Link

Association for Spina Bifida and Hydrocephalus/ASBAH 10p Jan/Feb 79

Another 20-page LINK—International Year of the Child: Halliwick swimming method; Wider Horizons-young people out and about: RSVP campaign for special vehicle: LINK 1978 Index.

LINK 60


INCO PANTS
INCO GARMENT
INCO ROLL

Link 60

Association for Spina Bifida and Hydrocephalus/ASBAH

Correspondence to ASBAH at the National Office:
Tavistock House North,
Tavistock Square,
London WC1H 9HJ.
Registered Charity No. 249338
Tel: 01-388 1382/5

Patron:
HRH The Duchess of Gloucester

Chairman: Mr O J Colman

Hon Treasurer: Mr R M Nichols

ASBAH has an experienced staff ready to help with any problems relating to those with spina bifida and hydrocephalus.

Chief Executive Officer:
Miss M P Gilbertson, MCSP

Finance Officer:
Mr F G Armour, FCA

Appeals Secretary:
Miss Judy Kay

Liaison Officer:
Mr H D Macfarlane

Education, Training & Employment Officer: Mrs B Newman

Head of Social Work:
Mr Rod Harper, MBASW

Aids & Appliances Officer:
Miss J Vernon, BSc.

Young ASBAH Officer:
Miss Jan Tomlinson

Information Officer:
Miss B Holland

LINK Editor:
Mrs S I Gearing

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OUT OF THE mouths of children . . . . Fieldhouse School Rochdale was joint first prize winner in the 11-14 age group of the Silver Jubilee Committee's schools competition on access. The school for 70 physically handicapped took a look at local buildings and facilities and came up with some truths.

They went along to see if a handicapped person could gain access to a local exhibition of paintings. Their 'guinea pig' got into the building easily enough but was completely defeated by the flights of stairs leading to the gallery. Further progress would have to be via a pulley—used for lifting pictures to the gallery. And reaching the pulley involved going round the side of the building, and up a dual carriageway facing oncoming traffic.

The school uses a swimming pool which is part of a new community building. Each week teachers struggled to help the children use two small toilets. Then somebody spotted a door, in the entrance hall, labelled 'Ambulant persons toilet'. Inside? You're right—a beautiful big toilet for the disabled being used as a store room. The children remind us that ambulant means . . . walking etc.

At the Oulder Hill Community Centre theatre teachers found easy access to the foyer and a toilet for the disabled. But access to the auditorium was via narrow steps.

The phone box at the end of their street was simply a 'no go' area.

The Fieldhouse researchers took their findings along to the local town planner, a meeting which led them to conclude that it would be a good idea if a disabled person could be employed, part-time, as a consultant to architects and planners.

Other points: Access to many old buildings was out of the question and nothing was being done about it. Where access was possible there was too little publicity and too few signs indicating alternative entrances. There were too few seats around the town, and none at all in the new shopping centre, for people who needed to take frequent rests. Check-out counters were often too narrow and ramps too steep.

And sadly things don't appear to be getting any better. At the new community theatre the children report that there is a sign, at the foot of some stairs, indicating that up the stairs, somewhere, is a toilet for the disabled.

The study goes on in similar vein and concludes with a number of practical suggestions including more signposts, more information and more consultation.

The children have pinpointed the problems with startling clarity. Let's hope the authorities take heed and action. And since these problems are probably universal it's important that the Fieldhouse study, and others to emerge from the Silver Jubilee Committee project (Link will bring you further reports), get a wide airing. Nobody expects buildings to be pulled down and rebuilt. But we might make a start by widening a few doors, and making other fairly basic alterations.

FRONT COVER

ARCHERY is just one of several sports that fill Avril MacDonald's spare time. Avril, 36, who has spina bifida, also putts the shot, throws the javelin and takes part in different field events from her wheelchair. She lives in Skene, Scotland and is training for a worthwhile career. Avril is a pupil at the School of Occupational Therapy in Woolmanhill—driving herself to and from school each day—and will qualify as an occupational therapist in two years.

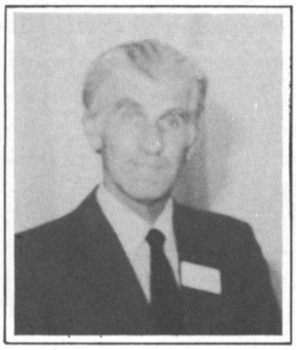
Photo: RAF Kinloss and courtesy of the Evening Express, Aberdeen.

LINK: The last date for material for March/April LINK is Feb 1. *Write to Mrs Susan Gearing, Editor, LINK, at ASBAH.*

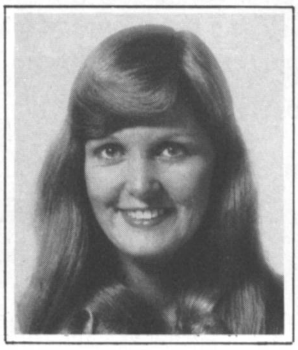
The yearly subscription for LINK (UK) is £1.15, which includes postage.

WHO DOES WHAT AT ASBAH

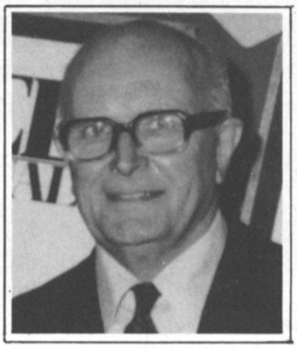
Miss Moyna Gilbertson, MCSP, Chief Executive Officer.



Mr Frank Armour FCA, Finance Officer. He deals with all the money matters of the Association—from investment policy to the petty cash.



Miss Judy Kay, Appeals Secretary. Judy has the difficult task of initiating and co-ordinating fund-raising for National ASBAH.



Mr Harold Macfarlane, Liaison Officer. 'Mac' communicates with local associations and relates families and individuals to statutory and voluntary bodies.

Mrs Barbara Newman, Education, Training and Employment Officer. She gives advice and information on special needs and facilities.

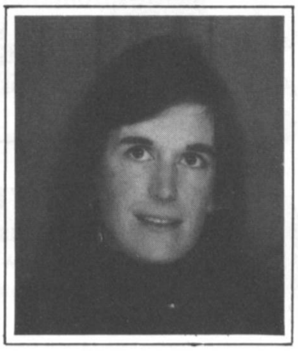
Rod Harper MBASW, Head of Social Work. Rod is responsible for co-ordinating and expanding ASBAH's social work programme.

Miss Jill Vernon, B.Sc. Aids and Appliances Officer. Provides information about complete range of aids and equipment.

Miss Jan Tomlinson, Young ASBAH (LIFT) Officer. Edits the newsletter LIFT, organises events, and the National Independence Training weeks with Barbara and Jill.

Miss Beverley-Ann Holland, Information Officer. Responsible for building up an information service and library.

Miss Pat Silverthorne, Senior Administrative Assistant. Carries out many general duties concerned with running the office, organising the annual ASBAH Conference, and liaising with Five Oaks.



