Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p Sept/Oct 82

Wirral goes to the Palace: Clive makes herbs his business: ASBAH-backed research: New magazine on the bookstalls: The benefits of yoga: Travelling with PHAB: A galaxy of fund-raising

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Association for Spina Bifida and Hydrocephalus/ASBAH

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Lives in Question

HOW HEARTILY I endorse the sentiments expressed by Alison Davis in the last LINK (July/Aug). I, too, am an adult married spina bifida sufferer.

Like her I have a University degree and have had a letter published in 'The Guardian' defending the right to life of the handicapped child. Last year I appeared as a witness on 'You the Jury' defending this proposition. In the past ASBAH has asked me to contribute to one of its booklets and to a Study Day for teenage spina bifida sufferers.

Unlike the majority of them and Mrs Davis, I am not wheelchair-bound and have, therefore, always been fortunate enough (if that's the right word!) to mix with the able-bodied at school, university, in my chosen profession, and now as a busy wife and mum.

You acknowledge in your comment on Mrs Davis' letter that parents and the medics face a terrible dilemma and choice when a handicapped child is born. Dare I suggest that they might be helped if they knew what some of us *have* achieved, if they could meet some of us, if ASBAH told them about some of us. I feel your reply ducks the issue, although I do accept you did not exclude us perversely.

Of course, I have ups and downs but then so does my husband who was recently diagnosed diabetic, and no-one so far has decided that he should no longer be allowed to live!

Please make use of those of us of whom you know who live successfully (for the most part) with spina bifida. I am appalled that so many people pick on us and Downs' Syndrome babies for extermination, and wonder how much is due to their embarrassment when faced with our obvious physical handicaps.

Once it is established that we should be killed, who will be next... the spastics, the deaf, the blind, the elderly... Finally, Like Mrs Davis, I greatly resent Professor Lorber's description of us as 'clumsy, fat dwarves' which you are apparently prepared to endorse.

MRS DIANA SANDERSON
DURHAM

Mediscreen goes into films, video

ASBAH is a member of Mediscreen Productions Ltd, a new consortium of voluntary organisations which hopes to produce programmes for television and video about disability, its prevention and related issues, with a strong appeal to a general audience.

Mediscreen has received a commission from the new Channel 4 to make four programmes which will discuss different aspects of disability—access, employment, education and community care.

Disabled and able-bodied people will be involved in production work for Mediscreen at all levels. For further information contact Anne Dillon, Mediscreen, Brittanic House, Moor Lane, London EC2Y 9BO. Tel: 01-920 6241.

COVER PHOTO: PHAB members enjoying the facilities of the Metro at Washington. It is completely accessible for disabled people. See pages 18 and 19 for article about PHAB's travel opportunities.

Special flats will soon be available

APPLICATIONS are welcomed now from people who have a need for specially adapted flats to rent. The Shaftesbury Society has a number of schemes underway, due for completion in 1983, in which bedsitters and one and two bedroomed flats specially built for disabled people are being included.

There are resident wardens at each housing scheme with an emergency call alarm system. All flats are newly built and are self-contained with central heating, fitted kitchen and own bathroom/wc.

The schemes are at Basildon, Essex; March, Cambs.; Bournemouth; Alton, Hants. Other sites are being developed in London and the Home Counties.

Applications are welcomed from people who need this type of accommodation and either live in the area where a scheme is situated or have close relatives there.

For details contact: Mrs P. Garner, Tenancy Secretary, Shaftesbury Society Housing Association, 112 Regency Street, London SW1P 4AX. Tel: 01-834 7581.

NAIDEX—In part

THE NAIDEX '82 Conference this year has been cancelled, but the Exhibition which is held alongside the Conference will go ahead as usual and the organisers hope that as many people as possible will be able to visit. It's at the Cunard Hotel in London 13-15 October.

January deadline for Education Act

THE REMAINING provisions of the Education Act 1981 should come into force by January 1 next year said Junior Education Minister, Dr Rhodes Boyson, in the House of Commons recently. These deal with the procedures for assessments, and statements of special educational need, and for the approval of special schools and of independent schools taking handicapped pupils.

Section 14 of the Act came into force in January this year. It introduced requirements on the closure of maintained special schools, bringing the arrangements broadly into line with those for county and voluntary schools.

HER MAJESTY the Queen, meeting members of the Calvert Trust, when she visited the site of the Kielder Adventure Centre for the Disabled after opening Kielder Reservoir in Northumberland recently.

During her visit, the Queen saw demonstrations of sailing, canoeing and climbing by 27 young disabled people from schools in the area.

The Calvert Trust has raised £660,000 towards its target of £800,000 to build the Adventure Centre which is due to be completed next Spring. It will cater for all types of disability and its facilities will allow disabled people in groups, or with their families, to enjoy a holiday at the centre.

Moving home made easier

THE NATIONAL Tenants Exchange Scheme has been launched by the Government to assist tenants of local authorities and housing associations to move to other areas. Tenants wishing to exchange can obtain a registration form from their local Housing Department, Citizens Advice Bureau or Housing Aid Centre.

The form asks for details of the tenant's present accommodation and the area to which he wishes to move. This completed form has to be sent to a central computer bureau and a print-out is then sent to each relevant local authority. The approval of the landlords will be needed before the exchange can be completed.

The scheme complements the National Mobility Scheme under which tenants can be nominated to other local authorities. The Housing Department of RADAR would be pleased to hear of any disabled people who seek to use either scheme. Contact the Housing Dept., at RADAR, 25 Mortimer Street, London W1N 8AB.

Review assesses IYDP

A COMPREHENSIVE review of the initiatives launched during IYDP in this country has recently been published by the Department of Health and Social Security.

Introducing the Report, 'IYDP and After—the UK Response', the Minister for the Disabled, Mr Hugh Rossi, said that it aimed to both record the 'impressive response to the Year', and to indicate how these beginnings can be built on.

Copies of the Report can be obtained free of charge from: DHSS, Health Publications Unit, No. 2 Site, Manchester Road, Heywood, Lancs.

Scoliosis group growing steadily

REGIONAL sub-groups are already being formed for a new self-help organisation which started up last year—the Scoliosis Self-Help Group.

It is an independent Association which aims to put people with scoliosis (or parents of children with scoliosis) in touch with each other, if they wish. Mutual support and exchange of experiences and advice are the aims of the group. A quarterly newsletter provides a forum in which problems can be discussed.

Scoliosis (or lateral curvature of the spine) affects about two per cent of the population, and can occur any time between birth and maturity.

For more details contact Mrs A. Harrison or Miss S. Clark, at 20 Prince Edward Mansions, Moscow Road, London W2 4EN.
Tel: 01-229 1674 or 01-289 1578.

Holidays: Scouts give help

THE THEME for this year, the 75th Anniversary of the Scout movement, is 'Scouts help others'. The Scout Holiday Homes Trust is one way of fulfilling this theme.

The trust finances and manages self-catering chalets and caravans for disabled people. They are for use by all disabled people and their families—not just members of the scout movement.

For details write to The Booking Secretary, Holiday Homes Trust Association, Baden-Powell House, Queen's Gate, London SW7 5JS.

Disabled flying club is target

FLYING for the Disabled is a new voluntary organisation formed to enable disabled people of all ages to enjoy the thrill of learning to fly and to train as pilots.

