

LINK



Association for Spina Bifida and Hydrocephalus/ASBAH 15p

Nov/Dec 80



ASBAH's part in IYDP: White Paper "Special Needs in Education": Duchess of Gloucester attends Annual Meeting; Annual Report—how ASBAH tackled a difficult year: Reassurance about chest infections: Problems of curvature of the spine; Cross channel by parachute

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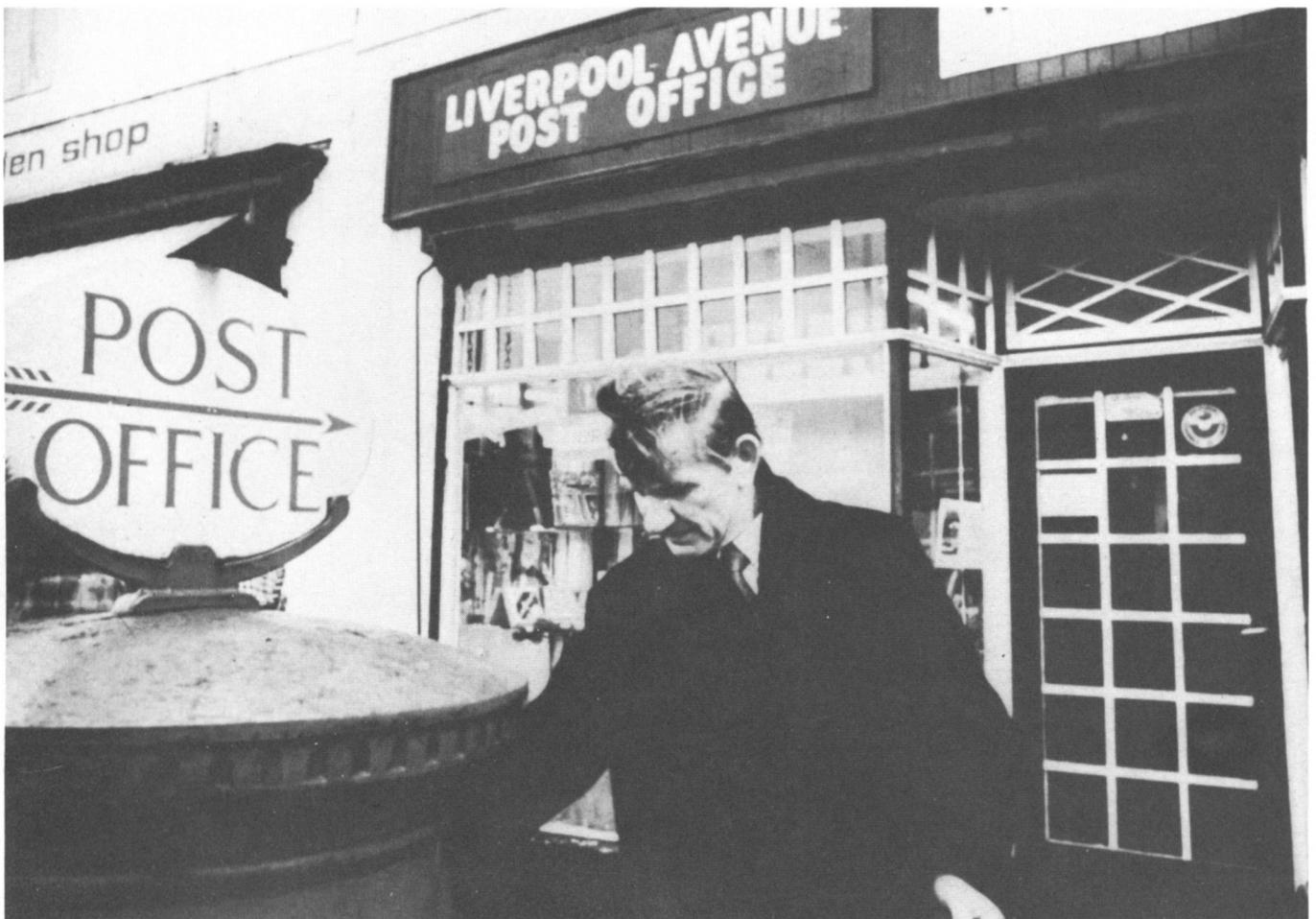
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71

Association for Spina Bifida
and Hydrocephalus/ASBAH

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CONTENTS

Pages

4/5 IYDP News

6 News

7 Round-up

8/9 White Paper—"Special Needs
in Education"

10/13 Annual Meeting

14 Chest infections

15 Problems of curvature of the
spine

16 Book reviews

17 John Grooms holidays

18 Speedwell Enterprises

20/21 Appeals news

23 Classified advertising

THE YEAR just round the corner won't be an easy one and Britannia may well need some help to get along in these inflationary times as Gus's cartoon on the front cover aptly suggests.

But for the disabled, their families friends and allies, 1981—International Year of Disabled People—will be a year of real opportunity, and a chance to improve the status of the disabled. It could provide the right climate of opinion in which to harness the energies, and win the acceptance of the public who, in the past few years, have become more aware that there are disabled people in their midst deserving, and demanding, the right to enjoy life.

If we can all in some way or other give just a little time and effort to the Year it could mean a big push in the *right* direction for the disabled.

ASBAH is actively involved with the Year, as reported on pages 4/5 of this LINK, but its main duties will continue to be the welfare and support of its members far and wide.

People often come up to me and say 'Would you like me to write something in LINK?'. The answer is invariably 'Yes', but too rarely does any article materialise.

This is to be regretted because if LINK is to continue to remain in touch with its readers, it must hear from you. We don't promise always to publish, but we do promise to read and consider anything you may send that is relevant to the magazine. If you can't write an article then let us know what you want to read about, any problems, suggestions, views, ideas you may have.

If you know of an organisation who might like to advertise in LINK please do let us know, and we can send full details.

Very best wishes to all readers of LINK for the year ahead.

FRONT COVER

A special thanks to Gus for the very apt illustration on the cover. This is the third year in succession he has given his time and talent so freely to ASBAH to produce the Christmas cover.

● STOP PRESS

THE DISABLEMENT Income Group is seeking views on a disablement costs allowance from organisations concerned with disability, including ASBAH. In a questionnaire which arrived at national office just before going to press, DIG points out that the need for a disablement costs allowance is more urgent since the simplification of the supplementary benefit scheme, which fails to take proper account of the needs of disabled people and particularly the extra expenses incurred through disability.

DIG's consistent arguments for a disablement costs allowance have met with success only in so far as the need for a disablement costs allowance is now fully and openly accepted by all three main political parties. However, when pressed by DIG to prepare a Green Paper the government refused on the grounds that it would raise false hopes.

Consultation lasts until December 31st, 1980, when DIG hopes to have consolidated support for its campaign and sufficient information to determine the form and scope of a disablement costs allowance.

More details in a later LINK . . .

The yearly subscription for LINK (UK) is £1.85, which includes postage. While every care is taken to ensure accuracy of information published in LINK the publishers can accept no liability. Opinions expressed in articles are not necessarily those of ASBAH.

International Year of Disabled People

With IYDP just around the corner ASBAH staff outline some of the developments so far, the hopes and expectations, and their part in it all.



PLANNING for IYDP started, as far as ASBAH was concerned in September, 1978, when the first meeting was held at the Department of Health and Social Services, so we can really say that we were in at the beginning. I was a member of the Selection Board when Stephen Crampton was appointed as Secretary in February, 1979 and concerned with recommendations for the IYDP National Committee and am very pleased that Lady Masham, Vice-President of ASBAH and Lady Jean Mackenzie, a leading member of ASBAH, are both members of this executive Committee.

A number of Working Groups have been set up to make recommendations to the National Committee relating to suitable projects and activities to be initiated during 1981. ASBAH is represented on most of them (see separate reports on this page).

Our Spring Conference will have as its theme the Role of ASBAH in the 80's and Kit Aston, Chairman of the IYDP National Committee, will be our Opening Speaker. We are also, along with other member charities of the Friendship Group, organising a Day Conference in November, 1981. Topics will relate to Rights of Disabled People and Dr. Adrian Stokes, a member of our Executive Committee, will be one of the speakers.

Since October, 1979 we have been planning, along with other countries, the formation of an International Federation of Associations of Hydrocephalus and Spina Bifida and this Federation will be inaugurated at a meeting to be held in Dublin in September, 1981. At this meeting there will be contributions from various European countries and England's presentation will be by members of ASBAH staff.

We hope that representatives from other continents will attend and join. More than 20 countries have so far indicated their interest and support for the Federation.

MOYNA GILBERTSON

Employment

The IYDP committee on employment is interested broadly in the kind of life young handicapped people are going to have with or without employment. I am a member of two sub groups on Sheltered Work and Disabled School Leavers.