Mrs Susan Gearing, Editor of LINK.

Miss Gwyn Fergie, Receptionist. She is the first person you are likely to see or hear if you make contact with National Office.

OF COURSE, THE OFFICE COULD NOT RUN SMOOTHLY WITHOUT THE SECRETARIES AND ERNEST IN THE POST ROOM!

SPOD Conference

THE Committee on Sexual Problems of the Disabled (SPOD) is organising a first International Conference on the subject of sexual and personal relationships of disabled people. The Conference is entitled Caring and Counselling and will be held at the University of Sussex in Brighton from July 10–13. ASBAH will be there and will be able to report on some of the main points arising from the Conference.

On the move

SPOD has recently moved offices to: Brook House, 216 Torrington Place, London WC1E 7HN. The telephone no. remains the same: 01-222 6067.

Opera offer

The English National Opera at the London Coliseum is now offering parties of disabled people the low party rate formerly available only to OAPs. The special rate of £1.60 for good stalls or dress circle seats is available to parties of 20 or more disabled people, the only proviso being that the party organiser contacts the theatre's Assistant Publicity officer before booking to ensure that adequate accommodation is available.

Although it is an old theatre the Coliseum can offer limited wheelchair accommodation in the stalls boxes at the lowest stalls price. Please contact the House Manager to take advantage of this concession. Access to the stalls from the street is good and Coliseum staff are always pleased to give help as needed. Special catering schemes are also available for parties and backstage tours can be arranged prior to the evening's performance. To take advantage of these special concessions contact Jan O'Neill, Assistant Publicity Officer, London Coliseum, St Martin's Lane, London WC2N 4ES. Tel: 01-836 0111. Ext. 111.

NAIDEX '79

AT WEMBLEY

NAIDEX '79 (the National Aids for the Disabled Exhibition) will be held at the Wembley Conference Centre from Nov. 20–22. As usual a RADAR Conference will be held in conjunction with the Exhibition and the theme this year will be ***Disabled People and their Place in the Community.***

Rating guide

A GUIDE to the *Rating (Disabled Persons) Act 1978:* This Act comes into force in April and the free guide has been produced by the Association of Disabled Professions. Please send medium sized s.a.e. to: Mrs Peggy Marchant, General Secretary, Assoc. of Disabled Professionals, The Stables, 73 Pound Rd, Banstead, Surrey SM7 2HU.

Christine steers a skilful course

PROUD parents, Lois and Frank Oglesby wrote to LINK about their daughter Christine and the progress she has made over the years, much of it due to the help of the small village school she attended:

"Christine was born in 1967 with spina bifida and is completely confined to her wheelchair.

"She went to a normal school at 5—just a small village school at Hindringham being two miles from our village of Thursford near Fakenham. Christine was collected from home and brought back by a welfare assistant.

"The school was almost perfect for a handicapped child—just a change round of the toilet door so Christine could wheel her chair in.

"There were two steps leading into the cloakroom but there was always someone to give Christine a helping hand.

Highlight

"Christine took part in most things. The highlight of 1978 was when she took her wheelchair proficiency test (see photo) while 19 other pupils took their cycling test. It was said that Christine went right through the course with one of the girls pushing her. She was able to cope with hand signals, emergency stops, traffic lights and crossings."

For three years she took part in the Cromer and North Norfolk Music and Drama Festival, playing her descant recorder and winning second class certificates.

"I must say we did wonder from time to time if we had done the right thing for our daughter, but at the Leavers' Service, I'm sure we had the answer.

"I expect Christine was one of the lucky ones with approximately 50 children at the school and with a most understanding headmaster, staff and pupils. How much easier it would be if there were more schools like the one at Hindringham.

"Christine is now settling in at the Palace School, Ely as she has reached the age of 11."

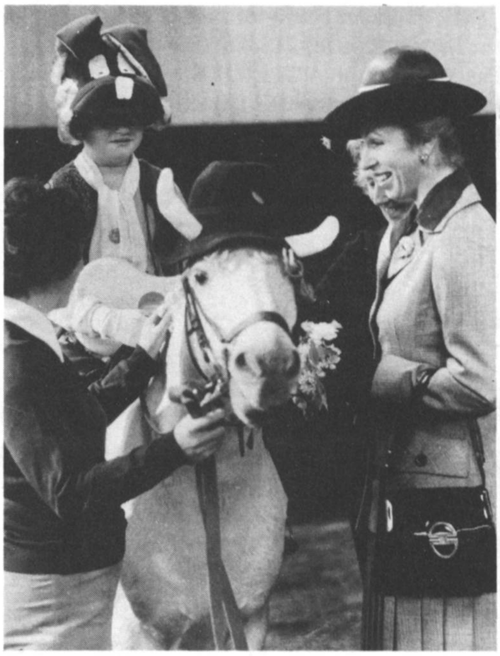
Christine Oglesby receiving a certificate for passing her wheelchair proficiency test last year at Hindringham village school, Norfolk.

Horse and rider all dressed up

FANCY dress of a different kind, both horse and rider Andrew Stiller, dressed up in fine style when they had the opportunity of meeting HRH Princess Anne.

The Princess was on a visit to the Riding for the Disabled Centre at Crowborough, Sussex. Andrew, 7½, who has spina bifida lives in Crowborough, and so is 'on the doorstep' of the riding centre, and has the opportunity to enjoy rides in beautiful Ashdown Forest.

Photo: Evening Argus, Brighton



JANET PICKS A BEAUTY

Surrounded by a bevy of bedtime beauties! Janet Swainger of Hull and District Association has the difficult task of judging a fancy dress parade. The occasion was a pyjama dance in aid of a new community centre for Hedon.

Sara Katon, 10, of the Cambridge Branch of the East Anglian Association tries out one of the three special tricycles bought for the branch by regulars of the Five Bells public house, Burwell. The pub raised £300 during last year and plan to carry on fund-raising, this time to help the East Anglian Association with its plan to buy a holiday bungalow or chalet on the east coast. Photo: Cambridge Evening News

Independence Weeks for 1979

INDEPENDENCE Training Weeks for young people with spina bifida and hydrocephalus.

Dates for 1979

March 10–17: Five Oaks, Ilkley, Yorks. 16+ age group.

April 28–May 5: Jane Hodge Holiday Home, S. Wales. 13–15 year age group.

August 20–29: New Mossford, Barkingside, Essex. 9–13 year age group.

November 10–17: Five Oaks, Ilkley. 13–16 year age group.

These dates and venues are provisional, but will be confirmed as soon as possible.

In addition to these Independence Weeks which are being run by National LIFT, I hope that there will be several weeks run by Local Associations, hospitals and/or schools in conjunction with national staff.

For more details about any of these Independence Weeks please get in touch with me at National ASBAH office, Tavistock House.

Jan Tomlinson
Young ASBAH Officer

INTERNATIONAL Year of the Child, launched on January 1 provides all those working for young people with an excellent opportunity to promote events, gaining impetus from the publicity that will be connected with United Nations year.