Civil Aviation has approved an all hand control for the popular Cherokee aircraft, and this now makes it possible for disabled people to learn to fly.

Flying for the Disabled, which will be registered as a charity in due course, hopes that money can be raised as soon as possible by sponsorship and other means, so that any disabled person who is interested in flying but who hasn't the funds can obtain his private pilot's licence at little or no cost. The charity hopes also to provide necessary books and navigational equipment.

The pioneer of Flying for the Disabled is Mrs Dawn Marler who can be contacted at 28 Addenbrooke Drive, Wylde Green, Sutton Coldfield, West Midlands B73 5PY, (tel: 021-355 4384) or at the Warwickshire Aero Club, Elmdon Airport, Birmingham.

Photography and drama on offer

DRAMA and photography are the subject of two special interest fortnights being run in Nottingham this year by the Winged Fellowship Trust for disabled people.

The drama fortnight (16–30 October) is in the hands of the professional Highway Theatre Company, and Pentax and other photographic specialists are giving their support to the photography fortnight (13–27 November) which is for novices and those with more expertise.

As both courses are being sponsored, the charges are £210 for each fortnight which covers full board and nursing care. For details contact: Elin Prichard, Winged Fellowship Trust, 2nd Floor, 64/66 Oxford Street, London W1N 9FF. Tel: 01-636 5575.

Wirral goes to the Palace

WIRRAL Association received an invitation to a reception at Buckingham Palace in the Summer, given by Prince Charles to mark the closing of the Wedding Present Fund. Mrs Alice Rowlands, Mrs Carol Garland and Barbara Baker of the local association were delighted to be able to attend.

The Association had applied to the Fund for a grant for their playgroup and had sent a history of the playgroup, outlining its aims and objectives. As a result the Association received a grant of £500 from the fund.

'Needless to say we felt very honoured to be represented at the reception as only a selection of the beneficiaries were invited' writes Barbara Baker. 'We had a memorable day'.

Claire, Andrew win awards

THREE of the top ten 'Children of Courage' (The annual Achievement Awards presented by the Spastics Society) were young people with spina bifida.

LINK featured one of these young people, Paul Davis of Reading, in the last issue.

Five-year-old Claire Pitcher received her award for the way in which she is fighting back after many setbacks in her struggle to learn to stand and walk. Claire is one of spina bifida twins. Her sister Karen is less handicapped than Claire.

Andrew Smart, aged 14, not only learned to walk after six major operations but also took up riding. He is now an accomplished horseman, spending much time grooming, tacking and riding a pony owned by a Riding for the Disabled Group.

At his school, King Edward VI Grammar School, Stratford, his headmaster Mr N. W. R. Mellon said 'Andrew makes light of his disability to such an extent that he is taken for granted by his fellows'.

WHEELCHAIR sportsman, 15-year-old Ian Jones practising for the 13-mile Great North Run. Practise clearly paid off because Ian, who lives at Pallion, Sunderland, came second out of a field of 60 in the wheelchair class, aided and unaided.

For Ian, the run from Newcastle to South Shields was just one of a number of sporting events in which he has been successful. He has completed a mini marathon in the Lake District, and represented Northern England at last year's Gateshead Games. He has often taken part in races over various distances, and is also an excellent archer, canoeist and sailor.

Ian was sponsored for the Great North Run this summer by family and friends to raise money to send some of the children from the school he attends—Barbara Priestman School—on an independence holiday.
Photo: Sunderland Echo.

Memories of the summer—young people from Cornish ASBAH group getting together at a picnic and parents' evening held at Pencalenick School, Truro.

New President

MR DUNCAN Forrest, FRCS, known to so many people for his work for ASBAH, was elected as President of the Society for Research into Hydrocephalus and Spina Bifida for a three-year term at the Society's recent meeting in Boston.

Mr Forrest is a member of ASBAH's Executive, and Chairman of the Disabled Living Advisory Committee and the Aids and Appliance Committee. He is also the valued chairman of the Medical Committee.

DEEP IN the heart of Devon, a young man with spina bifida, Clive Essame, is working round the clock to build up his own business—as a herb grower. Clive has written for LINK about how it all started, and the physical stamina that growing and marketing herbs has required of him and his fiancee.

In an English country garden

BEING DISABLED and running a herb growing business seem to be totally incompatible to most people but it can be done. Whether or not it can be done successfully remains to be seen.

Pictures show Clive at work.

I started the business about eighteen months ago after being unemployed for over a year. I had worked for a few months in the health service, as a clerical officer but that bored me silly so when my contract ran out that was the end of my office worker's life.

What I wanted was to be my own boss and to work out of doors, preferably growing things. So after waiting around for a job to come up I decided that I would take up a few people's suggestions and start growing herbs.

Gardening was not new to me so I did not have any new problems to overcome at first. I had a 10 ft greenhouse and I managed to keep everything within reach. That was fine for the few plants that I was producing then, but it obviously wasn't big enough to produce enough plants for me to earn a living.

Then, as luck would have it, I sold some plants to someone who I knew had some vacant flat land so I laid it on a bit thick that I didn't have enough room to grow, and a few days later she offered me the land.

So I then had about one-quarter of an acre of land which was waist high in brambles which hid heavens knows what. So I set to with a sickle to crawl around on my hands and knees chopping down the brambles. For months I had thorns in my hands and knees. Most of my family pitched in and helped, as well as friends, and we cleared the land discovering all sorts of frames and an old greenhouse left over from the last occupier.

When it was cleared it had to be dug and as I have plenty of strength in my arms that was no problem as I worked kneeling down, crawling backwards. Of course jobs like carrying peat bales are just not possible, I have found a way round most problems but carrying weights around is beyond me.

I seem to spend a lot of time on my knees doing various jobs such as weeding while my fiancee does the heavy work such as pushing wheelbarrows and carrying compost, and of course I end up with more than my fair share of the tedious jobs such as pricking out and potting on.

I never take the attitude that I am disabled and I don't let anyone else do so either. We don't allow ourselves any concessions, both my fiancee and I work between 10–12 hours a day, six days a week and sometimes even seven. It is fun but it can be exhausting!

Most of our business is done by post. Herbs seem to travel well. We also do markets and shows which are time-consuming but reasonably profitable. Sometimes when people see that I am disabled they ask me what charity I am selling the plants for. What better charity than myself is there!

The business is not really booming, just ticking over with the occasional rush when we have to panic and work overtime. Recently we have been given the use of about half an acre of walled garden so that is another few hours a day needed.

We are always trying to think of new outlets for the plants so if anyone has any clever ideas please let us know, and of course if you would like to see our latest catalogue you are more than welcome.

Clive Essame, Herb Grower,
Oakmount,
Honiton,
Devon.
Tel: Honiton 2712.

AS PROMISED in the last issue, LINK now carries further details of research projects supported by ASBAH.

IN THE Paediatric Research Unit run by Professor Paul Polani at Guy's Hospital, London, work is going on to discover the exact mechanisms that cause an embryo to become malformed and develop spina bifida. Dr Andrew Copp, MA, DPhil, who is conducting the research, explains:

How the curly tail mouse may help us understand malformations

BEFORE we can hope to prevent spina bifida and other neural tube defects, it is important that we understand not only the cause(s) of these diseases but also the mechanisms of embryonic development which, when deranged, lead to the malformations. Indeed, if we are able to explain *how* the embryo becomes malformed we will be in a better position to recognize the types of factors which actually cause or prevent the defects.