The Sheltered Work committee is carrying out a survey of all sheltered work in this country, and the report will be presented to the Manpower Services Commission and the Department of Health and Social

Security to be used as a basis for planning the future role of sheltered work.

The Disabled School Leavers committee is a continuation of the International Year of the Child group who commissioned "A Guide for Disabled School Leavers" and this will be published in 1981.

I am chairing an interest group within this sub-committee, looking at the ways of improving services offered by day centres, and we would like to hear from people attending centres who can give examples of good practices—such as further education opportunities—or particular aspects they would like to see improved. A forum in November will give disabled young people the chance to air their views.

BARBARA NEWMAN

Attitudes

THIS is your opportunity to really make IYDP *your* Year and attitudes towards the handicapped are frequently referred to as a problem. This may be so. However, how often have we said: "It is not my problem . . . it is theirs"? The only way to resolve this or any problem is to meet it half way. How about taking the initiative? Perhaps those who have anxieties need to be encouraged to share them with you. As one person said: "If we all knew a neighbour or friend who was handicapped, we would not be talking about attitudes".

HARRY CROYDON

Information

Switchboard—a clearing house for information for disabled people is to be set up in conjunction with RADAR and the Adult Literacy Group. After any TV or radio programme on disability a number will be shown or announced which disabled people can ring with information queries.

It has been arranged with the GPO that disability will be a new category in the Yellow Pages Directory and will cover organisations, aids and welfare. Contact your GPO locally if you wish to make an entry.

Relationships

A project is being carried out nationwide, to set up a voluntary service to enable disabled people to lead fuller social lives. The idea is that volunteers will act as escorts and, after basic training, be able to help disabled people to get ready and into bed after they have been out in the evening. This will give some relief to parents and care staff in residential accommodation.

Prevention of Handicap

- ASBAH is involved with three projects:—
- An examination of the damage done to hearing by excessive noise in discos and elsewhere.
 - An attempt to increase public awareness of the need to take up ante-natal care early and to prevent accidents at home and work. Existing poster material will be put into many public places, shops, clinics etc.

- A project to encourage people to learn more about their family histories, including medical history. Many handicaps might be prevented and proper genetic counselling sought if families would only talk together, especially among the generations and pass on history of the family. The project will include a children's competition through the BBC and hopefully involvement of the media in special articles.

BEVERLEY HOLLAND

Access

This IYDP group on Access believes that during 1981 the success of a national campaign to improve access will depend largely on local initiative and enterprise. It has drawn up guidelines to help organisations and individuals locally, for example, on how to approach local shops, stores and cinemas in the right way to get them to improve their access facilities.

It also recommends involvement by disabled people in planning procedures right from the start, perhaps even before a planning application is lodged. Again guidelines have been drawn up.

It is important that you let us know at national level what you are doing locally to improve access, so we can build up a picture of the scene nationally, and perhaps help with publicity or in other ways.

Three major national projects are being undertaken:—

- "A Building for the Disabled Award" is to be

presented next year for public buildings, new or adapted, with good facilities for disabled people. The buildings must have been completed between September 1975 and the end of 1980. Anyone may make a nomination and it should be sent to RADAR, 25 Mortimer St, London WIN 8AB. Judging will take place in the Spring and the award will be presented in November. It is being sponsored by RADAR, the Department of the Environment and the Royal Institute of British Architects.

- A series of booklets on adaptations to theatres, shops and public buildings, illustrating imaginative solutions, will be published by the Centre on the Environment of the Handicapped.
- Proposals have been put forward for a project which could have international significance—the adaptation of Canterbury Cathedral.

Please contact me if you would like further information on any of the projects mentioned.

JILL VERNON

Publications

LINK will be going international in the sense that it will carry the IYDP logo on the front cover and each issue will feature a particular country. The intention will be to give readers a picture of the activities of those with spina bifida, and their families, in different parts of the globe. A number of other articles will also have an international flavour.

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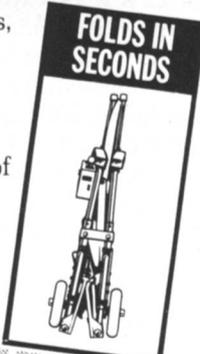
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Help with the heating

AT THE TIME of rising fuel costs, the Government has announced its measures for advising people about energy conservation, and for helping the poorer consumer faced with heating bills.

The 'fuel package' directs particular help to the disabled in recognition of their special needs.

The middle and upper rates of supplementary benefit heating additions—at present £1.90 and £2.85 a week—will be combined at £3.40 a week. Also, under—'fail-safe' arrangements announced by Patrick Jenkin in March, supplementary benefit claimants getting attendance allowance, constant attendance allowance, or mobility allowance will automatically receive the £3.40 rate of heating addition.

Low-income families, including lone parents, living on supplementary benefit and in their own homes with a child under five will get a £1.40 heating addition automatically. Even when the children are older, if any member of the family is ill or the home is hard to heat, a heating addition may still be payable. Families with low wages who qualify for family income supplement will get a total of £2 a week extra for heating costs. All families are eligible for home insulation grants.

People with central heating, who are on supplementary benefit, will get more help. If there are less than five rooms in the home the addition will be £1.40 per week, and for a home with more than five rooms there will be an addition of £2.80.

Help will be given to enable people to insulate their homes properly and thus conserve heat. Supplementary pensioners and pensioners on rent or rate rebates will be eligible for higher home insulation grants amounting to 90% of the cost, up to a limit of £90. Other pensioners can apply for the ordinary grant of 66% of the cost of insulation, up to the new higher maximum of £65.

National Office would like to hear how these measures affect you.

Courses set for 1981

THE SPASTICS Society's Castle Priory College at Wallingford in Oxfordshire have announced a new series of courses up to May 1981. These include:

22nd-25th January 1981. Number 16/111
Caring for the Handicapped Child.

This post-basic or "refresher" course is for personnel with the NNEB or similar qualification. Emphasis will be on common handicapping conditions, care, management, stimulation and play activities, equipment, aids and resources, and it will be of benefit to staff in day or residential nurseries or special schools.

Tuition: £36. Residence: £41.25.

6th-8th March 1981. Number 16/130

Nutrition and Diets for the Handicapped.

This course is intended to outline existing knowledge and to investigate further the nutritional requirements of the chairbound and slow moving in residential and domiciliary settings. It is hoped that participants will include various staff.

Tuition: £28. Residence: £27.50.

8th-10th May 1981. Number 17/11

Drama for the Handicapped.

Drama can be a rewarding medium for those with physical or mental handicap, to become involved in.

This course is intended for those who would like to include drama in educational or leisure programmes.

Tuition: £29. Residence: £28.90.

Further information is available from Castle Priory College, Thames Street, Wallingford, Oxon, OX10 0HE.

Reminders on Access

THE COMMITTEE on Restrictions Against Disabled People (CORAD) has issued a leaflet on access to buildings. The leaflet has gone to local authorities and it is designed for them to hand out to developers and architects.

The intention is to remind them of the need for good access.

Announcing the leaflet, CORAD's Chairman, Mr Peter Large, said: "The environment is still an obstacle course for disabled people and inaccessible buildings are still being put up because developers and architects are unaware of the needs of disabled people.

This design guidance leaflet will remind them of their obligations under the Chronically Sick and Disabled Persons Act and encourage them to make their buildings suitable for everyone and not merely for an athletic minority. I am convinced that good access can be provided both easily and cheaply if it is incorporated at the design stage.

"We must not go on building an environment that discriminates against people because their sight or walking or hearing ability is less than perfect."

CORAD was established by the then Government in January 1979. Its remit is two-fold: to campaign for improved access in England and, on behalf of the UK as a whole, to consider the question of discrimination against disabled people. CORAD's work has been confirmed by the present Administration.

A limited number of copies of the leaflet are available from CORAD, DHSS, Alexander Fleming House, Elephant and Castle, London SE1 6BY.

Encouragement for the athlete

A FIVE Star Award Scheme, designed to bring out the best in handicapped children in athletics is now available for use in schools.

It has an obvious value for schools for the physically handicapped, but, as Moira Gallagher, the scheme's coordinator pointed out in a recent

article in the Times Educational Supplement, there is no reason why it should not be used in ordinary schools with handicapped children.

Further information is available from Moira Gallagher at 26 Barfield Crescent, High Ash, Leeds, LS17 8RU.

David—in champion form

David Statham of Horsell, for the last five years, has been breaking record after record in his wheelchair on the sports field.

This year he has carried away three gold and one silver medal at the Stoke Mandeville Junior National Championships; seven golds at the Southern Region Championships, and five trophies at the Peter Ward Memorial Sports in Pirbright.

