair to many places of interest. "I think that the Germans have many more beautiful buildings than the British people have. There was a church called 'Church of the Fourteen Saints' and that was the most beautiful building I have ever seen in my life. There were all the colours you could imagine.

"Also the countryside appealed to me. It seemed to me more natural than England and it was very green.

Bordeaux—sampling the unexpected

Carole Armour, and nine other handicapped people and five helpers stayed at the University in Bordeaux where they were joined by French and German parties which gave the holiday a truly international flavour.

It was all very enjoyable, if sometimes a little unexpected.

"We had several outings—two of which were quite amusing. We looked forward to a guitar concert at Arcachon, 40 miles south of Bordeaux, which turned out to be a lecture on the history of the guitar—in French. A boat trip on the lake became a baling exercise with paper cups when a hole was discovered in the bottom of the boat!

"We visited an oyster farm and bought two dozen to sample but for some reason they disappeared and were never seen again. We also went to see a folk festival there which was very good and well worth seeing.

"We visited the vineyards at St. Emilion which is about 40 miles east of Bordeaux. St. Emilion dates back to about the 13th Century a.d. We had a look round the old town and wine cellars. We tasted some wine and then had a chance to buy some if we wanted. Everyone had a day trip to Sarlat which again dates back to about the same time as St. Emilion and is about 100 miles from Bordeaux. It is situated on the Dordogne River so is very picturesque among the hills.

"I would certainly recommend this kind of holiday to anyone because it gives both parents and the handicapped person a rest from each other if only for two weeks.

Mobility Allowance to be extended to 11-14 year olds

Mr Alfred Morris, MP, Minister for the Disabled announced on 23 July that the Mobility Allowance (£260 pa, at present) is to be extended to children between the ages of 11 and 14 years. Claims can be made from 25 August and payment of the Allowance to those who qualify will start on 24 November. Leaflet N1211 from Social Security Offices gives details including a form on which to apply.

Relevant points regarding the allowance where it applies to disabled children are:

"Those who satisfy all the conditions will qualify for mobility allowance in their own right but the allowance must be claimed on their behalf by a parent or other adult responsible for the child.

If the child lives with both parents, one parent (normally the mother) should make the claim and the other parent should countersign it, if possible.

If the child lives with one parent only, that parent should make the claim.

If the child is not living with parents, the claim and the other parent should countersign the person in whose household the child is living and who has responsibility for the child. If the child is in residential care, and out of contact with its parents, the appropriate responsible official should apply."

Looking back over the Duke of Edinburgh's Award Scheme's first twenty years, one can see how the trail was blazed by men and women of vision into schools, clubs and organisations, who saw what it could mean for the boy or girl lacking a purpose in life, whether able bodied or disabled. Coney Hill School in Hayes, Kent was one such school under its then Headmaster, Mr Allen Field—now principal of the National Star Centre for Disabled Youth nr Cheltenham.

Vision was not all that was needed: boys and girls with spina bifida and hydrocephalus had to have imagination and courage to have a go, perseverance and the backbone to win through. That is why I call them spinal pioneers!

Tribute is due to the boys and girls who have gained Bronze Awards at Coney Hill and to Vernon Gill and Douglas Miller, amongst others, who won Silver; and of course to John Brough who won through to Gold.

It is clear that the severely disabled young person has as good a chance of gaining an Award, as the able bodied, but no better. The pioneers have shown the way.

There are four Sections to the Award and the entrant must attain the required standard in each of them:—
SERVICE. This involves practical service to the community after learning the theory on such topics as "people matter" and how help can be given to the elderly, to children, to immigrants and

Duke of Edinburgh award: How it can be done

others. Alternatively it can involve training in such fields as first aid, the care of animals, home nursing etc.

EXPEDITION. After training and practice in such subjects as map reading, compass work, country code, food and cooking, journeys are planned with an object in view, either of discovery or recording people and customs, historic places and so on. A voyage of discovery need not necessarily be a long hard foot slog. The mind too can make its explorations.