We are studying the mechanisms of neural tube defects in mice of a mutant strain, *curly tail*, which develop a form of spina bifida closely resembling the human disease. We have shown that spina bifida develops in *curly tail* embryos even when they are grown in culture, outside the uterus.

At present, we are making a detailed analysis of the changes which occur in *curly tail* embryos early in the development of spina bifida. A recent finding has been that the growth of a particular cell type in *curly tail* embryos is abnormal, whereas all other types of cells appear to grow in the same way as in normal embryos.

In future, we shall pursue this line of investigation, firstly, by studying the reasons for abnormal cell growth in *curly tail* embryos and secondly, by testing whether spina bifida can be prevented in these mice, either by replacing the abnormal cells with normal ones, or by treating the embryos with drugs which affect the growth of cells.

DR ROGER BAYSTON, M.Med Sci, PhD, of the Institute of Child Health, reports on two new tests to diagnose shunt infections. The tests appear to be accurate, and have the advantages of being very easy to carry out and they are inexpensive.

Tests give accurate warning of shunt infections

THE SYMPTOMS of shunt infections differ depending on whether the fluid is drained into the heart (VA shunt) or into the abdomen (VP shunt).

In the latter a common feature is blockage at the bottom end, usually occurring within three months of operation, but infection of a VA shunt does not usually lead to blockage. In both cases the symptons are vague and may be very mild. They include fever, loss of appetite, lack of interest, palor, shivering, and later in patients with VA shunts, rashes, joint pains and possibly backache with blood in the urine.

It is important to note that any combination of these symptoms may indicate an illness which is not associated with the shunt, and the diagnosis of shunt infection is sometimes difficult to make on these grounds alone.

Because of this, various laboratory tests should be carried out. The most common one, after the blood count, is the blood culture which looks for bacteria in the blood with the implicaton that if found, they are coming from the shunt. This test is sometimes negative in shunt infections, and this is almost always so in VP shunts. It may also be positive due to accidental contamination, and the organisms which cause this are indistinguishable from those which cause shunt infections.

In view of these difficulties, while working as ASBAH Research Fellow, I developed a test for shunt colonisation.

Most shunt infections are caused by an organism called Staphylococcus albus, which lives on our skin. Just as in measles and chickenpox, when these bacteria are allowed to enter the blood in large numbers as from an infected VA shunt—the body reacts by making antibodies to them. These do not cure the shunt infection but by measuring the amount of antibodies in the blood we can show that, in an infected shunt, they rise steadily. This test is virtually free and very quick and easy to carry out, and we have now had over ten years' experience with its use.

These antibodies are usually not produced in infected VP shunts and we therefore have to use another test for a substance called CRP. This substance is present in very low quantities in the blood of healthy people, but its level rises rapidly in inflammatory conditions such as infections of VP shunts. Therefore using these two tests together, the diagnosis of infections in VA and VP shunts is made much more easily and accurately.

We have developed a refinement to these serological tests, in that, if they are done before a shunt operation and then at intervals afterwards, changes in levels of antibody and CRP can tell us very quickly whether the shunt is infected, often before the patient becomes ill.

This is called serological surveillance and it has several advantages. It is very cheap and easy to carry out and can be done on a small amount of blood. Shunt infections are, apart from very exceptional cases, contracted at the operation and not at some time afterwards, and we need only to carry out the surveillance for a few months after the operation, to give the antibodies time to rise before we can say that it is unlikely that the shunt will be infected from then on. Also, complications such as shunt nephritis, which arise only in those cases where an infection is not detected until months or years after the operation, is prevented as early diagnosis by surveillance should lead to early effective treatment.

I feel that these tests should be used routinely on all patients who undergo shunt operations, whether they are ill or not, so that the diagnosis of shunt infections can be made earlier and more accurately.

DR ROGER BAYSTON is also looking into the best method of clearing shunt infections by drugs.

Treating shunt infections

RECENTLY we have been taking a new look at the treatment of CSF shunt infections because of advances in our understanding of how antibiotics work against these infections (and why they fail to work), and because many new drugs have become available since the original largely unsuccessful attempts.

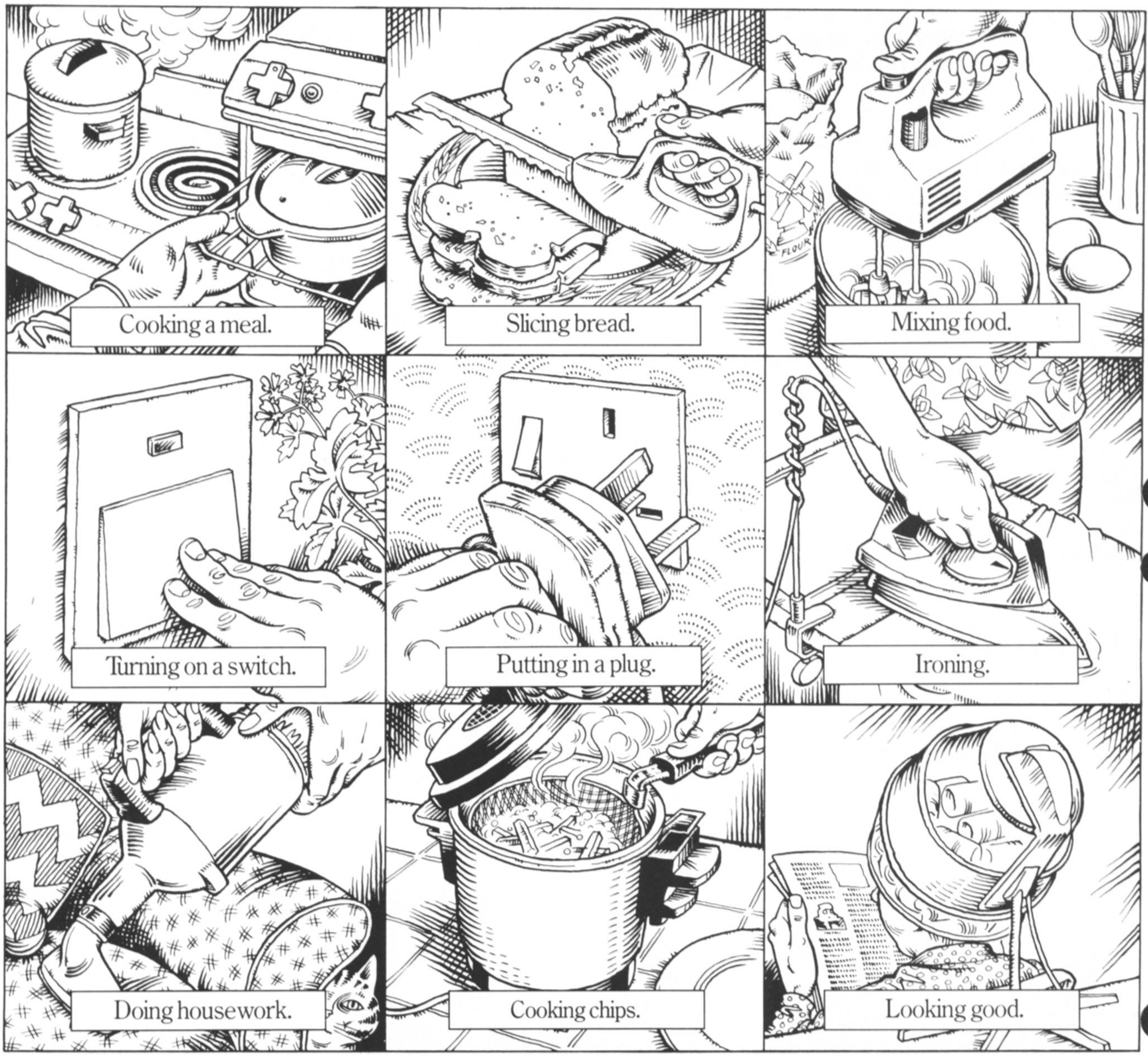
In a pilot study we have found that two drugs given together by mouth, in some cases supplemented by injections into the cerebral ventricles for one week, have cleared shunt infections rapidly without further surgery. We have now begun a trial to see which of three treatments based on these drugs works best. One advantage in the pilot study, apart from avoidance of revision was that where the treatment was successful, the patients became better in a few days and could continue the remainder of the treatment at home and at school.