The thinking behind International Year of the Child is to draw everyone's attention to the problems that beset children and to focus on their statutory rights and welfare in general.

The British government has allocated £100,000 towards creating awareness, and various fund-raising events will be held throughout 1979, the proceeds of which will be distributed among those organisations working for children.

The staff of ASBAH at Tavistock House will be pleased to provide further information about I.Y.C.

Book Now for . . .

ASBAH SPRING CONFERENCE 1979

(Bath University, 6-8 April)

Title: One Life—Live It!

Theme: The needs, hopes and aspirations of adolescents and young adults with spina bifida and/or hydrocephalus. The programme will cover aspects such as accommodation, occupation and leisure. Minimum age for attendance as a delegate: 18 years.

Fees: £30 for non-members of the Association.
£25 for adult members of Association (i.e. over 18 years of age).
£15 for children accompanying a conference member.

These prices are heavily subsidised by the Association. We are having to pay the full fee for all children and for this reason it is not possible to charge less than £15.

If LIFT members would like to have a special meeting on the Saturday afternoon they should contact Jan Tomlinson at National Office with ideas for discussion and any requirements for a speaker.

Leslie giving Matthew a helping hand.

A stroke of independence

Leslie Davenport reports on the Halliwick Method of teaching swimming to the handicapped

THE HALLIWICK method is a specialist way of teaching swimming, water happiness, and water safety to people of all ages regardless of the severity of the handicap, but subject to medical approval.

It is the method used by the Association of Swimming Therapy which has clubs operating in most areas of the United Kingdom. The Association considers swimming is only part of the activity. In the water the handicapped often gain independence and freedom for the first time. This helps in the development of personality and character.

When teaching we use no swimming aids such as rings and arm bands. Often, for the first time in their lives, the pupils are actually doing everything for themselves and this freedom ensures that the handicapped swimmer learns to find and control his own balance in the water.

Purpose in play

We work on the basis of one helper to each swimmer, gradually withdrawing the support as the swimmer progresses. We play many games, each one having a fundamental purpose—teaching head control, balance, breathing, the ability to walk in the water, submerge and float etc.—in fact all the skills necessary to be safe and happy in the water. I find the pupils thoroughly enjoy these games, and, without realizing it, make rapid progress.

We also teach the swimmers to enter the water unaided, usually from a sitting position to a sitting dive, thence turning onto their backs and floating. Thus, when this is achieved the swimmer is completely independent.

The Association of Swimming Therapy has a series of badges for non-swimmers which are given as each set of skills is achieved. When the pupil has learned to be independent and mobile in the water the clubs run galas, competing with each other within their areas, and on a national basis. Each swimmer is timed and given a handicap so all have a chance within their ability.

If you are interested in joining a local club they would welcome you along to watch and see their activities.

The Association of Swimming Therapy also runs courses for helpers to teach you how to teach. The right method of progression is very important. One skill must be mastered before the next is introduced otherwise the pupil can become frightened and not want to swim again.

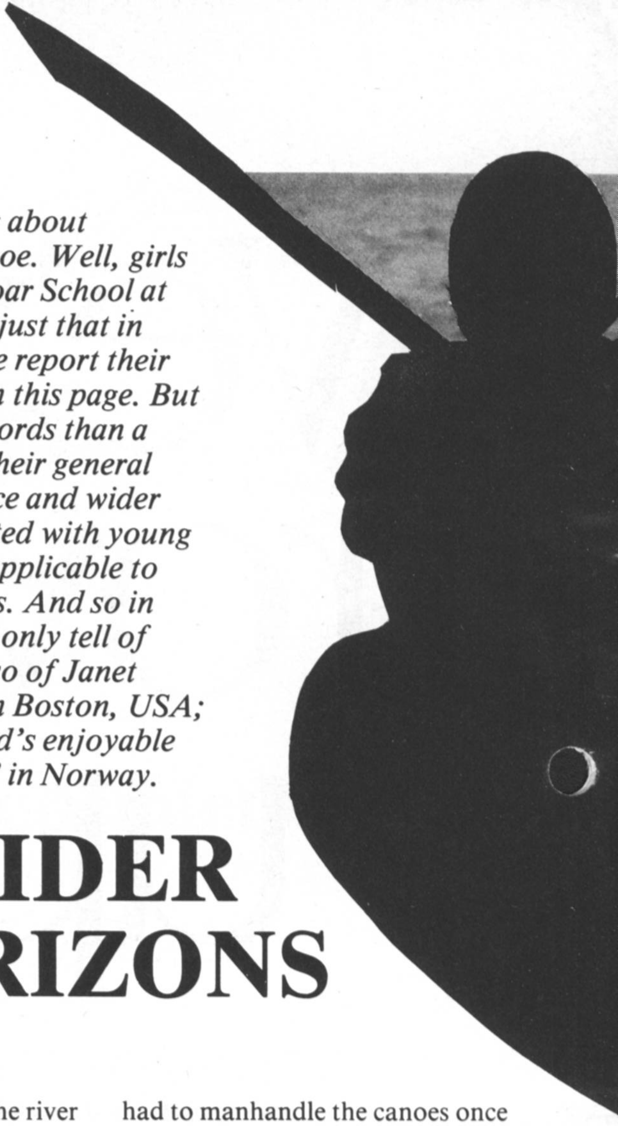
But using the right progressions at the right time, the pupil quickly gains confidence and independence. It is a very worthwhile activity especially when for some pupils it is the only time they are mobile without help or support from anyone or anything.

The Association is running a weekend training course for Instructors in the New Year in North London. If anyone is interested in joining this or one of the clubs contact:

Mrs P. McMillan, 24 Arnos Grove, London N11 1AP.
Tel: 01-368 3251.

Or ASBAH has a list of the clubs throughout the U.K.

● Leslie Davenport is a swimming therapist, and ran morning swimming sessions at ASBAH's Independence Week at New Mossford in August last year.



THERE's an old saying about paddling one's own canoe. Well, girls from the Florence Treloar School at Alton, Hampshire, did just that in France last summer. We report their experience beginning on this page. But there is more in those words than a literal interpretation. Their general message of independence and wider horizons, often associated with young people, is increasingly applicable to handicapped youngsters. And so in these four pages we not only tell of the girl canoeists but also of Janet Handley's adventures in Boston, USA; and of Hild Sommerstad's enjoyable taste of life at 'Frambu' in Norway.

WIDER HORIZONS

Girls have a taste of France—by canoe

FRANCE, hot summer days, peaceful canoeing punctuated by the excitement of shooting rapids and a return to the relative calm of camp site evenings conjures up a picture of an enviable holiday.

The fact that the holidaymakers were eight handicapped girls—most of them with spina bifida—from the Florence Treloar School at Alton, Hampshire makes the scene all the more remarkable.

The girls were accompanied by Mrs Kathleen Bell, the school's head of physical education and physiotherapy, Marie Wallace, school house matron and Brian Barton, the area adviser for further education. Mr Oliver Cock, director of coaching for the British Canoe Union went along to provide the necessary canoeing expertise.