INTERESTS. Entrants must choose and sustain an interest in an activity (or hobby) such as collecting stamps or coins, music appreciation, drawing, chess, aquarium keeping, heraldry, drama, Bible study. There are at least two hundred to choose from.

DESIGN FOR LIVING. Courses are undertaken in such subjects as Making the Most of Yourself, You and Your Money, You and Your Friends, and Fun with Flowers.

PHYSICAL ACTIVITY. This includes events such as athletics, swimming, physical efficiency, individual sports and games. Points are given for training sessions as well as trials.

What then were the activities in the programme of gold award winner John Brough?

SERVICE. John took the Adult First Aid Certificate of St John's Ambulance Association. As actual service to the community he read bedtime stories to a group of five-year-old children also disabled and continued over a period of six months.

INTEREST. John took advanced photography as laid down in the Handbook of syllabuses.

EXPEDITION. Here the alternative was to learn from scratch how to drive, then in an invalid vehicle to plan and carry out routes ever farther afield, after passing the Ministry of Transport driving test. Finally he had to undertake a journey of fifty miles, over two days and make a full log of the places visited.

PHYSICAL ACTIVITY. A three part programme was devised for John. It involved doubling the distance he could walk when doing the Silver Award, archery as laid down in the manual, under guidance of a recognised club, overcoming of his disability in climbing stairs, getting into bath and in many other ways of independent daily living.

John Brough thoroughly deserved his Gold Award and I hope this example will inspire some Link readers to 'have a go'. For more information about the scheme write to me, Mr F. A. Evans, Duke of Edinburgh's Award, 5 Prince of Wales Terrace, London W8.

ASBAH was privileged to have Mr W. R. F. Stewart, the Development Officer of SPOD (the Committee on Sexual Problems of the Disabled) as one of the speakers at its Spring Conference at Culham. As promised Link now carries a full report of his talk which proved of such interest.

Human beings are social beings, needing to mix with others. We depend on other people and have a deep need for close relationships. It seems that some people are highly gregarious, some are highly dependent on one person, while others fall between the two extremes.

Professor Eysenck has likened relationships to a trading, with two people having something to offer to each other. Once one person has stopped benefiting the relationship breaks down. A good relationship is a two-way process.

Early influences

Our upbringing has a profound influence on our life and the relationships which we form. Central to this is normally the parent-child relationship, though as the child grows, wider spheres of influence play an increasing part. Development is influenced by the personal satisfaction which we get from our contacts with others, as infants, children, adolescents and adults. And the way in which we see ourselves—our 'self-view'—also has a tremendous effect on the way in which we behave.

Mother and father are all-knowing when we are very young. If they see us as developing as we grow, so we mature. If, on the other hand,

they see us as helpless, we tend to feel useless, or rejected, and so unwanted.

We are also sexual creatures, and sexuality begins to develop in our lives when we are children. Psychosexual development will be much affected by early upbringing. Deep within us all is the need for love and the sexual relationship.

Another extremely important influence is disability, which cuts across the other influences of customs, parental feeling, etc. The whole family has to learn to adapt to the situation and help the disabled member to grow up to be his best self in every way. But the feelings of parents toward their disabled

Mr Stewart is the full-time Secretary and Development Officer of SPOD which exists to offer help to the disabled and their families who are experiencing problems concerning sexual relationships.

If you have any problems or anything you would like to discuss of this nature then Mr Stewart would be pleased to hear from you. If he and his team cannot help directly they should be able to suggest someone else who can. You may also wish to write to SPOD to find out more about their activities. The address is:—Committee on Sexual Problems of the Disabled, 183 Queensway, London W2. (Tel: 01-727 4426).

RELATIO

The mix that makes the complete person

children are almost inevitably mixed. They may be rejective or over protective.

If rejected or too protected the child may always have a high need for other people on whom he can depend. If he suffers isolation he will probably grow up to be very retiring.

As people we are all the same, yet different. Our outer shells differentiate us from each other, but what counts is the people that we really are 'inside', and that we have feelings and a capacity for relationships. We must strive to bring up our children to feel they are the same as other children 'inside' with the same need for friendships.