AN IMPORTANT new study is starting to try and resolve the problem of why some valves are faulty when fitted. Again Dr Roger Bayston reports:

Examining problem of faulty valves

THE major cause of failure of CSF shunting other than infection is blockage at one end or the other, but occasionally the valves themselves are found to be the cause. Valves have to be tested by the surgeon before use to ensure that they are fit for implantation, and sometimes they are found to be faulty.

There is reason to believe that certain manipulations can make a faulty valve pass this test so that it can be used, but that it later returns to its faulty condition and may be the cause of a revision. Mr Forrest, Dr Dervin, and I are to begin a study to investigate the problem of faulty valves, to see just how much trouble they cause and to see what can be done about it.


Cooking a meal.
Slicing bread.
Mixing food.
FLOUR
Turning on a switch.
Putting in a plug.
Ironing.
Doing housework.
Cooking chips.
Looking good.


ELECTRICITY AND YOU
MAKING LIFE EASIER FOR DISABLED PEOPLE

Magazine aims to bridge the gap

''HANDICAPPED LIVING'' is a new monthly magazine catering exclusively for all disabled and handicapped people, and as such is the first publication of its kind in the world.

The idea was first conceived by the publisher, Tony Ellis, who then spent several months developing the project. The problem was to provide an interesting, entertaining and educational glossy magazine that would have common appeal to all handicapped and disabled people, their families and friends, in a way that had never been thought possible before because of all their completely differing handicaps.

Judging by the success of the first issue, which appeared on the bookstalls in May, and the many congratulatory letters received from readers, this initial goal has been readily achieved.

There is a small energetic editorial team consisting of Tony Ellis, Publisher and Editor, Pat Saunders, Assistant Editor, Carol Andrews, Features Writer and Christine Mecklenburgh, Art Editor. Tony Ellis has been involved in publishing for most of his working life, and before beginning work on the launch of ''Handicapped Living'' had been running his own publishing company, involved mainly with trade and technical magazines. Pat Saunders is himself disabled and well-known in the world of disability for his role as a Director of DIAL.

The magazine has a regular forum for readers' letters and problems (which are answered by John Linus), as well as a free classified advertising service for handicapped readers enabling them to sell items or make new friends. The News and Aids pages keep readers up-to-date with current affairs and aids on the market. There is a prize crossword every month, plus a regular horoscope section.

One of the most popular articles is the Collecting series, which so far has covered biscuit tins, Devon earthenware, teddy bears and hatpins. The pet keeping series is also proving popular, and deals not only with the more common pets such as canaries and cats, but also the rather more unusual pets like goats and terrapins.

The aim of the magazine is to promote self-help and to stress that handicapped are able to do most things that able-bodied people can. This has already been illustrated with articles on sailing and fencing, and a story about a group of blind bowlers. The publication is definitely about LIVING, not just existing, and sees life with a disabled prospective in a unique way.

''Handicapped Living'' is available from all leading newsagents (W H Smith, John Menzies, etc.) It is also available on subscription direct from the publishers—Living Publications Ltd., 9 West Street, Epsom, Surrey KT18 7RL—at £12.00 per annum.

DR BARBARA Brosnan is one of the leading experts on yoga for handicapped people in the country. She has practiced yoga herself, and for several years has been taking yoga classes for groups of residents at Servite House, a home for physically handicapped people in Ealing, London, which she runs.

The yoga students have a variety and range of handicaps, and several of them have spina bifida.

One of the groups is for severely disabled residents, and their classes, of necessity, are conducted from wheelchairs, and consist mainly of controlled breathing exercises and small movements, but even these can bring real physical and mental improvements.

This article is based on a visit that Link paid to Servite House, as well as extracts from an article written by Dr Brosnan for Nursing Mirror, and from her new book 'Yoga for Handicapped People' (see details on these pages).

Breathing in new life: the benefits of yoga

THE TERM 'yoga' is taken to have two principal meanings. The state of yoga is that in which man is 'yoked together' with the Divine. It also signifies the state in which the 'apparent man' binds himself likewise to the 'real man', that is to say, recovers his true nature and lives according to it. The technique of yoga is the discipline in whatever form it is practised, by which man attempts to attain the state of yoga. The word yoga is related to the French 'joug' meaning 'yoke'.

IF YOU are disabled, what are the benefits that you may derive from yoga? This no doubt will be one of your first thoughts, before you buy a piece of foam rubber matting and join a class.

Apart from the feeling of improved well-being, relaxation and harmony, the regular practice of yoga has some particular advantages where there is disability of any degree.

People may be enabled to help compensate for—even overcome—some specific disability; they may acquire skills of protective value to their disability—i.e. breath control, improved lung ventilation and the ability to get at least to a sitting position if they fall over.

They may develop a calmness enabling them to master those tensions integral to being a disabled person in the world today; they certainly receive the great morale-booster of doing yet another thing done by the non-handicapped—in some ways this is a greater advantage than any of the others!

It teaches body posture and encourages the right posture. It helps concentration by combining physical effort with 'one pointedness' in the mind. As a result the depressing feeling of inferiority gradually but steadily diminishes and self-confidence is built up instead.

The physical postures undertaken, if practised regularly, improve the overall circulation and strengthen the heart. Consequently oxygenation is increased throughout the body and this brings improvement in the whole level of functioning. Good breathing increases energy, and deep, rhythmic breathing produces a calm, contented mind. Deliberate regulation of breathing relieves tensions, bringing valuable relaxation to the body and mind.

The great thing about yoga is that it is easy to achieve success. If you are disabled you may find that being successful at something is very difficult indeed, and this can be very frustrating. It is also totally uncompetitive—everyone works at his or her own pace, and within their own capabilities. And there is value in even miniscule movements. (These were the factors that led to the starting of yoga classes at Servite House).