Mr Barton takes up the story:

‘We left Alton on the night of Tuesday July 11 and joined the night boat Southampton–Le Havre, arriving at Le Havre on the Wednesday morning, having had cabin accommodation on the way over.

We also received VIP treatment from the ship's crew, the captain sending a gift of perfume to each of the girls.

We travelled on by minibus with all our luggage, tents, six wheelchairs and various pieces of canoeing impedimenta (life jackets etc.). We drove on the quiet roads of France and Wednesday night stayed at a youth hostel at Bourges.

The following evening we eventually arrived at Villeneuve D'Allier where we set up camp on a municipal camp site right at the side of the river.

LAUGHTER ECHOED IN THE CAMP

The Friday was spent on the river right next to the camp site where we were introduced, for the first time, to rapid water canoeing and Mr Cock (the national coach for canoeing), gave the girls instruction in how to canoe in rapid water.

On Saturday we journeyed about three miles upstream to some different water, where another series of techniques were practised on a different form of rapid.

Invited

During this day we met up with some boys from Millfield School in Somerset and, to our delight, we were invited to take an evening dinner with them at their camp site in the nearby town of Brioude. This was a most pleasant social occasion, and in no time at all gales of laughter were echoing round their camp site—a most memorable evening.

On Sunday we made our first long paddle on the river Allier, paddling about 12 kilometres from a place called Langeac to La Voute Chilac. We lost count of the number of rapids that we paddled through on this day. The river was beautiful, the temperature was 104 degrees in the shade and the girls had a very enjoyable, but very tiring trip. We had to manhandle the canoes once where the river went over a concrete barrier.

At the end of this long paddle we came round a bend in the river to the last rapid of the day, and the most fierce, to find that one of our girls—Janet—had capsized in the middle of the river and was clinging to a rock, having completely lost sight and contact with her canoe. However she was none the worse for her experience. A few minutes after her capsize she was rescued by a handsome young Frenchman in a Canadian type canoe.

On Monday and Tuesday we spent our time canoeing the river from La Voute Chilac down to our camp site, a distance of about six kilometres. We decided to count how many rapids were involved in this short piece of river and, in fact, we counted 29.

The girls enjoyed French food, and we had a French breakfast every morning, with fresh crusty bread. In the evenings we enjoyed a typical meal, cooked in true French style,

RESCUED BY A HANDSOME FRENCHMAN

with lashings of garlic and other garnishings and, when appropriate, the right liquid refreshment. The weather for the whole of the journey was superb.

On Wednesday July 19 it was decided, because our vehicle had not been behaving itself, to make a leisurely start homewards.

The next day we continued and made an overnight stop at Chartres, where the girls visited the Cathedral and the old town and also took the opportunity to buy presents in the local hypermarket. On Friday there was a leisurely journey back to Le Havre, a little bit more shopping with what money had been left and we boarded the boat at about 10 p.m. and crossed again at night, with the same superb treatment by Townsend Thoresen to Southampton.

It was obvious that the many hours spent in the school swimming pool learning the basics of canoeing, the time spent learning strokes and rescue routines proved to be time well spent, and the canoeing on the river was an absolute delight. A holiday well worth remembering.

■ ■ ■

JANET HANDLEY was born prematurely on December 29 1956. When her mother left hospital on the sixth day she went home with her. She received no treatment. The prognosis was grim. Now, putting a dressing on her back is the only thing she cannot do for herself.

Janet has myelomeningocele and the lower part of her body is completely paralysed. When she was seven years old she was fitted with calipers and elbow crutches but despite great effort was able to make very little progress. When she was fourteen she had a Shrewsbury Splint and did remarkably well with it, on flat uncarpeted surfaces.

Two years ago she decided to give it up and now she relies on a wheelchair.

Janet had an ileal bladder operation when she was almost ten and her spine was straightened by a Dwyer procedure when she was sixteen years old.

She attended the local special school where she took CSE and then an ordinary F.E. college where she followed a "O/A" level course.

Janet is now in her final year at the University of Warwick reading for an honours degree in Sociology. She hopes to work in local government.

With her sister, she has also spent a holiday in the USA. Her account of the holiday starts below.

How Janet fulfilled her own American dream

GROWING up in the 1960s, I was exposed to American television programmes. They influenced my reading and I became engrossed in the history and the development of the "New World". I was determined that one day I would go there.

In October 1977 I wrote to all the organizations offering foreign travel opportunities to disabled people. I quickly realised that most were concerned only with the ambulant.

Eventually I did contact an association which was taking a party of disabled students to Boston. Unfortunately the dates clashed with my examinations so it was not possible for me to go. However the organization made arrangements for me to go in September 1978.

My "independence kick" took a tumble when I learned that although I knew I could cope alone the airline would not carry an unaccompanied paraplegic on a journey lasting more than four hours. My sister agreed to come with me and I admit I was glad of the moral support.

We left on September 3. I was very impressed with the facilities at Heathrow. On reporting at the TWA desk a wheelchair was brought to me and mine went with our luggage. A porter took me through the formalities and straight to the plane. It was a tunnel boarding and I was taken, in a carrying chair, to my seat.

HEATHROW FACILITIES IMPRESSIVE

The flight was superb, I enjoyed every minute, and we landed in glorious sunshine. I was taken through customs with a minimum of formality and met the family with whom we were to stay.

The thought of staying with strangers had caused me a few anxious moments—would they understand disablement? It was with relief that I learned that Don and Betsy Anderson, my hosts, have a son, Michael, 14, with spina bifida.

Michael confirmed my belief that every disabled child of normal intelligence should attend his neighbourhood school. Michael has been normally educated and is the most independent, self-assured, normal, disabled teenager I have met. He has held down a holiday job, he visits the cinema alone and

Continued over

USA—through the eyes of a disabled person

Continued from page 11

runs errands for his mother. In his wheelchair he is entering a marathon race for normal runners.

We were primarily tourists and as such we traversed Boston's Freedom Trail, took boat trips round Boston Harbour and visited the Tea Party Ship and the Aquarium. We spent days at Salem, Concord, Lexington and Plymouth, where we visited the Pilgrim Village.

Speed Boat

We spent one weekend at Cape Cod and another in New Hampshire where I had my first ride in a speed boat.

It was interesting to compare the facilities for the disabled. The equivalent of the "Sick and Disabled Person's Act" is Amendment 504 to the Constitution. This makes discrimination against disabled people in work and education illegal and all new buildings must be accessible.

Inevitably progress is slower than one would wish. Roads are not systematically ramped and there seemed fewer wheelchair "comfort stations" than in Britain.

However I am not in a position to judge how the anti-discriminatory legislation is working.

The State of Massachusetts has helped to set up the "Federation for Children with Special Needs", an organization for which Betsy Anderson works. One of its main functions is to ensure equality of educational opportunity.

I can offer no explanation but the disabled were more visible in Boston. I saw more wheelchairs there than I ever see in Coventry. The general population seemed more aware of the needs of the disabled and on telephoning a building to enquire about accessibility the relevant information was instantly available.