The outlook of disabled people in and on society varies. Some disabled people are too ready to say that they are ill-shaped and unloved, and to look for slights, and so shrink into themselves. It is very important that all people and particularly the disabled should have a good self-view. We all have faults and attributes we wouldn't wish for, but we need to see

ONSHIPS



ourselves as having something to offer, and to be prepared to offer it.

Sexuality

Some people feel that an element of sexuality enters all relationships.

Sex relationships will be enormously affected by our self-view—the way in which we rate ourselves—and also by whether or not we have the chance to meet other people. What chance has an isolated disabled person of forming friendships, let alone forming a sex relationship? (Sometimes, however the walls are self-made). Quite obviously physical disability can bring problems when it comes to sexual performance; most of these can be partly solved, but there are often psychosexual problems which have to be overcome too.

People who are disabled may feel themselves barred from sexual relationships not only because of possible physical difficulties, but also because of social feeling, and family upbringing.

Very few disabled people get much sex education. Parents need to bring up all children with a sound view of sex, and the handicapped also need special help because they have special needs. Parents owe it to their children to help, and have a duty to learn how to discharge this duty, either directly or by finding others to help.

(Mr Stewart explained that SPOD was such an agency and was developing local contacts to meet local needs).

Friendships, and particularly in childhood, friendships with people of one's own age, are vital. Most children do find it quite easy to accept disability as being a natural fact of life. Parents should bring up their children to regard disability in a matter of fact way... 'o.k. this is the way God made me—take it or leave it'.

Where should a disabled person look for friends and for a partner? There is no single answer—it is up to the

individual. Some disabled people look for an able-bodied partner, others are more naturally drawn to those who share the experience of disability, although this may be limiting.

All parents should stretch their children to the limit of their capabilities, although obviously one would not push to a painful degree. Parents should encourage and challenge their children and not be afraid of minor danger or hurt. We must all face hurt through life. Unless we are pushed we do not learn to cope or to have a protective skin. Virtually all experience is good experience.

Relationships depend on family influences, to be challenged and motivated is vital.

Remember the need for a good self-view. We must see ourselves as having rights, duties and a place in the network of relationships which makes up society.

Continued from page 3.

David Ennals tells us that since the mobility allowance has been available the majority of the disabled have opted for it rather than the tricycle. But the very statement implies choice. And he adds, "When my predecessor announced her mobility policy there was no reason to believe that the trike would not be available for issue as long as could be seen ahead." Again the suggestion of choice.

That choice needs to be established once again. The reassurance for the existing users of tricycles is welcome. What we want now from the government is a guarantee that there will be an energetic search for a successor to the invacar for those who would benefit.

Existing users of the invacar should tell their MPs and the various organisations representing the disabled why they chose the invacar and the advantages of this type of vehicle in the interests of preserving the same option for the future generation. Parents of that generation can also raise their voices in the same cause.

BOOK REVIEW

"Entitled to Love" by Wendy Greengross, published by the National Fund for Research into Crippling Diseases. £1.95.

Member of SPOD, the well known broadcaster Dr Wendy Greengross has recently had a book published on the sexual and emotional needs of the handicapped. It is called "Entitled to Love," and was read for Link by Mr and Mrs Frank Armour and their twenty one year old daughter who has spina bifida. Here is their report:

This little book (113 pages) on 'emotional needs' should be required reading for all handicapped young people, and perhaps more importantly, for all who care for them, whether as parents or as professional workers.

Dr Greengross starts from the premise that "for the present, sexual success, being beautiful and loved and cared for, is one of society's ideals. And in this rat-race of relationships, the deformed and the incomplete are not even in the running" and she goes on to point out that "the disabled do have sex feelings and they do, like everyone else, have problems and need help—far more help than is available at present".

The book carefully analyses both the problems and the kind of help needed, and in many instances it sets out solutions to the problems without mincing words. Separate chapters deal with the adolescent, marriage, parents, problems in residential care centres both for staff and residents, sex education, and special problems of the mentally handicapped.