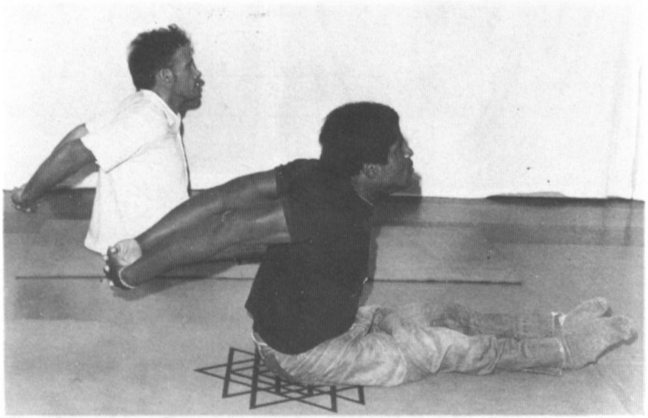
Although the whole weight of opinion is now in favour of integrating the handicapped with the non-handicapped in almost all activities, this is not the case with yoga. A person with any other than minimal disability would be out of place in the ordinary yoga class. He needs specially adapted postures and a very differently worked out sequence of postures. Often someone with a handicap has a lot of work to do to reach even the starting position of a posture, and will have to work at a slower pace.

However, the aim and purpose of yoga for the physically handicapped is the same as it is for anyone. Yoga is not an alternative form of physiotherapy, a work or a modified PE. It is a form of life, a philosophy of living. This is why it is of such value even if the particular posture is in no way achieved but is only started and 'thought' through to the end. If the person has the pose in mind and 'flows' towards it mentally, the actual achievement is to some extent less important.

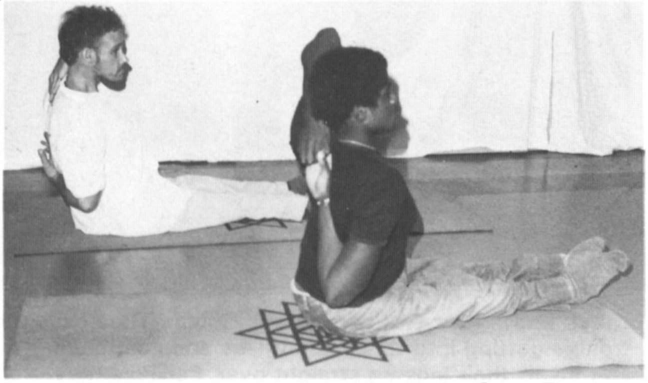
If you are disabled you will probably need a helper for yoga, and be prepared to do variations on postures according to your disability. A yoga class should not be a jargon-filled, obstacle course, but humble, hard-working, and thoroughly enjoyable.

A great advantage is that it costs very little to equip yourself. Wear something loose, easy and comfortable, like slacks and t-shirts and then all you need is a blanket, or rug, and a piece of foam-backed carpeting or foam matting (about 6′ × 3′). If you are staying in your wheelchair you obviously won't need the matting.

If you are really to benefit from yoga, classes need to be small and there must be enough helping hands. Six to eight seems the ideal number in a class—large

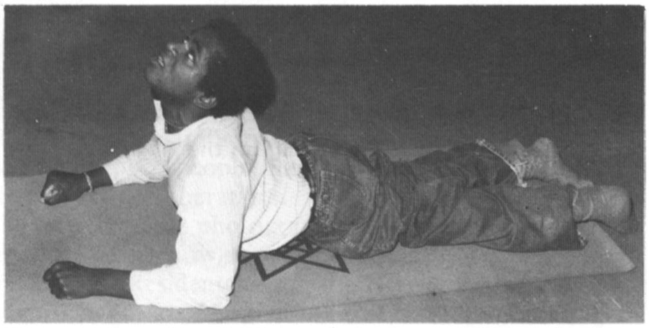


The Shoulder Stretch, as demonstrated by Derek and Trevor. They both have spina bifida and balance is a little precarious owing to the lack of weight in the bottom and the legs.



Derek and Trevor demonstrate Head of a Cow. Trevor (in the background) has restricted shoulder movements which makes it particularly difficult for him. He also has more balancing problems than Derek.

Derek who has spina bifida working on the Sitting Twist posture.



Derek in the Cobra position. Derek can't straighten his arms (which is normally the next stage of Cobra) because if he does the bottom part of the body will come up off the floor due to a rigid spina bifida back.

enough for it to be a real group activity, but small enough for each person to be checked on and helped with each posture, without the others getting bored by having to wait too long.

Everybody will need some help with most postures, not always the same kind of help, so a ratio of one helper to two class members may do; some members may need a helper with them all the time, while the very severely handicapped may need one on either side.

You will be able to tell your helper, if you have one, when a posture starts to hurt. This is the time to stop.

Most people with spina bifida can do yoga movements with their head, trunk and arms and can usually move their legs by hand into any yoga position. However, standing postures are usually not possible.

As there is virtually no weight in the bottom part of the body, overbalancing is easy, and in some postures it is necessary for the helper to hold down the legs to achieve a balance. If you have hydrocephalus, also, you can do any pose within the limitations imposed by your legs. The head makes no difference. Where you have a valve this makes no difference. Clearly if you have a headache you should not do yoga at all, other than relaxation and the simplest of breathing exercises.

It has to be remembered that if you are physically disabled you are almost invariably less fit than someone who is able-bodied, and so most movements are a great deal harder work. Consequently shorter classes are the rule of the day—30–45 minutes at a maximum.

As has been mentioned before some class members will have to remain in a wheelchair, and there is unlikely to be much standing work for anyone with much disability. However, for those who can make it, there is much to be said for getting onto the floor, down to 'mother earth' for a spell.

It is useful if a yoga teacher knows something of the medical aspects of his pupils, and it can be argued that a medical practitioner, who knows little about yoga, could also be a possible contender for the position of yoga teacher. The teacher will find that he or she learns more and more with every class. The possibilities of benefit seem great even for those handicapped who have almost everything done for them.

Particular attention must be paid to the warming up process, but apart from this, classes can follow a normal pattern—preparation, warming up, postures, relaxation and meditation.

The results that can be expected from yoga classes for the physically handicapped are those of any yoga class—with some additional ones.

Pupils can achieve integration, wholeness, the ability to relax and to relieve tension, an increase in muscular strength, suppleness and co-ordination within the limits of the disability, greatly improved breathing, fewer chest ailments, better sleeping and enhanced vitality.

Continued over page.

'There's no harm in trying'

YOGA IS for everyone, from toddler to octogenarian, whether you are fit and able-bodied, physically handicapped, overweight, happy or depressed.

If you have a disability you are in just the same need of the benefits of yoga as anyone else—a sense of harmony, and well-being.

The benefits of yoga for *all* are being recognised more and more. The Yoga for Health Foundation (see article on facing page) has done much to help, both at its centre, Ickwell Bury, and at clubs around the country. But generally speaking the more enlightened attitude which seems to exist nowadays has meant that yoga teachers are willing to accept a pupil with a physical handicap like spina bifida and hydrocephalus. It's best not to turn up just before class and expect an enthusiastic reception. Find out the name of the teacher beforehand, and go and discuss the possibility of joining the ordinary class.

Unless your disability is fairly minimal it is best to join a special yoga class for the disabled, or try on your own at home. An ideal situation would be where a group of you can get together perhaps at a special home, or day centre, or at a local club (perhaps a Phab Club) and enlist the services of a yoga teacher to lead you.