"The Ride"

Amendment 504 says that each City must provide a form of public transport suitable to the disabled. Washington DC is making its Subway stations accessible. Boston's new subway stations will also be accessible but the greatest asset we found was "The Ride".

This is a private, non-profit making corporation founded by a disabled man but financed by Federal Funds and the local transport company. The vehicles have hydraulic lifts and radio equipment. They work as a normal bus service to meet the transport needs of the disabled. A charge of 75 cents is made for each journey.

I used this service regularly and cannot praise it enough. "The Ride" should be instituted in every city here.

I was able to discuss many aspects of disablement with the people I met and all were frankly envious of the National Health Service. They have medical insurance through their employers but it is nothing like the "womb to tomb" care that we take for granted here.

In these discussions I learned of new procedures of urine control but as mine suits me I prefer to leave well alone.

New York

After three wonderful weeks in Boston we travelled, by Greyhound Bus, to New York City where we spent the last four days of our holiday. The hotel into which we were booked was unsuitable so we transferred to the Hilton. Even there I could get into the bathroom only after the door had been removed.

In New York we depended for transport on taxis. Despite the dire warnings that drivers would not stop for me I met no discrimination. The taxi drivers were just as I had imagined and we had many interesting conversations with them, especially the one who took us with all our luggage to Kennedy Airport. He was a Pakistani who had lived in Bradford for many years before emigrating to the USA.

The Empire State Building, erected in the 1920s, is outside the aegis of Amendment 504 and we never did reach the top. The World Trade Centre, now the tallest building in America is new and the view from the top is fantastic.

We visited all the tourist places, including the UN Centre, Central Park, The Statue of Liberty and Greenwich Village. We had a wonderful view of New York from a helicopter. At the time I was petrified but in retrospect it was wonderful.

Although we checked that J. F. Kennedy Airport was expecting us the facilities and expertise of Heathrow were sadly lacking. I could not find a wheelchair toilet and enquiries met with a blank stare. A stewardess pushed my chair to the aircraft, put on my brakes and irritably asked why I did not walk on to the aircraft. A member of the crew seeing my dilemma carried me aboard.

The journey home was through the night. It was a wonderful experience flying into a new day and watching the dawn break. We landed at 7.40 a.m. Our parents were standing at the barrier and we were soon safely home.

I took with me all the medical equipment I thought I would need, which proved to be far too much. The bag behaved well. The worst problem I encountered was a tummy bug. I had not experienced this for over ten years and was completely unprepared for it. However with my sister's help I coped.

Achievement

Many people I met were amazed at what I achieved during my stay in the USA. They failed to understand that to me life in a wheelchair is the norm. I know no other life. Whatever I achieve or fail to achieve will be from a wheelchair. I prefer to take a calculated risk than to sit at home bemoaning my fate.

I made my dream come true and to all the people in Boston who helped me I would like to say Thank you again (they receive LINK) especially Betsy, Don, Michael, Jennifer and Sam Anderson.

The only ill effect I suffered was jet lag but four days later I returned to university to begin my final year and my holiday is now only a happy memory.

■ ■ ■

Hild finds lasting friends at Frambu camp

MY NAME is Hild Sommerstad. I am Norwegian, and I am fifteen years old. I was born with spina bifida. I walk with two sticks and use a caliper on my left leg. I also have an ileal bladder.

Three years ago I was in the Children's Hospital, Sheffield and had two spinal operations because my back was very curved. I am very happy I had these operations as I am quite straight now. I liked it at the Children's Hospital. They were awfully nice to me there.

Special camp

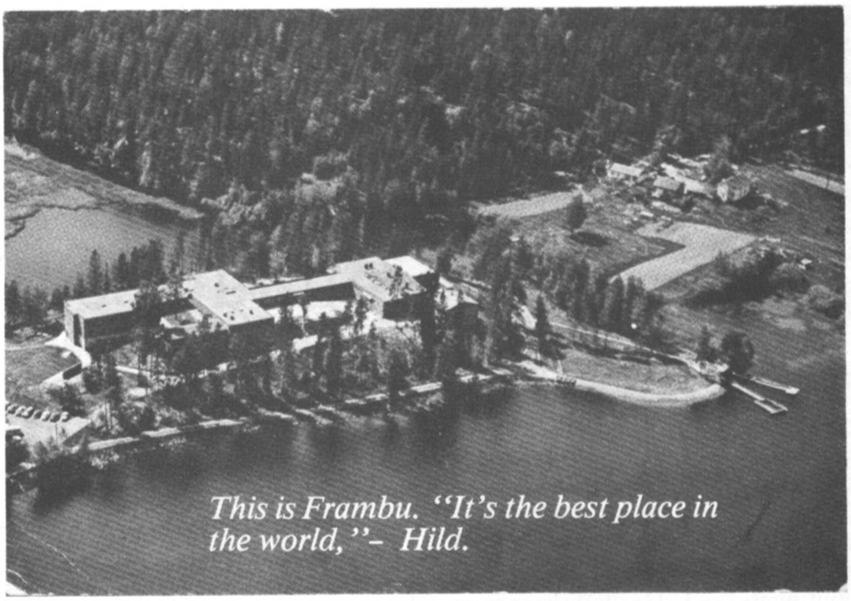
Every summer I attend a camp for handicapped children in a place called Frambu and this summer we had a visit from Dr Lorber, who asked me to write to *LINK* about Frambu.

Frambu is a purpose-built estate which is designed to make living an easy matter for anyone in a wheelchair or with sticks. It is used for treatment, recreation, camps for children and youth, and information courses for families with different kinds of handicapped children.

Activities

Frambu is surrounded by idyllic lakes. There are parks and playgrounds where we join in different activities. When the weather is nice we can swim in the lakes or use Frambu's rowboats.

WHEN CAMP ENDS WE ARE SAD


This is Frambu. "It's the best place in the world,"- Hild.

The participants live in units, two in each room with two rooms sharing a bathroom. There is one hall for indoor activities, one for physical training, and an indoor swimming pool as well. There are also three kindergartens, mainly used on family courses.

Our day starts at half past seven, and we eat breakfast at half past eight. From 10 a.m. to 12 we swim, or exercise in the gymnastics hall. It is dinner-time at 12. After dinner we rest in our rooms for two hours.

During the "rest" we usually visit each other and play games, cards or sing and play guitars and records. It is so nice to be surrounded by friends.

Beach tea

At three o'clock we go to the beach. There we swim, play football, play with swings, slides, seesaws, jungle jims and many, many other things. We also have tea on the beach.

There were about 60 of us last summer, 23 with spina bifida. The others were spastics. All together there were 40 young people there to help us. They were mainly students.

Dancing

At 6 o'clock it is supper-time. Most of all we enjoy the dancing in the evening. We have a band that plays for us sometimes.

These are just a few of the things we do. We also spent one day with the King's Guard as their guests.