His sports include basketball, throwing the discus, the javelin and the shot. Peter is a pupil at Lord Mayor Treloar College, Alton in Hampshire.

Very special 'launch'

A VERY special launch is being planned in time for International Year of Disabled People. It is a 4-6 berth narrowboat being built by Coles Morton Marine of Stockport.

The narrowboat will have an electric hydraulic lift to give easy access for wheelchair passengers. It will also have other special adaptations and general equipment, designed to the highest standards.

The boat will be based at Stone in Staffordshire and operated by Midland Luxury Cruisers (Stone) Limited. It should give more physically disabled people the chance to have a holiday with their family.

The day celebrities shot it out

NORTH Wales ASBAH is now the proud owner of a £9,000 converted ambulance as the result of the Jackie Stewart Celebrity Shoot which was held at Deeside, North Wales in August.

There were teams of Royal marksmen, Lords, and Celebrities. They included Mark Phillips, ex King Constantine of Greece, Prince Andrew, Lord Litchfield, Lord Beaulieu, Lord Roxburgh, Gene Hackman, Jackie Charlton, Ian Botham, Gareth Edwards and many others.

Campaign raises £30,000

A FUND-RAISING campaign started by NASBAH (Surrey) reached its target of £30,000 in an amazing 18 months. The money has bought a special X-ray machine (an image intensifier) for the treatment of physically handicapped children at Queen Mary's Hospital, Carshalton which is now in use.

A special campaign committee was formed, following the tremendous start given by NASBAH, and it enlisted the support of local associations, other voluntary organisations, firms and individuals.

Trevor Brooking calls in

A BUSY and noisy afternoon at Stratford Fire Station in East London was the special September treat for families from Essex branch of ASBAH.

There was a display of fire fighting, to the accompaniment of klaxons and sirens, and some of the children had a ride in a police land rover with sirens wailing.

They were allowed to clamber all over the engines, police cars and ambulance and the older children were shown the control room.

The afternoon was rounded off with tea and cheese and wine, and the special guest was Trevor Brooking, West Ham and England footballer, who spent two hours with the children. It was an afternoon to remember.

The ambulance was presented to the Association by HRH Princess Anne.

Each team was sponsored for £1,000 by various organisations who supported the day most generously.

The result of the Shoot?—An honourable draw for the Royals and Lords.

The ambulance will be very useful for a great variety of special events and special journeys for members of the association.



Mrs Christine Longworth

Dancing their way to success

BURY and Bolton Local Association are proving to be a very active group in more ways than one!

Three of the members excelled themselves earlier this year in the North of England Wheelchair Dance Festival in Oldham. They won the Formation section and the Team Championship and the highlight of the day was when the Secretary, Mrs Christine Longworth won the North of England Couples Championship with her partner, John Berry.

They were dressed in matching gold and lemon outfits and looked superb on the floor. They received maximum points from the judges.

The Association has also become affiliated to the British Sports Association for the Disabled, and is getting together a sports team. So far individual members of the Association have entered sports events and the juniors have won three gold and one silver medal, and the seniors, 38 gold, 23 silver and seven bronze awards.

It was a proud moment for the Association when the Chairman's wife, Mrs Kathleen Reading, was elected Sportsperson of the Year 1980.

Retreat Centres

A booklet is now available on the accessibility of retreat houses, conference centres and monastic guest houses run by Christian organisations in England and Wales. Contact the Social Welfare Commission, Catholic Bishop's Conference, 1a Stert Street, Abingdon, Oxon OX14 3JF. Price 50p.

AN IMPORTANT shift of emphasis is promised in the government's White Paper "Special Needs in Education". As the Warnock Report on the subject recommended, the old concept of education for people with certain disabilities is to be abandoned in favour of a new concentration on the fact that some students have special educational needs.

Among other things this *should* encourage a much wider approach to the subject, taking into account that children often have more than one handicap, and fostering the idea that special educational arrangements should be extended to more children.

It will be up to Local Education Authorities (LEAs) to decide which students, following a multi-professional assessment need to be, as the White Paper puts it, formally 'recorded' and regularly assessed.

Wherever possible, and practicable, it is the intention that children with special needs should be educated in ordinary schools. However for those who need them the present system of special schools will be retained, and a new category of independent schools added.

Local Education Authorities will have a statutory duty to meet the needs of children of school age, but in the case of the under fives, this duty will apply only where the needs of the child have been drawn to the attention of the authority, and with the permission of the parents.

Parents rights in theory are also protected in respect of the process of 'recording', when it comes to access to certain information and a right of appeal.

Education: new dawn or the cold light of day

In principle the system is intended to be more flexible and more open. But interested bodies (including ASBAH) who have been asked to make representations to the DHSS are showing signs of alarm—not at the underlying principle but at what appears to be a serious lack of resources to make the system work.

Despite general cutbacks in education the government says there will be no reduction in real terms in the money spent on special education up to 1983-84. It also says present arrangements for handicapped persons make relatively modest calls on local authority budgets and; "In the government's view authorities will be able to give progressively fuller expression to the new approach outlined in the White Paper by the gradual redeployment of resources".

Later in the White Paper, the consequences of this 'make-do and mend' approach is spelt out more clearly. "Only when the economic situation improves sufficiently will it be possible to bring to fruition all the committed efforts of those engaged in meeting special educational needs."

The White Paper admits the importance of nursery education, but says, "the present economic situation precludes any large scale expansion". As ASBAH has commented, LEAs will have the duty and power to meet the needs of under fives who come to their

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attention, but, how is the group to be identified if playgroups are not going to be provided for children to attend; if health visitors are not given training and encouraged to play a part in helping and advising parents at developmental stage.

The White Paper acknowledges that the concept of special education puts a premium on the teacher's skill and touches generally on the question of training. But it holds out little hope for the extra support services which would be necessary.

The White Paper seeks to protect the rights of parents in certain areas, but, in what is a complex and emotional field, it rejects the Warnock proposal that parents should have a statutory right of access to a named person within the LEA. ASBAH says this is to be regretted.

The White Paper stresses the importance of those involved sharing experiences, but says the government is not convinced that the Warnock recommended National Advisory Committee is needed.

What is not in the White Paper is also significant. ASBAH has commented: We see no reference to the need for longer working days in special schools; to the advantage of four-term school years; to the use of special schools in school holidays to stimulate and maintain skills and to provide broader social education; to the undesirability of all-age schools. Guidance on numbers and the role and training of auxiliary staff is also missing.

ASBAH concluded: "We think the comments in the White Paper show little understanding of the present deficiencies in meeting special needs and retreats from the recommendations made by Warnock.

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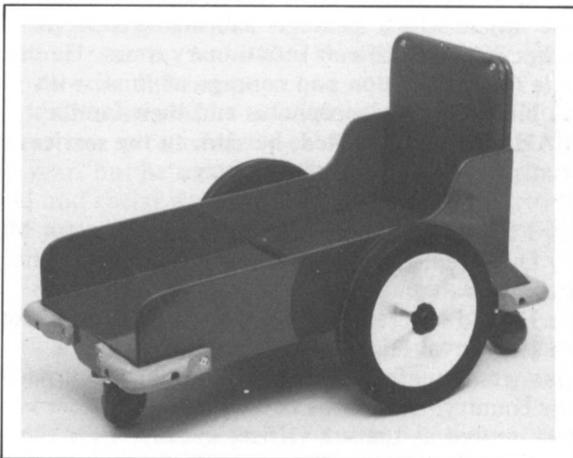
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ASBAH's 14TH ANNUAL MEETING struck a note of 'cautious optimism' for the future, and delegates were glad to hear that ASBAH had managed to pull through a very black financial period last year. The occasion was an especially happy one because of the presence of ASBAH's Patron, HRH the Duchess of Gloucester. She had particularly asked to attend the meeting so that she could meet more of ASBAH's members and supporters. The meeting was held at Westminster Cathedral Conference Centre, London on October 11.

THE REAL concern and interest in ASBAH's work shown by the Patron, HRH the Duchess of Gloucester have always been warmly appreciated and perhaps never more so than at the Annual Meeting in October.

At her own request, the Duchess spent the morning at the meeting and after lunch she was able to meet and talk with a great many Local Association members from far and wide and to get to know ASBAH officers she hadn't previously had the chance to meet. 190 people attended the meeting.

Pulling together in hard times

THE RT HON. Lord Maybray-King, PC, President, in his opening address, said he was proud to be associated with ASBAH and he made special mention of the way in which members had managed to pull together in these difficult inflationary times. He paid tribute to the devotion and courage of those with spina bifida and hydrocephalus and their families. ASBAH was also indebted, he said, to the services of specialists up and down the country.

Lord Maybray-King had a special welcome for Miss Mary Oughtred, the former General Secretary, who had come to the meeting.