Anyone in the least concerned with the handicapped should buy, beg, borrow a copy of this paperback book which cannot fail to benefit them.

Royal Commission on the National Health Service

The terms of reference of the Commission are:—"To consider in the interests both of the patients and those who work in the NHS the best use and management of the financial and manpower resources of the NHS".

ASBAH has been invited to submit evidence—either facts or opinions—on matter bearing its terms of reference. A sub-committee has been set up to consider the issues to be submitted. Any Link reader who would like to make suggestions is invited to send these c/o The General Secretary by the end of October 1976.

Five Oaks is open!

There seems no better way to try to convey the atmosphere of the home in its first two weeks in business than to publish the messages given to an independent 'reporter' by four of the first visitors.

"It's a great place and it's got great scenery. I'm coming again next year".

Tim Claypole.

"It's pretty. I like the flowers and there is plenty of room to wheel around inside."

Simone Power.

"It's nice. I like all the ladies and the budgie".

Daphne Mitchell.

"The bedrooms have beautiful coloured curtains. The lift is very easy to work and there is a very big colour television which is lovely."

Mary Steele.

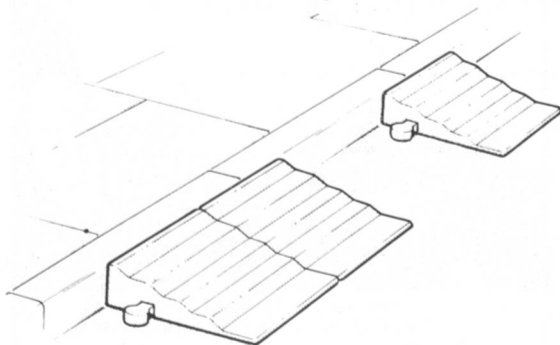
Readers will like to know that the Home is fully operational and can offer places for short-term care to most applicants. "Five Oaks is intended for spina bifida and hydrocephalic members up to 18 years of age and anyone interested should ask the National Office in London for further information and application forms.

FRONT COVER. Donna Piper of Basildon, Essex—shopping early for Christmas by the look of it! Donna, aged 6, is a little girl who has shown much courage and determination. Although paralysed from the waist down, she refuses to use a wheelchair. She has really persevered with her calipers and has now had them shortened to her thighs, and is doing well walking with crutches. Her mother, Mrs Gloria Piper says, "She is a wonderful little girl. You couldn't wish to have a happier child. She is loving, considerate and we are very proud of her." Photo: Southend Evening Echo.



Aids and equipment

Rubber ramps



Here is a useful and practical alternative to concrete or wooden ramps, for use with one step. They are made of strong rubber and each ramp (measuring 12" square and 3 1/2" high)

can be interlocked with another so that any width can be accommodated. Each ramp costs £4.30 (plus carriage) from Typrod Limited, Industrial Estate, Harbour Road, Lydney Gloucs. (tel: Lydney 2186).

Odd Shoe Service

Link readers who saw the article in the July/August 1975 issue about the odd shoe service run by Queen Elizabeth's Foundation, should please note that this service has now been taken over by a voluntary organisation, 'Sole Mates'.

All shoes, enquiries and orders should now go to 'Sole Mates', 29 Hillcrest Rd, Walthamstow, London E17 4AP. (Tel: 01-531 3067 or 01-524 2423).

Tape and slides on offer

The Medical Recording Service Foundation is responsible for producing audio tapes, with or without slides, mainly for doctors and other professional people. They do also, however, make sets which may prove of interest to some of our Local Associations. To hire such a set, i.e., a tape and set of slides, could make a very interesting part of an Association meeting.

The most suitable ones are:—

"**Clothing for the Disabled**", Ref. 72-42 by Lady Hamilton, Chairman, Disabled Living Foundation. 41 illustrations, 28 minutes.

"**Incontinence Protective Garments**", Ref. 72-41 by Lady Hamilton, Chairman, Disabled Living Foundation. 40 illustrations, 22 minutes.