When the three weeks come to an end we are very sad to leave each other although we are looking forward to joining our families again. I always feel like crying when I leave Frambu, but I look forward to the next camp and write lots of letters to the friends I have met there.

I send my best wishes to all the English boys and girls with spina bifida, and a special greeting to all I met in the Children's Hospital during my stay there in 1975.


Hild Sommerstad

■ ■ ■

Should we have our children immunised and vaccinated?

by

J. LORBER, MD, FRCP

MOST readers of LINK will have read in their newspapers, and heard on the radio, about the discussions on whether immunisation, in general, is safe or not; whether whooping cough vaccination, in particular, is safe or dangerous, and whether handicapped children, such as those with hydrocephalus or fits, should be vaccinated against whooping cough.

Readers will have also heard that because of destructive and ill-informed writing the number of children who are protected by immunisations has radically fallen in this country.

One result is a major epidemic of whooping cough. Other epidemics may well follow if this trend continues.

I therefore thought that readers might like to know that immunisation against diphtheria, tetanus and poliomyelitis is absolutely safe for anybody as indeed is immunisation against measles and German measles.

I consider that there is no evidence whatever that whooping cough vaccination ever caused brain damage to babies and children.

It is true that a very few children who are vaccinated against whooping cough do develop very severe brain damage soon afterwards. This incidence is about 1 in 100,000.

However, the type of brain damage from such an illness is exactly the same as has happened for a long time, without whooping cough vaccination, to babies in that age group. The incidence of such an illness is no greater in those who had the vaccination than in those who did not.

It is, of course, easy for the parents and, unfortunately, even for some doctors, to imagine that the vaccine caused the illness when this illness followed vaccination within a matter of days. Not a single case, however, has been proven to be due to the whooping cough vaccination and there are no investigations available today which could do so.

It is generally advised that children with an abnormal nervous system, or fits, should not have whooping cough vaccination. This is also a major mistake, although it is true that children of this type are more likely to suffer from some form of brain damage. It is not true that it is the whooping cough vaccine that causes this.

On the contrary, whooping cough is an extremely serious disease, particularly in young babies and particularly in those with a weak chest such as many spina bifida babies have.

In my mind, therefore, you would be wise to have all your children protected against these totally unnecessary and easily preventable infections. You may show this article, if you wish, to your family doctor or your infant welfare clinic and I would not be put off your wish to have your children properly protected.

New campaign for special vehicles

THE Replacement Specialised Vehicle Project (RSVP) has been formed to fight for all those disabled people for whom the Mobility Allowance and Motability are no answer to their need for independent movement.

Young people reaching the age of 16 and adults who are newly disabled are among those affected, together with those who, at present, have invalid tricycles but who feel very uncertain about their future.

Motability can help those who are able to drive an adapted production car, but very many disabled people achieved independence in the past because a specialised vehicle, such as the invalid tricycle, was available to them.

The invalid tricycle, which was provided on permanent loan from the Department of Health & Social Security, had the advantages of sliding doors for easier access, tiller control, the choice of petrol or battery power, and the annual cost to the disabled person was negligible.

The RSVP Committee intends to fight for the right of these disabled people to be mobile, and their first action is to invite the completion of questionnaires by as many disabled people as possible who have need of a specialised vehicle.

The Committee consists of the heads of many organisations who have first-hand knowledge of the present disastrous situation, including Miss Gilbertson representing ASBAH.

Write NOW for a questionnaire from: RSVP, Queen Elizabeth Foundation for the Disabled, Leatherhead Court, Leatherhead, Surrey, KT22 0BN.

Questionnaires should be returned by end of March.

Disabled may be exempt from duty

FOLLOWING this year's Finance Act, from 1 December 1978, vehicles used *'by or for the purposes of'* disabled people in receipt of Mobility Allowance may be exempt from paying Vehicle Excise Duty.

The Department of Health and Social Security has issued an application form for claiming exemption to all those receiving the Mobility Allowance. Although the DHSS has issued this form to all Mobility Allowance beneficiaries, it is up to the **Department of Transport** to decide whether individual claims are valid.

Problems

ASBAH is receiving a large number of queries about exactly who is eligible to claim this exemption, and problems arise because it is difficult to know how to interpret the phrase 'by or for the purposes of the disabled person'.

If, for example, the car is used to transport the disabled person, or to do his errands, such as collecting prescriptions, etc., then it is legal to claim the exemption.

If, however, the Mobility Allowance beneficiary is a disabled child, and the father also uses the vehicle to travel to and from work, it is unlikely to be legally valid to claim exemption.

The present situation is very confusing. So far there have been no legal 'test' cases. If you are in any doubt as to your eligibility, ask the Department of Transport to comment.

HOLIDAYS

The English Tourist Board has a number of publications about holiday accommodation, and different holidays carrying the wheelchair symbol to denote suitable accommodation for the disabled. The publications include:- *'Where to Stay', 'Special Interest and Hobby Holidays,' 'Outdoor Activity and Sports Holidays,'* and *'Breakaway Holidays for Unaccompanied Children'.*

Copies available from Regional Tourist Board offices or from the English Tourist Board, 4 Grosvenor Gardens, London SW1W 0DU.

CORRECTION

WHEN reporting, in the last issue, on the election and re-election of members to ASBAH's Executive Committee, LINK in error, omitted the name of Dr D. Gompertz. Dr Gompertz was elected to the Committee at the Annual Meeting and we apologise for this omission.

LETTER

Karen looks for a pen friend

HI! I am Karen Winter. I am 14 and I have spina bifida, and I would like to know if any young people in Britain are interested in having a pen pal from British Columbia with a similar problem.

If they are they can write to me at the Children's Hospital, c/o the O.T. Department. Here we can arrange for other kids to become pen pals with the kids in Britain.

I myself would be interested in having a friend from Britain with a similar problem and learning how they handle it. I hope my interest will be shared. I hope to hear from you soon.

KAREN WINTER,
Children's Hospital,
250 West Fifty-Ninth Ave,
Vancouver, British Columbia,
V5X 1X2,
Canada.

ASBAH is planning regional appeals staff

HAVING been Director of Appeals for ASBAH for a few months, the time has come for me to say a few words in LINK by way of introducing myself.

Kate White, with whom I worked for two months before her departure, certainly gave me the best handover that anyone could wish for and despite our short acquaintance I know that I miss her probably as much as you do. I feel very humble faced with the task of proving a worthy successor.

Raising funds for ASBAH is a challenge which I very much enjoy and you will be pleased to know that the Christmas appeal, which has occupied most of the appeal department's time of late, is showing an excellent return. People, appreciating the difficulties of charities in these hard times, have been generous enough to increase their donations from previous years.

I know that Local Associations fund raising is most expert and I suspect that Associations will have enjoyed the generosity of others at Christmas but I would like to emphasise that if I, and my staff, can be of any assistance to you at any time please do not hesitate to contact us and we will do everything within our power to help.

We are hoping to recruit members of Appeals staff in various regions, in consultation, of course, with the Local Association concerned, and I would welcome any comments which they may have.