Mr Harold Macfarlane was given a great reception when Her Royal Highness presented him with a cheque from members of the Association in all parts of the country. 'Mac'—as he is known to so many—retired as Liaison Officer in July. Over the years he made a tremendous contribution to ASBAH's work, helping individual families as well as Local Associations, and strengthening the bond between local members and national office. Fortunately ASBAH is not losing his services. He continues as a field worker.

After the presentation Mac spoke of the tremendous regard he had for Local Associations who had given so much by way of friendship, kindness and hospitality to him. "I look back and praise your work. I wish there were many more local associations. The one-to-one welfare work and support which you can give is so valuable. I am working with more and more school leavers and young adults and they need it just as much as the babies and young ones" he said.

Carole Armour of Sussex Association presented Mrs Macfarlane with a bouquet of flowers.

Bringing the family to the fore

ASBAH was pleased to welcome as guest speaker at the Annual Meeting, Mr Peter Bottomley, MP for Greenwich and Woolwich West, who spoke about his work as Chairman of the Family Forum Organising Committee.

Having just returned from a visit to southern Africa, Mr Bottomley said that although it was true that our problems were nothing compared with those he had encountered there, it was nevertheless very important that we did as much as we could for families in this country. He felt that in this way our children would grow up able to develop a responsible and caring attitude to others.

Mr Bottomley said that it was to be regretted that family policy matters did not form part of the main political argument and did not feature very heavily in the business matters of Parliament. No-one, unfortunately, represented household or domestic interests in the way that the TUC or CBI represented work interests.

The Family Forum, which was being inaugurated on Nov. 25, was an attempt to redress the balance and to see that there was a voice for families.

"It is an attempt to bring together many organisations who have some interest in the family or family policies" said Mr Bottomley. He said that Miss Gilbertson had been involved in helping to get the Family Forum under way, a process which had taken over two years.

The Family Forum aimed to have a voice at both national and local level. Nationally it could help to fight for the family on issues such as housing. He spoke of the anomalies whereby the bulk of help with housing (mortgage relief, housing subsidies, etc.) went to established families, and not on the whole, to the most needy and new families.

"We should, for instance, recognise the need to get young couples into their homes, and see that help goes to families when they really need it," he said.

Mr Bottomley spoke of the need to try to keep families together and said that a few years ago this country was spending £12 million on divorce and separation proceedings, but only £300,000 on all forms of marriage guidance and counselling.

"Isn't it possible to do it better?" he asked, and gave the Bristol Reconciliation Service as an example of a local organisation that was attempting to tackle the problem properly.

He added, the Family Forum could be effective in helping to make more MPs aware of the needs of

ASBAH's future — a little brighter

MR OLIVER COLMAN, Chairman of ASBAH's Executive Committee told the delegates at the annual meeting that ASBAH's present financial situation, although 'not rosy' was a little brighter than last year. "At least we are now able to pay for everything we are doing," he said.

"Last year I reported that we were in very straitened financial circumstances and that we were unable to take any new initiatives. Indeed, we were worried that we would not be able to continue the existing services. I am relieved to say that the picture is more rosy, although not something to throw our hats over the moon about. We still have to tread very carefully."

Mr Colman thanked the Local Associations for coming to the rescue. "You listened to us when we came round to the regional meetings, and altogether put up about £30,000 either as loans or donations."

"Thank you for seeing us through what we hope will prove to be a short, bare patch." He praised, too, the energetic work of the Appeals Department under Miss Judy Kay.

He said that the work of the Local Associations was invaluable and he was very much aware, too, of the need for a strong national body. Peter Bottomley in his speech had shown the need for a strong national presence to keep MPs and the public aware of our work and needs.

Mr Colman said he would leave it to Miss Gilbertson to report fully on ASBAH's work during the year, but he made mention of the merging of the field and social work staff under Mr Harry Croydon who joined ASBAH during the year as Head of Field Work.

There are now 20 field staff throughout the country. Unfortunately, shortage of money makes it impossible to fill gaps in areas where there are no field workers. Hopefully this may be possible in future.

Mr Colman said that Mr Croydon had also been responsible for reappraising and analysing the work at Five Oaks, in co-operation with Miss Harrison and the staff of Five Oaks.

He told the meeting that the Research Fund was now supporting two training fellowships in community paediatrics in cooperation with the Spastics Society. Because of the increasing emphasis on community health services there was a practical need for community paediatricians with special training and expertise in the problems related to handicap.

ASBAH was also continuing its support of two projects into vocational and non-vocational training for young people with hydrocephalus—one at Banstead Place and the other at Derwen College. Mr Colman gave special praise to ASBAH's well run national office and the work of Miss Gilbertson and her team.



Photo: Richard Young

Dr Adrian Stokes, a member of ASBAH's Executive Committee, is presented to the Duchess of Gloucester.

families. And on a local level it could help to support families when they went through periods of "low resources and high responsibilities."

He felt there was a tremendous gap in aid to families, and he mentioned, in particular, families needing help during times of illness, or help with looking after children at holiday times, or after school, if parents were working. Such help, he said, would do much to give them a little respite and help to keep the family together.

Mr Bottomley said that the Family Forum was hoping to run seminars and meetings on subjects covering broad areas of family interest and to initiate open debate on important subjects such as contraception for children under 16, and abortion.

During question time, Dr David Gompertz Chairman of London Central & North asked Mr Bottomley what he was going to do to pressure the government to restore services which had been cut. Cuts, he said, were causing a lot of hardship to families.

Mr Bottomley spoke of the great waste in spending and regretted that cuts were all too often made in the wrong places. He urged organisations like ASBAH to get closer to the political 'microphone' and to make more MPs aware of the situation. He felt strongly that more people from voluntary organisations should get involved in Parliament. He gave as an example Frank Field, formerly of Child Poverty Action Group, and now a Labour MP.

It's been a busy and difficult year. ASBAH's Chief Executive, Moyna Gilbertson told the meeting how National Office had set about tackling some of the problems.

How we tackled a difficult year

PERHAPS one of the most significant points about the financial problems we have been encountering is that all the staff looked very carefully at their roles within the organisation and, in an effort to economise there has been a greater pooling of knowledge, overlap between departments and a greater involvement of members of staff in activities which they would, perhaps, previously have considered to be somebody else's responsibility. This is I think, a very positive step.

We have put a great deal of effort into looking at ways in which the use of Five Oaks can be expanded. The Officers of ASBAH prepared a discussion document, following a detailed review of Five Oaks for the year 1st October, 1978 to 30th September, 1979. In preparing this paper we were particularly helped by the Bradford Local Authority, which endorsed its support for the House remaining open and welcomed the idea of modifying its use.

The December, 1979 Executive Committee meeting, following consideration of the discussion document, unanimously decided that Five Oaks should remain open and that a further formal review should be held after three years. During this year we have started to implement some of the recommendations. We have decided that, providing there is a suitable vacancy, children with other handicaps may be admitted and that we should encourage adults to use the House as a holiday base, living independently but knowing that help is available if required. So far this option has not been taken up, but as the possibility becomes more widely known we hope that people will take advantage of the opportunity.

It is recognised that there is often a need for parents and children to be together away from home for some specific training or counselling. This may be a mother with a new baby, or an older child and mother following discharge from hospital after surgery, and this is another service which we now offer at Five Oaks. So far we have had one parent and child for such an admission.

Perhaps one of the most important developments is the planned use of Five Oaks for 'mini-independence' courses and individually tailored independence training programmes. We did try holding independence courses similar to those at other venues, at Five Oaks, but have decided from the experience we gained that in order not to disrupt the House and its occupants excessively, it is more appropriate to take smaller groups of children and we hope that this will open the way to starting training programmes with much younger children than those we have so far been able to accommodate at Young ASBAH Training Courses.



Photo: Richard Young

Lieutenant-Commander E. C. Atkinson presents a cheque for £2,500 to the Duchess of Gloucester on behalf of the crew of HMS Arrow, who had asked that the money go to Sunderland local Association. It will be used nationally as well as locally. ASBAH was delighted that men of HMS Arrow were at the Annual Meeting and showed an interest in the Association.

In order to undertake this work efficiently and, indeed, to offer adequate facilities for holiday children when the House is full, the Executive Committee sanctioned the building of an Activities Centre. A special Appeal was launched to raise the necessary funds and the building has been completed on schedule and is now in use. The Appeal raised enough money to cover the building costs and equip the building and we are very encouraged that some of the donors have promised further money for maintenance and the general running costs of the activities centre. We are also most grateful to the DHSS for a grant which completely covered the cost of fire precaution installations.