"**The Importance of Play in Children**" Ref. 72-81.

"**Choosing Toys and Play Activities for Handicapped Children**" Ref 72-22.

"**Playthings for the Handicapped Child**" Ref 72-21

"**Nottingham University Toy Library for Handicapped Children**" Ref 72-23

The cost of hiring a set is approximately £2.00, but an invoice will be sent. For details of where to apply, see the advertisement, page 12.

Readers will be interested to know that one of the staff of the Medical Recording Service Foundation is Mr Patrick Browning, ASBAH's first full-time Fund-Raiser who is, therefore, particularly anxious to be helpful to us.

ASBAH will be represented at an information stand at the **Health Visitors Conference** in October, and at the **NAIDEX Exhibition** in November (9-12th), both of which are being held this year in Brighton, but each, of course, appealing to different groups. The subject of the **CCD Conference** which is held at the same time as the Naidex Exhibition is 'Employment and Leisure'. For more details contact Mr George Houghton, Central Council for the Disabled, 34 Eccleston Sq. SW1V 1PE. (Tel: 01-821 1871).

The Invalid Children's Aid Association is organising a **Conference** on November 11 on the subject '**Integration?—The Special Education Issue**'. The Conference will be relevant to those people working in the educational, social welfare and medical fields, as well as to parents and interested lay people. For further information contact Mrs H. Price, 95 Vista Way, Kenton, Harrow Middx. (Tel: 01-907 4688, and 01-730 9891).

'CHOOSING TOYS AND PLAY ACTIVITIES FOR HANDICAPPED CHILDREN'

This 36 minute tape-slide with 64 illustrations recorded by Joan Head and Kay Mogford, child psychologists with the Child Development Research Unit, will be of great interest to child care workers and parent groups.

The tape (C.60 cassette or standard reel) can be used on any domestic tape recorder and the slides (35 mm) are suitable for a domestic projector.

Loan charge for a 28 day period £2.16 including VAT and postage.

MEDICAL RECORDING SERVICE FOUNDATION

P.O. Box 99, Chelmsford CM1 5HL

Tel: (0245) 421475

An educational activity of the Royal College of General Practitioners.



THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN

(Now fitted with rubber caster on the front)

Patent applied for in

UK, Commonwealth Countries, USA, Canada

Standard model for children one to five years old costs £13.00 plus carriage.

Large model for children five to ten years old costs £16.50 plus carriage. Overseas prices on application.

Produced by **Southampton and District Spina Bifida and Hydrocephalus Association**

All enquiries to: Mrs. K. Charrett, 46 Tillbrook Road, Regents Park, Southampton.

Mobility for the disabled



Get out and about.

Range - up to 12 miles.

Just plug in for overnight battery charging.

No licence required.

Climbs kerbs and steep gradients.

Weather equipment and road lighting available.



Send for free folder and demonstration details

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

Telephone 045-3882243.

Name

Address

ASBAH Research Fellow appointed

Many readers of Link will already know that Mr Roger Bayston has been involved in research into infection occurring in the valve systems used in the treatment of hydrocephalus. This work has been undertaken in Sheffield and financed by the Association.

The work he has done has proved so rewarding that it is a great pleasure to announce that he has applied for and been awarded the Association's Research Fellowship for three years from 1 October, 1976.

He will be studying the effects of impregnating silastic (see below) with anti-microbial substances and the use of cerebro spinal fluid shunting devices constructed with these materials with reference to the prevention of shunt colonisation (colonisation is the term to describe a build-up of infection in the shunt) and other work.

This may all sound rather technical but the report of some of the work he has undertaken so far, written by the Association's Chairman, Professor Zachary, will give a picture of what is involved:—

Where does the infection come from?

If the infection occurred at operation it might be from the patient's own tissues or skin, it might be from the person operating or nurse, or it might be from the atmosphere. Alternatively, the infection might not be due to contamination at operation but might be the result of transient infection of the blood stream which all of us have from time to time and from which the bacteria could settle in the valve system.