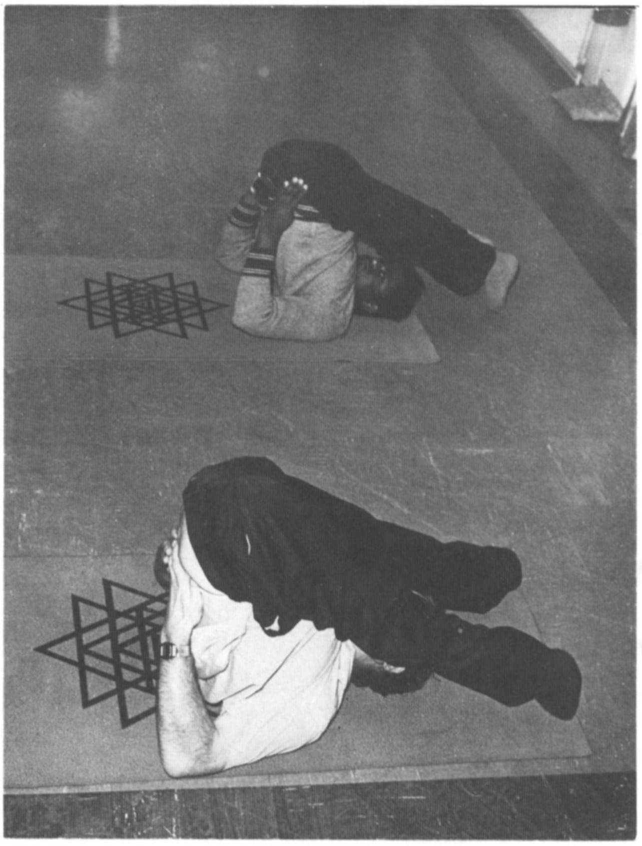
An approach to your local centre of further education should yield the name of at least two yoga teachers. Generally they are a fairly enterprising and sympathetic group of people willing to take on fresh challenges . . . and they may well consider you and your friends a challenge! One of the local ASBAH branches might consider starting up a yoga class.

Regular yoga does produce a marked sense of well-being. In effect yoga 'massages' the body, exercising and relaxing muscles. The breathing exercises which even severely disabled people can manage, bring great rewards. We all of us need to learn to breathe well, or rather re-learn, for we all knew it once in infancy. We breathe superficially and as a result never ventilate the lungs properly and this is particularly true of someone with a disability. Breathing is a vital source of energy.

There are different forms of yoga, and all yoga teachers will run the class in a different way, putting emphasis on different things. Some teachers will spend more time than others on meditation and the spiritual aspects; others will concentrate on breathing and postures, others on relaxation.

The classes in yoga for the physically handicapped which Dr Barbara Brosnan has been running for about the past seven years are evidence of the value of yoga, and show that it can bring a new dimension into the lives of everyone whether or not you are handicapped.

She is sure that given reasonable care, and providing your doctor knows what you are doing, no harm will befall you from taking up yoga.



Derek and Trevor working on the Plough. They have no trouble getting into this position—as soon as they try and invert their legs go straight over, because they both have spina bifida.

The wheelchair 'squad' working on the Rag Doll position with a little help.

The photographs on this and page 13 are taken from Dr Brosnan's new book 'Yoga for Handicapped People', Souvenir Press Human Horizon series. The postures are all being demonstrated by residents of Servite House, Ealing.

Exploring the therapy of yoga

THE YOGA for Health Foundation was set up to promote and explore the therapeutic values of yoga for everyone, and is increasingly tending to become involved with the physically handicapped (particularly multiple sclerosis) and the mentally distressed.

Yoga for Health branches exist in all parts of the country, but the main centre is at Ickwell Bury in Bedfordshire.

It is housed in a fine manor house set in spacious grounds. You can stay there at any time, for a few days, or weeks or a weekend. There are regular yoga sessions, time for individual attention, meditation, and sessions for arts and crafts.

There is likely to be a mix of people there at any one time. The Foundation places great value on having all types together regardless of ability. They feel it helps to break down barriers, and everyone comes together as an equal.

It is a beautiful, relaxing place to stay. Cooking tends to be vegetarian, but meat and fish can be provided if you want it.

For details contact: The Yoga for Health Foundation Residential Centre, Ickwell Bury, Northill, near Biggleswade, Beds. They will send their Programme and details of rates.

Book covers those with experience and the novice

Yoga for Handicapped People is the title of Dr Barbara Brosnan's book based on her experiences as a yoga practitioner and teacher of yoga for the handicapped over several years.

It explains the general principles of yoga, gives instruction on breathing, and the various postures, and also has a chapter on the therapeutic potential of yoga, and special notes relating to individual disabilities including spina bifida. There is advice on some postures that should not be attempted.

The book, published earlier this year, is designed to be used at two levels: those with yoga experience can refer to it as a complete handbook covering aspects they may know already, but providing new ideas also; the complete novice can use it as an introduction to the subject. It can be followed safely by parents of handicapped people, handicapped people themselves and therapists.

There are clear photographs, drawings and instructions on how each pose should be performed. Residents of Servite House, Ealing, where Dr Brosnan runs her classes, have posed for the photographs.

Published by Souvenir Press in the Human Horizons series. Paperback £4.95. Casebound £6.95.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Dwight walks for $100 a mile

CONGRATULATIONS to 18-year-old Dwight Baker of Bryan in Texas, USA, who recently realised his dream to raise a significant sum of money for research into the causes of spina bifida.

Dwight who has spina bifida and hydrocephalus raised nearly $9,000 through a 90 mile walk from College Station to Houston in Texas. The walk took him twelve days. A local company donated a travel trailer for Dwight and his family to sleep in en route and other local groups assisted.

Dwight's proud father wrote to tell LINK of his son's success. 'I hope it might encourage other young people with spina bifida'.

Martin Johns and Tammy Jukes at a farewell party on the last night of an independence training course at Jane Hodge, Cowbridge South Wales, organised by National and Midlands ASBAH. Martin was one of the helpers, having been a student on an earlier course.

BOOKS

The Commander takes off

The Comet and the Ice King, is one of the space adventures of a character called Commander Prosobi, and its the subject of a new little book for young children (aged about 5–8 years).

The book is beautifully and colourfully illustrated by Steven Bloomer, with the text in verse by Colleen Illingworth (Ziggy).

The reason for mentioning this book in LINK is that a donation will be made to ASBAH for each copy sold.

Price 80p including post and packing from: Alex Draco Publishing, 92 Simmons Way, Lane End, High Wycombe, Bucks, HP14 3JX.

Two donations add up to a £1,200 boost

HERTFORDSHIRE and South Bedfordshire Association recently received £400 from the Royal Ancient Order of Buffaloes in St Albans. The money was raised during two social evenings.

The Association also received a donation of £800 from member John Nugent of Hoddesdon who ran the full 26 miles of the Birmingham Marathon.

John was sponsored by friends, neighbours, colleagues and his management at Granada TV Rentals.

PHAB (Physically Handicapped and Able-bodied) celebrates its Silver Jubilee this year. This dynamic organisation provides many opportunities for young people through its local groups in this country. Overseas links, and travel abroad have become an important development of PHAB's work. Terry Thompson, Director of PHAB International reports:

AS PART of the plans for the PHAB Silver Jubilee—PHAB members at the Pan Am check-in desk at the start of their trip to America.

Seeing the world—the PHABulous way!

THE DATE is Monday, April 4, 1966. The location, Dover Harbour. The regular passengers watched in amazement as three ambulances and a mini traveller unloaded sixteen disabled young people (fourteen of whom were in wheelchairs), sixteen able bodied young people, two organisers, one nurse and four male drivers onto the car ferry 'The Maid of Kent'.