I would like to reassure all members that we have not lost sight of the original purpose for which the House was purchased. Holidays and service to families in times of any crisis remain top priorities and we have a very active and involved House Committee, under the Chairmanship of Mr Michael Booth of the Leeds and Bradford Association, which will, I know, make sure that we do not lose sight of our original intentions.

We were obviously determined that, no matter what economies had to be made, development of the work of Young ASBAH should be maintained. This has led to re-assessment of priorities, re-allocation of duties and involvement of more staff, including field workers, in the training programmes. Since the last AGM there have been six independence training weeks and five day conferences. Holding more courses,

How we turned the corner

obviously leads to a larger group requiring preliminary and follow-up visits and it is particularly in this area that field workers are making their contribution. Whilst, we hope a great number of young people with spina bifida and hydrocephalus are being helped by these courses, one of the other most important functions is to train volunteers—who may, or may not, be professionally qualified.

It is quite obvious that if all young people with spina bifida and/or hydrocephalus are to be given the opportunity of training in social independence, ASBAH cannot go it alone and we see the experience offered to volunteers to come to us to be trained, in order to run similar courses, as one of our most important roles. We are very pleased that among the volunteers who have attended our courses we can now number a consultant paediatrician, nurses, health visitors, therapists, social workers, teachers, and students from many disciplines.

Our advisory work continues and ASBAH is now represented on numerous organisations. Enquiries of general and specific nature continue to increase. This year there has been an increase of approximately 10%, with a significant increase in the number of enquiries from overseas. We can only think that this will increase even further when the International Federation is inaugurated.

There is now a network of Information Officers in order to try to avoid duplication and to share information appropriate to many organisations, for instance, relating to holidays. This new organisation was the brainchild of Beverley Holland, ASBAH's information officer, who acts as secretary.

We regard ASBAH publications as a very important part of our work and are pleased to be able to report that all our books sell well, not only here but overseas. It is a matter of regret that we have not had time to complete the production of other books which we know are very much needed.

This year has seen the publication of a new booklet "The Handwriting of Spina Bifida Children" by Joan Cambridge and Elizabeth Anderson. "Nursery Years" has been up-dated, and we are working on the second edition of Sex and Spina Bifida in conjunction with the Spastics Society and this should be ready soon. The first edition sold out more quickly than we had anticipated.

Our annual Report shows that the Appeals Department has been incredibly busy and its efforts are being enormously successful. There has been a greater emphasis on special events, the most dramatic of these being the cross-channel parachute jump and one of the great advantages of these events is that, as well as raising much needed funds, they are making ASBAH much more widely known and we have an ever increasing circle of celebrities who love coming to help with ASBAH fund raising activities.

It has been a great pleasure during this year to meet many representatives of Local Associations, particularly as we have travelled about to the regional meetings.

IN HIS Report, ASBAH's Honorary Treasurer, Mr R. M. Nichols, said that last year it had been essential to "ring the alarm bell". After the Annual Meeting last year the financial situation had continued to deteriorate until by the end of 1979 ASBAH was in deficit by £78,000.

But the early part of this year saw an improvement in the situation. Local Associations sensing the urgency responded well to the tune of about £30,000, and legacies increased. During the year legacies brought in £57,000, and nearly half of this came in during the early part of this year.

Under Judy Kay, ASBAH's special fund-raising events had also greatly helped the financial position, and Mr Nichols made special mention of one event—the House of Commons sponsored swim—which brought in £13,000 alone. He said that Cashcade Lotteries raised £12,000 but had not proved as beneficial as had been hoped.

The Association's Accumulated Fund at 31 March 1980 stood at £91,342, a deterioration on the previous year of only £9,000.

Mr Nicholls concluded by thanking Mr Frank Armour, the Finance Officer, for his work. "ASBAH is lucky to have such a dedicated man."



THE SHASBAH TROLLEY FOR HANDICAPPED CHILDREN

Patent applied for in UK,
Commonwealth Countries, USA, Canada
Standard model for children 1-5 years: £25 plus carriage.

Large model for children 5-10 years: £30 plus carriage:

Overseas prices on application

Produced by **Southampton and District ASBAH**

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

MANY PARENTS of children with spina bifida have a particular fear of their children's chest infections. To a great extent these fears are groundless.

I would like to look at some common worries about chest infection in children with spina bifida, with or without hydrocephalus, including the child's immunity, his ability to clear phlegm from the lungs, and the use of antibiotics.

But first I should state the obvious—all parents worry about chest conditions.

Probably all people have this worry at times, but particularly the generations brought up in the 1920's and '30's: today's grandparents. Prior to the second world war antibiotics had not been discovered, pneumonia was a fatal disease "carrying off" millions in 1919 and 1920, "double pneumonia" was a fear and a chronic cough in childhood often meant tuberculosis. This is no longer the scene, we do not even speak of double pneumonia, and tuberculosis when seen is readily treated.

Immunity

But to return to today and children with spina bifida; first there is the question of immunity, the body's ability to respond to and kill bacteria and viruses. It is not true that children, or adults, with a disability such as spina bifida have a reduced immunity to infections. Immunity is concerned with substances either carried in blood plasma or in all body cells and these are not affected by the spinal lesion or by hydrocephalus.

What about the effect of antibiotics given for previous infections, perhaps for urinary infection or following an operation for a valve? Some germs certainly can change so that having met an antibiotic once they become resistant to it. The common boil germ, the Staphylococcus, did this in the 1950's and penicillin was no longer effective against so called hospital strains. Other antibiotics were then developed and we have at least 20 useful and different antibiotics today.

But it is not true that if a patient has once had an antibiotic that

Children's chests: some reassurance for parents who worry too much

by
Dr J. H. Keen,
Consultant Paediatrician,
Booth Hall Children's Hospital,
Manchester

particular drug is "used up" and cannot be effective again. To give one example, penicillin given regularly can protect for 20 years against the common sore throat germ, the Streptococcus, and it is used in just this way in rheumatic fever.

While discussing antibiotics—substances which can kill bacteria—I should stress that the great majority of respiratory infections are due to viruses and not bacteria. We speak of a cold "going on the chest". The virus does just that. Antibiotics are almost never of use in treating virus infections but the body normally develops good resistance to viruses, a resistance which commonly lasts quite a long time.

Best answers

Finally there are mechanical factors in preventing and responding to chest infections, the ability to clear phlegm with a strong cough and to expand the lungs fully. Children with spina bifida high on the back particularly at chest level (thoracic and thoraco-lumbar lesions) are likely to have paralysed abdominal muscles and when sitting may lean acutely forward with the lower ribs resting on the hip bones. In some cases the rib muscles may be weak as well. Clearly this makes breathing and coughing more of a problem. The best answers lie, I believe, in two very Victorian

instructions: sitting up straight and deep breathing.

I think we should all, doctors, physiotherapists and parents, pay more attention to the chest in spina bifida. If you are worried because your child has difficulty in coughing, always ask to see a physiotherapist who will teach you the best way to help your child to cough. Rib muscles and diaphragm can be strengthened by practice in most patients with spina bifida and while sitting poker backed may not be possible, the sitting position can often be improved greatly by choosing desks and work surfaces the correct height. I would particularly suggest that those children who are in long calipers with pelvic or chest bands for part of each day should be encouraged to use some of that time practising deep breathing.

They have my sympathy. I so well remember those 20 cold deep breaths at the window of my boarding school dormitory. But cheer up it is doing you good!

Harmless

While on the subject of children and coughing it is worth knowing that most young children are unable to cough out phlegm, they swallow it and it is entirely harmless. Even when infected secretions are swallowed they are digested and rendered harmless. Occasionally vomiting results which is unpleasant but again harmless.

In an extremely weak or unconscious patient with spina bifida chest secretions and infection can be a very serious problem and even prove fatal, but in saying that I have in mind children with severe brain damage, the result of an infected hydrocephalus (ventriculitis).

So with that exception, depression of immunity in children with spina bifida is a complete myth, running out of antibiotics is hardly a problem and the mechanical difficulties can be tackled with the help of your physiotherapist.

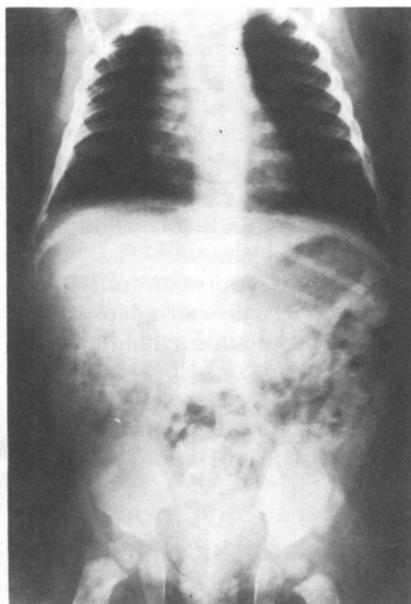
Another deep breath please and sit up straight dear.