ASBAH has been fortunate enough to be chosen as the main beneficiary from Aberystwyth University Rag in 1979 and the proceeds, which should amount to approximately £15,000, will be spent on providing a holiday chalet at Borth for the use of Association families.

As the students organise "raids" upon various cities throughout Great Britain I do hope that you will not feel that they are poaching on your reserves but will co-operate with them if the occasion presents itself.

It is very encouraging that these young people will throw themselves so wholeheartedly into raising money for charity and I am sure that those of you who have stood on drafty street corners with collecting cans will know just how courageous they are being to undertake this task during the months of January and February.

As time goes by I hope to have the pleasure of meeting you all but meanwhile I would like to emphasise that we are YOUR Appeals Department and I hope that you will regard us as such.

JUDY KAY
Director of Appeals

Mike donates a share in his exhibition

SINCE his baby son died of hydrocephalus, artist Mike Barton has had two ambitions: to do something to help those with this handicap and to mount a show of his own marine paintings.

In October Mike, a photographic retoucher with a large publishing company, unveiled his own one-man exhibition at Canterbury's Marlowe Theatre, and he donated £600, part of the proceeds, to ASBAH.

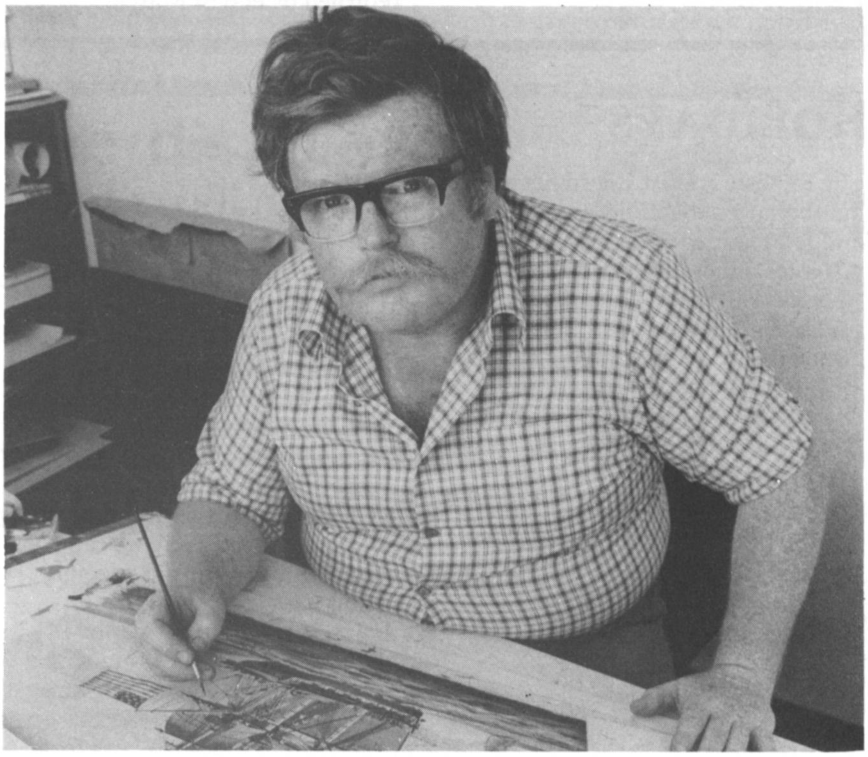
'This is one way in which I can help,' he said, adding 'My son's death, two years ago, knocked me off my pedestal.'

Since then he worked steadily at his paintings, until he had more than 30 ready to go on show.

Working in oils, watercolour and gouache, Mike aims at 'historically accurate representations with attention to fine detail.'

This is Mike's first full scale exhibition, but he is no weekend amateur. He has had work commissioned by the Peabody Museum, Massachusetts, USA, and his painting featured prominently in the N.E.L. partwork *History of Ships*.

His wide knowledge of ships has gained him membership of several leading bodies, including the Society of Nautical Research and World Ships Society.



Mike Barton at work

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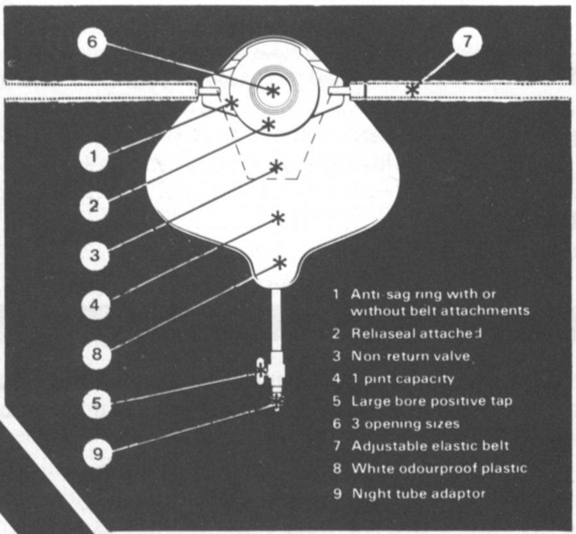
Troubles with leakage, odour, soreness around the stoma, skin excoriation, and allergy, are effectively dealt with every day.
Home visits can be arranged if it is impossible for an ostomist to visit one of our many stoma centres throughout the country.
Please write or telephone Salts if you have problems and help will be forthcoming.
The appliances shown below can be tried by you, free from charge and without obligation.

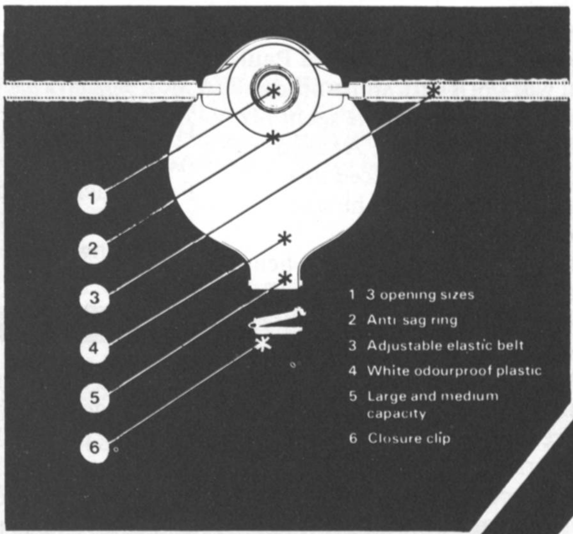
LW URINARY POUCHES

are complete appliances and can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.
LW is disposable, is odourproof, is soft and rustle free, is self-adhesive, and can be worn for up to one week before changing.
Cotton bag covers can be provided, and alternative adhesives are available for use with pouches without Reliaseal attached.
3 opening sizes available: 1″, 1$\frac{1}{4}$″ and 1$\frac{1}{2}$″.