The occasion was the birth of 'International PHAB', as the first PHAB group to travel overseas embarked on 'C'est Paris', the holiday with a difference.

It had taken just ten years for PHAB to get the 'travel bug'. Mary Robinson, joint founder and now a Trustee of PHAB, recalls the early planning.

'By the end of 1965, it was no longer a question of 'Shall we go next year?' but 'WHERE shall we go next year?'. It was obvious that as with other young people the PHAB answer began to be 'Let's go abroad'. It was a stage of development known to all youth workers.

But for PHAB the problems were different. Transport, parents permission, the right place to stay (where no limitations would be placed on a programme designed to bring achievement to both groups) all needed exploring.

Paris was the young people's Mecca and a journey was made by the Chairman of the PHAB Advisory Group and a member of staff to see if there was any possibility of a visit from a group in 1966 at Easter. There was immediate enthusiasm. The integration of these two groups was a totally new idea to the 'Association des Paralysees de France' and they felt it would be immensely valuable for their work if a party from the National Association of Youth Clubs (the parent body at that time) was seen to have accomplished this.

It is doubtful whether a happier and more hilarious group ever enjoyed 'The Maid of Kent' more than the group starting 'C'est Paris' on that bitterly cold April day.

That early visit established two basic principles which have guided our international work ever since. The first is that overseas travel is an excellent medium for promoting integration. As well as offering a marvellous and often otherwise unobtainable experience to both the disabled and the able bodied, that new shared experience leaves little room for the barriers of fear, ignorance and embarrassment that prevent integration. The participants really are on equal ground with contributions from both partners essential to the success.

Secondly, the PHAB group is the ideal way of 'spreading the word'. Other countries still find the PHAB approach as unusual and appealing as did the APF in France 16 years ago and PHAB clubs or their equivalent have started in many countries following visits by groups from England.

That first visit in 1966 was the spur to much international activity in the following years. In 1967, the Welsh Association of Youth Clubs took a party to Belgium. In 1968, as well as a return visit to Paris, NAYC planned a trip to West Berlin. By now, other PHAB groups were on the move and the Bradford Association of Youth Clubs began a tradition with their first visit to Majorca in October 1968.

In that same year, Mary Robinson was asking 'How long will it be before we can add to our offers of visits to Europe, trips to America and Canada? The answer was just eight years, and in the September of 1979 I had the privilege of leading a party of 43 which visited Chicago, New York and Washington and Niagara Falls.

The first Middle Eastern adventure was an exchange with a group from The Kuwait Society for the Handicapped. This was at a national level.

We must also remember the pioneering work done by many county and club groups. For instance, Lancashire have for many years both welcomed international visitors and sent parties abroad through the work of the Association of Youth Clubs at Borwick Hall; Surrey PHAB have arranged a homestay programme in the States through Rotary International; The Nottinghamshire programme gets more exciting each year, though how they will cap the last trip to the Bahamas is not quite clear! Leamington PHAB and the Durham group have both tried camping holidays in France; Leeds are just one of the groups who have tried Malta, and another group have been riding in the Algarve, Portugal.

To these experiences we shall be adding Israel and Hong Kong during this Silver Jubilee year.

There is no doubt that in recent months the international work of PHAB has been greatly enhanced by the formation of the International Advisory Group. This brings together on a regular basis representatives from our own international work, senior officers from other agencies working with disabled people, representatives from the travel world and the specialist groups such as the British Council, the Central Bureau for Visits and Exchanges, The Commonwealth Youth Exchange Council and Mobility International.

So what, then, is our international programme designed to achieve during the eighties? The Executive has agreed three strands as developed by the Advisory Group:

- The development of an international visits and exchange programme for integrated groups. This includes 'pioneer' visits organised on a national basis; regular European and other trips at regional level; support to clubs, counties and other organisations through the expertise and experience of the Advisory Group and the staff; and regular training days, the next of which will be held through the auspices of NAIDEX in London on October 15th.
- The further development of PHAB overseas using, where possible, other agencies and groups based in those countries.
- The receiving of groups and individuals from overseas. Much of this happens through exchange programmes and the 'in service training' sessions mentioned above. However, we are still anxious to cater for individuals who may wish to visit this country and also to offer programmes to groups using established and tried travel agents.

You will gather from all this that I am totally committed to the concept of 'International PHAB'. My first commitment, of course, will always be to the work in this country, and there are those who ask why we should be going overseas when there is still so much to be done here.

Part of the reason is the demand from the membership—our overseas trips are always heavily oversubscribed, particularly by the disabled members. But just as important is the need to spread the word about integration and the unique approach of PHAB.

We are still very much 'world leaders' in the use of social opportunities to promote integration and the attitudes towards disabled people in so many countries cry out for the PHAB approach and the PHAB answer. In budget terms, because of funds that are *only* available for international work, the net cost of our international programme is about one per cent of our total expenditure and there is no way of measuring the tremendous benefits that accrue not only to those of us who are fortunate enough to travel but to the whole PHAB concept in this country and throughout the world.

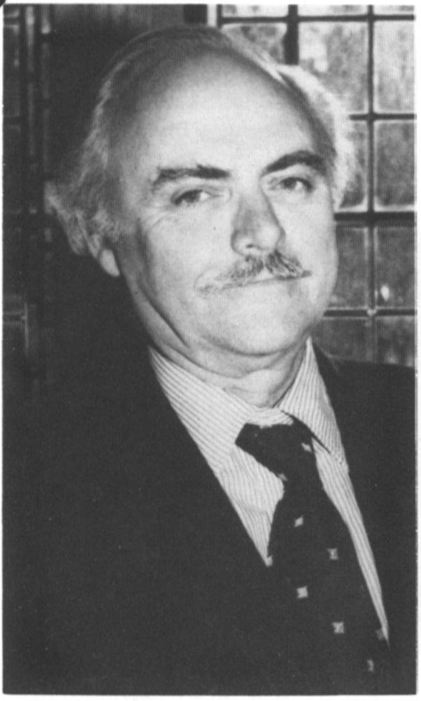
Perhaps it can best be summed up by returning to one of those early visits to Paris. The following paragraph is taken from a report by one member—as it happens, an able bodied young man.

> ‘I will remember PHAB not because of Paris, not because of what we did and saw, but because of the people (a more genuine set I have yet to meet); because of the sing-songs and the jokes we shared; the fascinating conversations; and the atmosphere that cannot be conveyed by words or photographs but must be experienced. By the end of the week, I think I had at least begun to appreciate what it all meant.’

PHAB members with the Capitol, Washington in the background.

• **The Front Cover picture and the photographs on this page were taken by DAVID LOADER of PHAB.**

So, what have the new Knight, some MPs, the actress and the oilmen, the fishmongers, and the parachuting Post Office people got in common?



Sir Michael Shaw, Chairman of the ASBAH Appeals Committee.

Mike Quilty and Alexis Thomson, parachutists with their feet back on the ground.

WE OFFER our sincere congratulations to our Chairman of Appeals, Sir Michael Shaw who received his Knighthood in this year's Birthday Honours, and we extend our best wishes to both Sir Michael and Lady Shaw.