Shall we make 1982 the year of the Granny?

CURVATURE of the spine is a common problem in children suffering from spina bifida. This is perhaps not surprising as spina bifida represents a congenital abnormality of the bony elements of the spine as well as the nervous elements.

A few definitions are necessary when talking about curvature of the spine. When looking at the child from front to back a backward curve of the spine is called a kyphosis.

In normal babies when they are born there is a long gentle backward curve or kyphosis of the spine shaped like a "C" throughout its length. As the child learns to hold up its head a forward curve or lordosis develops in the neck or cervical region which is called the normal cervical lordosis.



•A child, aged one year, with a straight spine.

Similarly as the child starts to sit and later stand a forward curve develops in the lower back or lumbar region called the normal lumbar lordosis. Thus by the age of one year to eighteen months a normal child has altered his original single backward curve or kyphosis into a forward cervical lordosis, a backward chest or thoracic kyphosis, which represents the original curve, and a second forward curve in the lumbar region, the lumbar lordosis.

Failure to develop either of these two normal lordoses or exaggeration of either lordosis or kyphosis is considered abnormal.

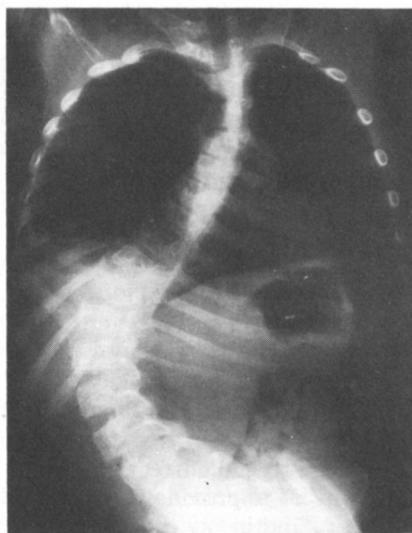
Curvature of the spine: problems facing parents and surgeons

by

J. A. Fixsen, Consultant Orthopaedic Surgeon

The Hospitals for Sick Children, Great Ormond Street, and St. Bartholomew's Hospital, London.

A curvature of the spine from side to side is called a scoliosis. Everybody flexes their spine from side to side when walking and frequently when standing unless they stand absolutely straight. This type of scoliosis is known as a postural scoliosis. It is not fixed or associated with rotation of the spine. It is therefore not considered a deformity. If, however, a scoliosis becomes fixed and rotated then it is known as a structural scoliosis. Such a scoliosis is considered to be a deformity and requires careful observation and frequently active treatment.



•The same child at the age of 12 with a severe thoraco lumbar scoliosis.

Children with spina bifida may suffer from an abnormal kyphosis, lordosis, scoliosis or a combination of any of these three.

Kyphosis:

In children with an extensive area of the lumbar or thoraco-lumbar spine involved by the spina bifida defect there are no muscles behind the spinal column. Furthermore the posterior elements of the bony segments or vertebrae of the spinal column are not present.

As a result they will inevitably develop a lumbar kyphosis as there are no muscles to extend the lumbar spine and produce the normal lumbar lordosis. Most of these children have severe weakness of both lower limbs. Although they may use calipers for a time they are likely to become mainly or entirely wheelchair users.

There are four important reasons for considering surgical correction of the lumbar kyphosis.

1. If the kyphosis is collapsing and the child is having difficulty with breathing when he sits up or pain from his ribs impinging on the pelvis.
2. If the child is developing intractable sores over the apex of the kyphosis which cannot be healed by conservative means.
3. If the child needs an ileal loop bladder for urinary drainage and the abdominal wall is too folded upon itself by the kyphosis.
4. If the child is a good walker in calipers (orthoses) and his kyphosis is preventing the fitting of reasonable appliances.

In the majority of patients careful attention to padding the kyphosis and the back rest of the wheelchair will solve the problem. Some years ago attempts were made to correct the spine surgically in the first year of life. Unfortunately the lack of muscles to hold the spine in the extended position meant that the kyphosis tended to recur rapidly over the next few years.

If surgery is necessary it represents a major operation removing the apex of the kyphosis and buttressing the front of the spine with bone graft. This type of extensive surgery is not without considerable risk and most surgeons only recommend it if it is absolutely necessary.



REVIEWS

Scoliosis:

This type of curve is often not noticed in the early stages when it is only present to a minor degree. However it can progress quite rapidly as the child gets older and heavier causing very troublesome symptoms both when sitting and standing.

In normal children with normal muscles and sensation who can develop scoliosis quite badly during growth, bracing the spine can be very effective. However, in spina bifida children who are already encumbered with calipers and other appliances a spinal brace is yet another awkward piece of apparatus to burden both the child and his parents.

The most effective form of spinal brace requires a very tight fit around the pelvis where it can easily give rise to pressure sores and extends right up to the back of the head and below the chin. This type of brace is very difficult for a spina bifida child to wear. As a result a simpler form of corset or jacket to support the spine, usually made of plastic lined with foam, can be used. This can be quite helpful to support the spinal curve but it is not corrective.

Major undertaking

Surgery for scoliosis is a major undertaking. Because there is deficiency of spinal muscle and bone in this condition it is often necessary to fuse the bones of the spine over a long area both from the front and the back. This type of fixation or spinal fusion as it is called involves using bone graft taken from the pelvis plus metal internal fixation devices such as wires, rods and screws to hold the curve while the bone graft is growing and fusing the elements of the spine together.

This commonly means two major operations for the child within a short period of time followed by a considerable period of corrective bracing until the bony fusion has healed solidly.

Fusion from the back (posterior fusion) is usually carried out using so called Harrington rods. In this operation the posterior elements of

the spine are fused with bone grafts. The position is held by a steel rod placed posteriorly which both corrects the curve and holds the correction while the bone graft is healing.

Fusion from the front (anterior fusion) is performed using the so called Dwyer cable and screw technique. In this operation the intervertebral discs are removed over the length of the spine to be fused. The anterior portion or bodies of the vertebrae to be fused are clamped together by a cable passing through screws inserted in each vertebral body.

Useful method

This is a particularly useful method if there is some lordosis as well as scoliosis. It is also useful for controlling that part of the curve where the posterior bony elements are deficient and so posterior fusion is very difficult.

Following such a bony operation the child will have to wear a supporting brace or corset until the bone itself has healed fully as the metal on its own will not hold the bone permanently.

Spinal deformity in these children is a great worry both to their parents and the orthopaedic surgeon as it is difficult to prevent it progressing by any form of bracing or corset. The surgical operations which may be necessary are extensive, time consuming and not without hazard for the patient. The child has often already had a considerable amount of surgery and the prospect of yet more surgery is not pleasant.

However, if a curve cannot be controlled satisfactorily by conservative means it becomes progressively more disabling and unmanageable. In this situation adequate surgical correction is the only way of improving the child's disability and in my own experience the children tolerate these large operations surprisingly well.

What Sort of Life? by Patricia Rowan. NFER Publishing Company, Darville House, 2 Oxford Road East, Windsor, Berks, SL4 1DF. Paperback £5.50.

This paper is based on a study of what is being done in nine local education authorities in the UK to help handicapped young people through the important period between school and adult life and work—or life without work.

It looks at examples of good practice and the gaps in the service. This UK project is directed by Barry Taylor, CEO for Somerset and is written partly for an international audience, but it is hoped that the report will be helpful in spreading information in this country.

★ ★ ★

Access to Public Conveniences 1980. RADAR, 25 Mortimer St, London W1N 8AB. £1 including post and packaging.

This guide reports on toilets that have been designed or adapted for disabled people in England and Wales . . . not only local authority loos but also those provided by public and private organisations in buildings such as stations and large stores.

Crossroads Care Attendant Schemes—publications. Handout leaflets—stating objectives and structure of the Trusts and where the schemes are situated. 10-30p plus postage.

'*Crossroads Care Attendant Schemes*' booklet. Written by Gavin Weightman, this explains the need for a Crossroads Scheme and how to go about setting up a new scheme. It has practical information and examples of forms used in the original Rugby Scheme. 35p plus postage.

'*Co-incidence—Or Meant To Be?*'. This small book is a factual account, with cartoons and photographs, of the first two years of the pilot Crossroads project in



Continued on Page 18

UNDER eighteen months ago John Grooms Association offered holiday accommodation for about 30 people. In 1981 over 100 holiday places will be available each week during the season for the physically disabled, their relatives, friends and escorts.

Here is a brief description of these holiday facilities.