LIGHT WHITE ILEOSTOMY POUCHES

can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.
LW is disposable, has bag covers, belts, closures, stabilising rings, is supplied in two capacity sizes, large and medium, odourproof, can be worn for a week without anyone knowing, and it looks as good as an appliance can look.
Any ostomy adhesive and sealing washers are suitable. None can harm the tough, soft plastic. Reliaseal is highly recommended.
3 opening sizes available: 1″, 1$\frac{1}{4}$″ and 1$\frac{1}{2}$″.





If you would like to try either of the above appliances, please complete the coupon opposite and post to the address below. NO STAMP IS REQUIRED.
You will then receive a sample of the basic appliance free from charge and without obligation.

IMPORTANT
To obtain the best result, please state the diameter of your stoma.
If you cannot measure accurately please ask Salts for a stoma measurement guide.

SALT & SON LIMITED,
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L/78/U/1

NAME ....

....

ADDRESS ....

....

....

TYPE OF APPLIANCE .... OPENING............

Paul needs a home with a family

Do you know someone who could care for a child like 7 year old Paul?

Paul was born with spina bifida and hydrocephalus and he spent his first months in hospital. At aged eight months he was placed in a Barnardo's home where he still lives today.

Paul's mother was only 17 when he was born and she was, and still is unable to care for her son. Three other children were born after Paul and two have been adopted. The last child remained with her and she has since divorced Paul's father and remarried.

Paul has contact with his mother and his maternal grandparents and although it is important that these links are maintained his natural family will never be able to care for him.

He has been cared for by residential staff who have helped him to progress to the stage he is at now and he has a particularly close relationship with one member of staff who has looked after him since he was admitted. However Barnardo's feel this is not enough and that Paul would benefit enormously from the kind of relationships which exist in a family.

Paul is a delightful child, small for his age and with a happy outgoing personality. He loves picture books, daleks, the Muppets and talking on the telephone. He also enjoys visits to the baths, where with rings and wings he has become a proficient floater and is reluctant to make a quiet exit from the water!

At school, where he is again well liked, Paul is a little behind his chronological level and he is struggling to keep up with the other children who are also physically handicapped.

Paul is not over confident and the staff have to work very hard to encourage him to walk using his calipers. Any family who think about caring for him would therefore need to be prepared to coax, bully and encourage Paul to do things for himself so that he can become more independent.

As readers of LINK will be aware, hospital visits play a major part in Paul's life, but he has weathered his many operations well. He is now healthy and has a normal life expectancy.

Paul is loved wherever he goes and he could give so much to a family. Could a family you know give him that opportunity?

Anyone interested in finding out more about Paul—and who lives up to one hour's travelling time from Blackpool and Liverpool—should please contact Liz Dodson, Senior Fostering Officer, Barnardo's, 7 Lineside Close, Liverpool L25 2UD. 051-487-5313.

LINK INDEX ..... Issues 54-59

BELOW is an Index of some of the major articles which have appeared in the last six issues of LINK. Back numbers are available from National Office. This new style, A4 size LINK is now one year old, and I hope readers have found it full of interesting, stimulating and informative reading. Please do let me have more of your views, news, ideas and pictures for future issues.

Susan Gearing, Editor

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CLASSIFIED 'ADS'

Adverts for next LINK must be in by February 1
The address is: LINK Advertising, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ.
Rate: £1.00 for up to 25 words. £2.00 for 25–40 words, £3.00 for 40–60 words. Please send remittance with your advert. You may like to pay for a whole year's advertising in one go.

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Old fashioned clothes. Victorian up to 1940. Please contact me before giving away Granny's old clothes, especially nighties and blouses. Cash paid. Please tel: 01-658 0660.

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ASBAH booklets etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	25p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	20p
The Nursery Years, by S. Haskell, MA, Ph.D, and M. E. Paul, 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
Sex and Spina Bifida by Bill Stewart ... ... (75p to LIFT members).	£1
Information leaflets	100 for £1.30

All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 9p per booklet.

Scottish Spina Bifida Association Booklets

Growing Up with Spina Bifida, by O. R. Nettles, MCSP, ONC...	30p

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

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All available from Appeals Dept.—postage extra.

The Appeals Dept. carries a range of fund-raising items, i.e. pens, balloons, calendars, tabards, car stickers. Send for list and order form.

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

STAINES, HOUNSLOW & DISTRICT
Mrs M McGuigan,
7 Winchester Rd.,
Hanworth, Middx.
Tel: 01-894 9230.

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

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

SURREY
Mr T J Denyer,
Flat 3, Cypress Lodge,
Cypress Rd., London SE25.

SUSSEX
Mrs M White,
Averys, Rusper, Horsham.
Tel: Rusper 217.

SWINDON
Mrs S J Trembling,
3 Church Place, Swindon.

TRAFFORD & SALFORD
Mrs J Gray,
9 Whitegates Close,
Timperley WA15 7PG.
Tel: 061-980 8359.

WARRINGTON & DISTRICT
Mr S J Charlton,
36 Park Ave., Latchford,
Warrington.

WESSEX
Mr P Chelton,
93 Wessex Oval, Wareham, Dorset.

WIGAN & CHORLEY
Mrs M Roberts,
87 Common Lane,
Culcheth, Warrington,
Cheshire WA3 4HF.
Tel: 092-576 4889.

WIRRAL
Mrs S Keeler,
7 Church Rd.,
Upton, Wirral L49 6JY.
Tel: 051-677 1104.

WORCESTERSHIRE
Mrs M Davis,
Lower Field,
Wynniatts Way, Abberley.

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

WALES

LLANELLI
Mrs Y Pudner,
83 Denham Avenue,
Llanelli, Dyfed.

MID WALES
Mrs J Carter,
1 Meadow Road, Craven Arms,
Salop.

NORTH WALES
Mr J Jones,
2 Llandaff Drive, Prestatyn, Clwyd.

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

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

NORTHERN IRELAND
Mr J Egar,
Flat 1B, Parkdale House,
Seymore Hill, Dunmarry,
Co Antrim BT17 9DA.

OTHER LOCAL ASSOCIATIONS

Blackpool & Fylde
Mrs D Sharples,
17 Queens Rd., St. Annes-on-Sea,
Lancs. Tel: St. Annes 723547.

Beeston
Mrs S S Goodfellow,
5 Cyril Ave., Beeston.

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

Chesterfield
Mrs K M Tomlinson,
23 Hathern Close,
Brimington Common,
Chesterfield.

Consett & District
Mrs M Holmes,
39 Derwent Cote,
Hamsterley Colliery,
Newcastle-upon-Tyne.

Herefordshire
Mrs C Davies,
Feather Cottage, Whitney-on-Wye.

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

Lunesdale (Lancaster)
Miss P Crook,

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

Shropshire
Mr P Bowcock (Chairman),
Church Farm,
Hadnall,
Nr Shrewsbury, Salop.

Somerset
Mrs E J Burston,
19 Golden Hill, Wiveliscombe.

Spenborough
Mrs M Cartwright,
9 Delmont Close, White Lee Rd.,
Batley, West Yorks.

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

Yorkshire South
Mr and Mrs Barringer,
10 Fullerton Crescent,
Thrybergh,
Rotherham, Yorks.