Shortly after this news broke, Sir Michael kindly arranged for us to make the presentation to the Parliamentary Swimmers of the Year at the House of Commons. Mr Ivan Lawrence, MP was the overall winner in terms of money raised, with Mr Keith Best, MP as runner up. Mr Dennis Canavan, MP also received a tankard for swimming the furthest. The sponsored swim raised approximately £1,500.

Another unusual presentation occurred at the Intercontinental Hotel in June, when Miss Joan Collins, who has so generously allowed herself to be depicted in jig-saw form for a fundraising idea aimed at the men who work in the North Sea, came to London in order to meet the lucky winners whose prize was an opportunity to meet the film star and join her for lunch. I think it would be true to say that a good time was had by all.

From personal experience, I can argue that it takes courage to jump out of an aircraft at 2,500 feet, even if one is wearing a parachute! Post Office Controller, of Mount Pleasant Sorting Office, London, Mr Mike Quilty, did display exactly that kind of courage in the company of one of the young ladies from the sorting office, Alexis Thomson, in order to raise funds for ASBAH. Showing even greater bravery, he selected June 13 for the jump.

Thirteen can be lucky for some, but Peterborough Parachute Centre would undoubtedly argue that the strenuous basic training which they gave eliminated the luck element and therefore displaying great skill Mike and Alexis both landed safely, although Alexis showed cunning by missing the drop zone and arriving in a cornfield rather closer to the club house than the jump master had intended! Their efforts coupled with those of Mount Pleasant's

Swimming MPs—from the left Dennis Canavan, Ivan Lawrence and Keith Best with their Parliamentary sponsored swim awards.

The day the picture came to life—Joan Collins meets the winners of the 'Rig-Shore' competition.

footballers and joggers have resulted in an impressive £2,000 donation to the Association.

To prove that there is no element with which ASBAH is not prepared to contend in order to raise funds, we have also looked seaward and have been fortunate enough to attract the attention and support of the National Federation of Fishmongers who selected the Association to benefit from an open day and auction of donated fish at Billingsgate Market.

In the hope of attracting some press interest for the presentation of the cheque on behalf of the Fish & Poultry Retailers Association and the London Wholesale Fish Merchants Association, glamorous Fiona Curzon agreed to receive the presentation on our behalf and dressed as a mermaid, sporting herself upon the slab of Ashdowns Fishmongers in Leadenhall Market to the glee of the assembled Fleet Street photographers, who all agreed that Fiona herself was quite a catch.

If any of LINK's readers can suggest any stones which we are leaving unturned in an effort to find the funds to finance the work of the Association, please let us know. Any serious suggestions would be given our most avid attention!

JUDY KAY
Director of Appeals

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The advertising rate is:
£2.25 for up to 30 words. £3.30 for 30–45 words.
£4.50 for 45–60 words.
Please send remittance with your advert.
Adverts for the next LINK (Nov/Dec) should be in by October 5. Send to the Editor Mrs Susan Gearing (or telephone her on Langton 3351).

HOLIDAY ACCOMMODATION

CAMBER SANDS. Well-equipped and adapted chalet (sleeps 6). Bookings taken by Mrs N. Kerswill, 28 Ilmington Rd, Kenton, Harrow, HA3 0NH. Tel: 01-907 8526 (2–7 pm).

HEYSHAM, Nr Morecambe. Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 9 Belton Road, Whitchurch, Shropshire. Tel: Whitchurch 3691.

MABLETHORPE. 2 fully equipped cedar chalets on Links estate. Sleep 6. Further details: Mr B Guest, 57 Bloxwich Lane, Walsall. Tel: Walsall 31725.

WINTERTON-ON-SEA, Nr Gt Yarmouth: 6-berth chalet. Indoor swimming pool, shop, play areas. Details: Mr R. Morris. Tel: High Wycombe 32184.

WITHERNSEA: Well-equipped 6-berth chalet at Golden Sands Chalet Park. Shop, licensed club, play areas, amusements on site. Details (sae please): Mrs P. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel: 0422 56402.

MABLETHORPE: Purpose built 6 berth chalet. All mod cons. Easy access for wheelchairs to all entertainment. Details: Mrs J. Davis (see below).

PRESTATYN: Caravan, 6-berth, adapted for wheelchairs. Close to entertainments and beach. Details: Mrs J. Davis, 42 Mount Terrace, Eccleshill, Bradford.

BORTH Nr Aberystwyth. 6 berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: J. Carter, 1 Meadow Road, Craven Arms, Shropshire.

FOR SALE

Leisure Wear: White cotton **Tee Shirts** with green family symbol and words 'Support Spina Bifida'. Adult sizes, small, medium, large: £3.75 each. **Sweat Shirts** in reverse colours. Adult sizes, small medium, large, XL: £7.50 each, postage included. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

Gerber Dri-Pride Incontinence Pants Side opening, cotton outer, bonded vinyl lining, machine washable. Take most pads/rolls. Children's waist sizes 21 in.–26½ in. Adults 24 in.–52 in. £3 pair. Please send exact waist size. P. Notton, 16 Crescent Drive North, Woodingdean, Brighton, Sussex.

BRADFORD, West Yorkshire: Three bedroomed luxury detached bungalow, offers invited around £36,500 for quick sale—fully adapted for disabled person. Extended by present owners and including many unusual and desirable features. Hallway, 25 ft lounge with beamed ceiling, stone fireplace, archway to 17 ft dining room and cocktail bar, 15 ft fully adapted dream kitchem. Three bedrooms one with ensuite shower-room, fitted robes. Luxury bathroom. Gardens, greenhouse, patio, garage and car port, level site, beautiful decor. Tel: 0274 585971, or contact McManns and Poole, Chartered Surveyors and Estate Agents, 30 North Parade, Bradford 1. Tel: 0274 728702.

ASBAH booklets etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	35p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	35p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	50p
Sex and Spina Bifida by Bill Stewart ...	awaiting reprints
The Handwriting of Spina Bifida Children by Joan Cambridge and Elizabeth M. Anderson ...	£1
The Nursery Years by Simon Haskell & Margaret Paull	35p
Little Joe (A Grandmother's story) by W. Foster ...	50p
Information leaflets	100 for £4.00

Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free from national office. Translations into Bengali, Gujarati, Hindi, Punjabi and Urdu. Welsh language sheets are now ready too. All available from ASBAH. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 15p per booklet.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida	35p
The Spina Bifida Baby	35p

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).

The Appeals Dept. carries a range of fund-raising and publicity items, i.e. posters, pens, key rings, games. Send for list and order form.

Flag Day equipment can be obtained direct from: Angal, 48a Holmbush Road, London SW15 3LE (01-788 5464).

JOHN GROOMS HOLIDAYS

All facilities specially adapted for wheelchair users (family friends and escorts welcome)

Seaside Hotels: at Llandudno and Minehead • licensed • level access • emergency call system • balconies overlooking the sea • tail lift bus for tours • colour TV lounge • **(Bargain Winter Breaks for only £10 per day including VAT).**

Self-Catering Units: Near the sea at Barnstaple, Borth, Poole, New Milton, Looe, and a country site at South Cherney, Gloucs.

Holiday Chalets: Near Skegness (Lincs.) Emergency generator for iron lung users.

London Holiday Flat: London, N4.

Motor Caravan: First season 1981. Can be hired for one or two weeks, and driven anywhere in Gt Britain and also the Continent subject to Insurance conditions. It has tail lift, special wheelchair WC/Shower unit, and other modifications. Black & White TV and Radio.

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