Hotels

The Association runs two delightful Hotels on the sea front at Minehead and Llandudno. Both hotels aim to give a very high standard of service, and the facilities must be among the most suitable in the country for those in wheelchairs. Here are some of the amenities—*level access *lift with wheelchair controls *hoists in many bathrooms and bedrooms *lever type taps *well positioned baths *closomat automatic toilet *wide doorways and corridors *tea making facilities in each bedroom *emergency call systems in bedrooms *balconies that overlook the sea *both hotels have a bus with tail lift for tours and general transport *colour television lounge *the hotels are run on a non-profit making basis *groups are welcomed *hotels are licensed.

Guests are encouraged to bring able-bodied relatives and friends. These are essentially *holiday hotels*, not hospitals or nursing homes.

Approximate price range per week in 1981 £56-£106.

Special Care Week

At Llandudno there will be a week in the Autumn of 1981 when extra care will be provided, i.e. where a disabled holidaymaker needs help with washing, dressing etc which their family, friends or escorts are unable to provide. Nursing care will also be available if required.

Holiday caravan units

John Grooms hires out four well adapted caravans for wheelchair guests and their families. These are situated at Borth, Mid-Wales; Barnstaple, Devon; Highcliffe, Hants and Poole, Dorset. There are ramped entrances, wide doors and corridors, wheelchair toilet and shower. The worktops, sink, cooker and power points are at

John grooms holidays



wheelchair height. Each unit has a colour television and modern comfortable furniture and provides accommodation for six people.

Approximate price range per week in 1981 £45-£95.

Self-catering flat in London

There is also a modern well-designed fully-furnished wheelchair flat in N4 with two bedrooms and panoramic view over London. Bookings are taken for a week or a fortnight.

Price in 1981 £50 per week.

Chalet

One of John Grooms' latest acquisitions is a three bedroomed chalet just north of Skegness. It can sleep up to eight people. Those in iron lungs are particularly welcome and there is a standby generator in the event of a power failure. It is self catering with electric cooker, refrigerator and colour television.

Approximate price range in 1981 £40-£90.

Motor Caravan

John Grooms' latest holiday project is a beautifully adapted motor caravan for wheelchair users (and their families). Five or six people can be accommodated, but only one wheelchair.

The facilities include the following—*wheelchair tail-lift—electrically operated *clamps to secure the wheelchair during travel *central corridor over 30" wide *toilet/shower compartment specially constructed for a disabled person *a cooker that can be easily operated from a wheelchair *hot water/boiler system *refrigerator

(gas/electric) *the beds are 6' 10" long *effective and safe heater *table for meals/games etc. with space for the person in the wheelchair *black and white television *reading spot lights *radio in cab and caravan *ceiling hand holds.

The interior is finished to a very high standard and the rear berth is collapsible to provide easier wheelchair movement if required. The vehicle will be kept in London and will be available for hire for one or two weeks.

The charges in 1981 will range from £90-£180 per week.

Future Projects

John Grooms is adding other holiday facilities to its range every few months, so do contact them to see if there is anything new in the offing.

London Hotel Project

John Grooms is supporting, along with several other charities, a project to build a hotel/accommodation centre in London for the physically disabled holidaymaker and their families. This project is still in its infancy and a suitable site has not yet been acquired.

If you would like further information on any of these holidays please write to:
The Holiday Department,
John Grooms Association for the Disabled,
10, Gloucester Drive,
London. N4 2LP.

Telephone: 01-802 7272

The births and infancy of Speedwell Enterprises and the Supakart

AFTER MUCH discussion, it was agreed by the Employment Service Agency and Berkshire County Council that there was a need for a sheltered workshop in Slough to provide employment for disabled people who were willing to work in a normal factory environment but who were unable to achieve an output acceptable to open industry.

The Divisional Director of Social Service, Slough Division, was charged with the task of organising the project. A Board of Honorary Directors was formed which included representatives from local industry.

LEARNING

A site was found and Berkshire County Council designed the factory and organised the construction. Meanwhile the team spent time learning all they could about sheltered workshops by visiting established factories for the disabled.

A great deal was learned about industry in general and sheltered workshops in particular, but especially that 'their' workshop must not be engaged in the usual, somewhat soul destroying, repetition work. What was needed was a proprietary product that

would provide a variety of interesting tasks for the workforce and would result in a finished article with which they would be proud to be associated. But what?

The question did not remain long unanswered. A member of the team met the father of two disabled boys who had recently converted a pedal Go-Kart into a battery/electric vehicle to provide his sons with independent mobility. It had achieved this objective and had also proved a social benefit; other children were keen to be friends of the boys who drove around in their own mechanically propelled car.

The father was keen to see a similar vehicle produced commercially to satisfy the need, which clearly existed, for a vehicle that looked like a Go-Kart but which conformed to the legal requirements of vehicles for the disabled, and so the idea of the Speedwell Supakart was born.

There was little time to turn a dream into a reliable, good-looking vehicle; the factory was to be completed within a year and disabled people were to work there within fifteen months. Then, providentially, two Final Year Students from the Chelsea School of Art, visited Slough Social

Services to discover whether there was an aid for the Disabled that they could design, where an existing need was not being met.

The Go-Kart project was discussed with them and they became enthusiastic. And at the end of their course in July 1978, they had designed and produced a suitable body, but mounted on a non-functional chassis.

PRODUCTION

From this point, the Workshop Manager developed, through many stages, an appropriate chassis for the Go-Kart. Later that year, three pre-production Supakart bodies were produced, followed by the mould for the finished production model.

A national competition was organised to find a name for the vehicle, and "Speedwell Supakart" was chosen. In April 1979, the first disabled employees commenced work, with the first Supakarts being collected by their purchasers in June 1979.

The product is already providing many disabled children with new-found independence, and several Supakarts have been delivered to Holland and Sweden.

Mr Bob Underwood
Manager, Speedwell Enterprises

Rugby. Noel Crane, a tetraplegic, writes about the time of his accident and the period leading up to his involvement with the Scheme. Pat Osborne, SNR, NCDN, gives a personal account of the problems encountered when implementing the Scheme in 1974/6 whilst she was a community nurse. £1 plus postage.

Please send no money. Invoices will be issued. Write to Crossroads Care Attendant Schemes, 11 Whitehall Rd, Rugby, Warwickshire CV21 3AQ.

Sports and Leisure—an access guide for disabled spectators. 75p (plus 50p post and packing) from RADAR, 25 Mortimer Street, London, W1N 8AB.

REVIEWS

Continued from Page 16

Many disabled people would like to go to sports events but feel that some of the centres get too crowded and uncomfortable, if not hazardous, for wheelchair users or ambulant disabled people. This guide looks at the access parking, toilet and refreshment facilities and other help available for the disabled at major sports centres all over the country. Football, rugby, cricket, horse riding, greyhound racing, speedway, motor racing and tennis are all covered.

The Good Toy Guide. Price £2.95 from bookshops or from Toy Libraries Association, Seabrook House, Potters Bar, Herts. Send 35p post and packing.

This new book should be a great help when shopping for toys for Christmas. It recommends 900 toys approved from thousands. They have been selected by the Toy Libraries Association panel of child specialists for their play value, durability and functional and developmental qualities. Mary Barton, Activities Organiser at Five Oaks is a member of the panel. There is advice on how to buy wisely and on toys and the handicapped.



Get out and about with the Speedwell Supakart.

Designed primarily for physically handicapped but is suitable for all children from 6 to 16 years of age who have reasonable strength in their hands and arms.

The Supakart is a rugged, stable, outdoor vehicle which has a range of six miles, will mount shallow kerbs and climb steep gradients.

The have one, is to have fun, and you will see more places and people.

Get out and about with the **SPEEDWELL SUPAKART**

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THE RELIABLE SOURCE OF SUPPLY



The winners of the Celebrity Treasure Hunt, James Hunt and Jenny Cresswell with one of Peter Stuyvesant's expert drivers.



The hunt is on . . . Terry Biddlecombe at the wheel and his partner Linda Cunningham, with an expert to keep them on an even keel.

James Hunt leads search for Thames treasure

WITH WINTER days here, perhaps it is no bad thing to invite you to cast your mind back to the warmer days of summer . . .

August 30 was the day of the Peter Stuyvesant Celebrity Treasure Hunt on the River Thames and I am delighted to report that this event was a most happy and successful occasion for all concerned. Despite torrential rain in the early morning, the sun began to break through as our celebrity guests arrived at the Tower Hotel for a pre-race lunch, coupled with a fairly stern briefing session by Commander Paul Satow of the Port of London Authority and Chief Inspector Allen of the Thames River Police.