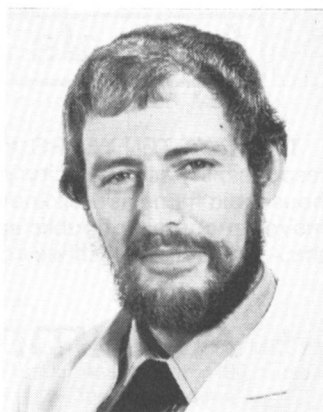
In order to determine precisely where the infection arose it was necessary to be able to identify the precise organisms in the infected valve and to compare them with infections on the skin of the patient, in the mouth or nose of the operator and nurse, or in the atmosphere. During the course of his study Mr Bayston has devised an absolutely new method of identifying bacteria which is so precise that it has been regarded as similar to fingerprinting of human beings. This development has been welcomed in bacteriological circles and is now

being followed in some laboratories of world-wide renown (for example Colindale).

Arising directly from this new technique it was established that infection arose from the skin of the patient and that the other possible sources of infection were not responsible.

Diagnosis

If infection occurs it is important to recognise this as soon as possible in order that treatment may be undertaken but under ordinary circumstances an infection may not come to notice for a considerable time, even several months. It has been shown in the research that it is possible to obtain early evidence of infection by checking the blood at regular intervals to see whether it contains any antibodies to infection. The normal level of these antibodies has been estimated and it is now possible to make a diagnosis of probable infection long before clinical symptoms occur.



Roger Bayston, who is in his thirties was born in Sheffield and is a Fellow of the Institute of Medical Laboratory Sciences and has presented papers to several meetings of the Society for Research into Hydrocephalus and Spina Bifida, the British Association of Paediatric Surgeons and other bodies.



Appeals and publicity

THE NEXT TEN YEARS. We—the Appeals Section of ASBAH—see our main responsibility as a publicity/public relations exercise to put ASBAH on the map and make it a household name as well known as Bovril. But four pairs of hands, however willing, can't move a mountain of public apathy and lack of interest without the help of every member of the Association. I wish we could all get together and talk through this very important subject.

Autumn/Winter programme

We are spending every penny of our advertising budget on a short-term advertising campaign which hopefully will “prime the pump” and bring in more income and spread the word about ASBAH.

We're re-designing collecting boxes and flag day emblems featuring our green “house colour” and Local Associations can soon order campaign kits (minimum of ten kits) comprising collecting box, emblems, emblem wallet, reseal labels and collector's badge all with the exclusive ASBAH design.

ASBAH bookmarks, as “give-aways”, are now available—perhaps your local library would have some on the counter? Your Secretary has full details.

Mainly for Londoners—a Charity Concert on Sunday 24 October in aid of ASBAH at the Shaftesbury Theatre with the Geraldo Orchestra and full star cast. Tickets £5, £3, £2, and £1. It promises a grand night out. Please contact me for tickets.

The Midwinter Ball at the Dorchester will next year be held towards the end of winter on 10 March and our Patron HRH the Duchess of Gloucester has very graciously promised to attend. Obviously the old name won't do. Any ideas for a nice glamorous name for the 1977 Ball?

Christmas is coming

We enclose a leaflet advertising our ASBAH Christmas cards. If you can get us some orders we'll be grateful. In the next issue we hope to be able to tell you about Christmas gifts by mail order—unfortunately the catalogue won't be printed in time for this issue.

Communication

This is an in-word I know, but is is vitally important that we should communicate sensibly with each other. And it's a two-way traffic so let's be hearing from you. All good wishes,

Kate White.

Continued from page 13

Prevention

Since the infection comes from the skin it is clearly important to exercise extreme caution in the preparation of the skin for operation and several different methods are at present under study, and it is hoped that in this way the risks of infection from the skin may be reduced. Mr Bayston finds that antibiotic can be

incorporated into the silastic of which the shunt is made, and the development of this initial discovery will form an important part of his new assignment.

In summary, this research over the past two years has opened up several promising fields in the study of shunt infections and their prevention and is well worth continued support.



**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
 A new book on equipment and aids will be available shortly.

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

Scottish Spina Bifida Association booklets.

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

Fund raising and publicity material

Posters

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-in-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 Dickens Way, Horsham, Sx, RH13 6BQ.

Skegness: Specially designed, well-equipped bungalow, sleeping 8. Situated at Chapel St Leonard's, nr. Skegness, on pleasant site near safe beach. Details: Mrs J. Brook, 11 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, 127, The Pastures, Downley, High Wycombe, Bucks. Tel: H. Wycombe 32184.

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

AFFILIATED ASSOCIATIONS – Hon Secretaries

BEDFORD AND DISTRICT

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

BOLTON AND BURY

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

BOURNEMOUTH

CHRISTCHURCH & DISTRICT

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

BRISTOL

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

BROMLEY & DISTRICT

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

BUCKINGHAMSHIRE

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

BURNLEY

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

CALDERDALE

Mr. A. L. Crowther,
42 Maridon Rd, Northowram, Halifax.

CHESTER & DISTRICT

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

DARLINGTON AND DISTRICT

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

DERBY

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

DEVON AND CORNWALL

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

DON AND DEARNE

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

DUDLEY & WOLVERHAMPTON

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

EAST ANGLIAN

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

ESSEX

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

GLOUCESTERSHIRE NORTH

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

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

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

HERTS AND SOUTH BEDS.

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

HUDDERSFIELD

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

HULL & DISTRICT

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

JERSEY (Channel Islands)

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

KENT

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

LEEDS AND BRADFORD

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

LEICESTERSHIRE

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

LEIGH & DISTRICT

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

LINCOLN, GAINSBOROUGH

& MID Lincs.
Mrs. P. Keyse,
Pinfold, Chapel Lane, Morth Scarle,
Lincoln.

LINCOLNSHIRE N.E.

& S. HUMBERSIDE

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

LIVERPOOL

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

LONDON, CENTRAL & NORTH

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

LONDON N. EAST

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

LONDON N. WEST

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

LONDON SOUTH

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

MANCHESTER AND DISTRICT

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

MANCHESTER CENTRAL

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

MANSFIELD, WORKSOP AND

DISTRICTS

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

NORTH EAST

(Northumberland)

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

NORTHAMPTONSHIRE

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

NOTTINGHAM & DISTRICT

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

PONTERFRACT CASTLEFORD

& DISTRICT

Mrs. N. Robinson,
4 Sandal Rise, Thorpe, Audlin,
Ponterfract WF8 3EX.

PRESTON

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

ST. HELEN'S & DISTRICT

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

SALISBURY AND DISTRICT

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

SHEFFIELD

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

SOUTHAMPTON & DISTRICT

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

STAFFORDSHIRE

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

STAINES, HOUNSLOW AND

DISTRICT

Mr. J. C. Edwards,
26 Rooksmead Rd, Sunbury on Thames,
Middx.

STOCKPORT

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

SUNDERLAND

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

SURREY (NASBAH)

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

SUSSEX

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

SWINDON AND DISTRICT

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

TRAFFORD AND SALFORD

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

WARRINGTON & DISTRICT

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

WARWICKSHIRE

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

WESSEX

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

WIGAN AND CHORLEY

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

WIRRAL

Mrs. S. Keeler,
7 Church Road, Upton, Wirral.

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 Rd, Edinburgh EH4 2BW.

MID WALES & BORDER

COUNTIES

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

NORTH WALES

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

SOUTH WALES

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

OTHER LOCAL ASSOCIATIONS

Blackpool & Flyde

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

Cannock and Walsall

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

Cheshire South

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

Chesterfield

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

Consett & District

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

Isle of Wight

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

Lincolnshire South

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

Lunesdale (Lancaster)

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

Oxfordshire

Mrs. L. W. Aldridge,
58 North Street, Marcham, Abingdon.

Rochdale

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

Somerset

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

Spenborough (Yorks.)

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

Teesside

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

NORTHERN IRELAND

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

Lurgan & Portadown

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

Mid-Ulster

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