Having been warned of the dangers which would result from misbehaving on the river, our celebrities, James Hunt, Shaw Taylor, Gareth Hunt, Tom Adams, Terry Biddlecombe, Bob Spalding, Fiona Curzon, Pippa Page, Jenny Cresswell, Judy Simpson, Linda Cunningham and Caro Greenwood set off in teams of two from the Tower Pier at the starting point at Cadogan Pier. The contestants started at precisely the appointed time and arrived on schedule back at the Tower Hotel about one hour later. Not surprisingly perhaps the race was won by former world racing driving champion, James Hunt, who told me afterwards that the essence of successful racing is to read all instructions carefully and

follow them to the letter. This policy undoubtedly paid off in this case and James Hunt was the winner and was presented with a bottle of champagne and a ships decanter by Mr Brian G'Napp, Promotions Manager for our sponsors, Peter Stuyvesant.

It was purely coincidental that James' partner in the race was the former Miss Jenny Cresswell, now Mrs. Brian G'Napp and full tribute should be paid to Jenny too, as it was she who correctly solved clues dreamed up by the devious minds of members of the Appeals Department.

Congratulations to James and Jenny and very special thanks to Peter Stuyvesant for their sponsorship of the race.

Sgt. Walters' team crosses Channel —by Parachute

HAVING WAITED three months for the correct weather conditions for the Cross Channel Parachute Jump, it is not difficult to imagine our alarm when, half way through the Thames Treasure Hunt we received news that the attempt would be made at first light the following morning, Sunday August 31.

Leaving the Tower Hotel in something of a panic we hastened to Dover and, having met up with the national press on a windswept promenade, caught the 1.00 a.m. ferry to Calais, there to spend a long, cold and sleepless four hours at the drop-zone. We listened anxiously to reports coming over a radio transmitter as to the progress

at Manston Airfield and then from on board the Piper Navajo, which took the six daring parachutists to the 25,000 feet above Dover Castle, from which they were to jump.

Despite grave worries that the wind force on the ground was much too strong for a safe landing, we heard that the team had left the aircraft and that all six canopies had safely opened. There then followed an interminable half-hour of watching the skies for some sign of the team. Sadly this effort was never rewarded, as the men flew over Calais, still at an altitude of 10,000 feet, and only landed some four miles further on, from whence they had to be collected by helicopter and brought back to re-join the waiting ground crew.

The first man to land was, appropriately enough, the leader of the team, Staff Sgt. Bob Walters, despite the fact that he had been last to leave the aircraft. As the idea of crossing the Channel by means of parachute had been Sgt. Walters' ambition for eight years, he was understandably jubilant about the success of the attempt.

He told me afterwards that there had been times during the crossing when it had seemed impossible that they would make the French coast but the speed at which they were overtaking ferries seemed to be a good omen.

Sgt. Walters had put a great deal of effort into recruiting a team, enlisting the help of the sponsor, Courages Brewery, and getting all the appropriate clearances through the Ministry of Defence and it is therefore principally to him that ASBAH owes a sincere vote of



Three of the parachutists.



The Red Devils van being taken "into custody" by the gendarmes.

thanks for the splendid financial outcome from the event, which currently stands in excess of £30,000. Other members of the team were: W. O. Ted Lewington, Pte. Ian Marshall, Sgt. Derek White, Marine Bobby Scoular and Staff Sgt. Geoff Ellis.

If the jump itself was without incident, the landing was not, in that the ground crew were accosted by an extremely irate French farmer who was not too happy at finding smoke flares illuminating his fields at dawn. Brandishing a double-barrelled shotgun and speaking very fast French, he contrived to give the landing party the impression that trouble was on the way. It arrived in the form of two members of the local police force who rounded up the entire party, parachutists, ground crew, sponsors, reporters, cameramen, together with ASBAH's two representatives and led us in a convoy of vehicles back to Calais Police Station.

There we were interrogated for

thence back to England for some much needed sleep. At least one could sleep very soundly in the knowledge that ASBAH now had fewer financial problems.

And Dave Smith walks from Harrow to Brighton

ON A MORE conventional fundraising level, Mr. Dave Smith, a dustman with the Harrow County Council, managed to raise the splendid sum of £1,250 entirely by his own unstinting efforts in recruiting sponsors for his walk from Harrow to Brighton.

Pushing a pram, which he had picked up while on his rounds with

the dustcart, Mr. Smith made such good time that he arrived in Brighton 24 hours sooner than expected. Nonetheless, local association member, Mr. John Notton, and his daughter who has spina bifida, managed to be there to meet him.

Dave Smith is now planning a follow-up walk to Harrow's twin town in France and once again will be supporting ASBAH. We all wish him every success.

Help for Five Oaks

MR. IAN Craig has joined the national fundraising team in a voluntary capacity. Mr. Craig, who has retired from a successful business career, will be approaching trusts and businesses in the Yorkshire area with a view to raising enough money to cover the fairly substantial deficit resulting from the operation of our short-term care home, Five Oaks. Should you wish to contact Mr. Craig, please drop a line to the London office.

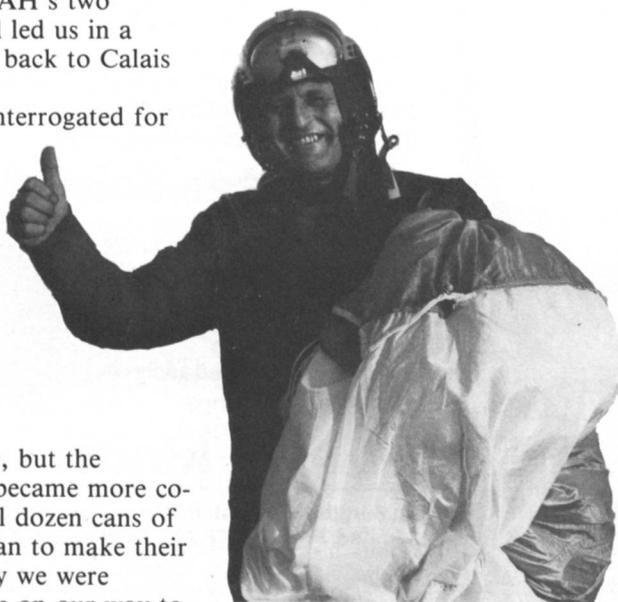
Christmas greetings

THE CHRISTMAS mailing has gone out to all our donors, including this year's Christmas card leaflet, which I hope you have found attractive.

This seems an appropriate moment to wish you all the compliments of the season together with our best wishes for a happy and successful new year, when we will all be uniting under the banner of the International Year of Disabled People.

JUDY KAY
Director of Appeals

more than an hour, but the gendarmes slowly became more co-operative as several dozen cans of Courages beer began to make their appearance. Finally we were allowed to continue on our way to Calais airfield with wishes for a bon voyage ringing in our ears and



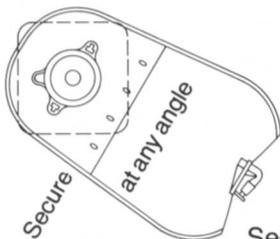
One of the team members, Ted Lewington.

New for Urostomy!

a new standard of comfort and security

Surgicare™ System 2 saves the patient from the trauma of peeling off adhesive bags. The Stomahesive™ Flange can be left on the skin undisturbed for several days whilst the pouches are replaced as often as necessary.

The non-return valve permits easy access of urine to the lower part of the pouch and efficiently prevents the return of urine to pool in the area of the stoma thus the Stomahesive™ wafer is protected from the breakdown effects of urine and therefore remains secure and leak-free for several days.



Secure closure: easy drainage

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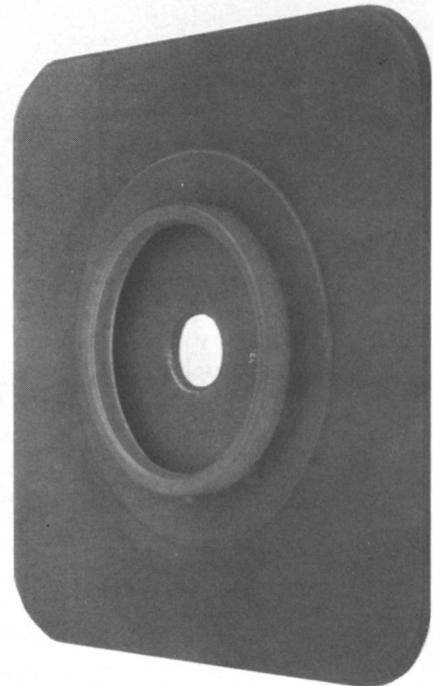
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Please send me your illustrated brochure on Surgicare™ System 2 Urostomy management
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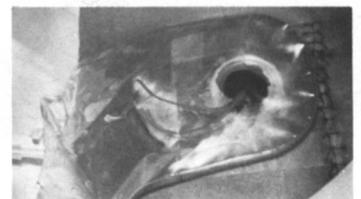
System 2

Few innovations in the last decade have contributed as much to stoma management as the introduction of the Stomahesive™ wafer. Even in the most adverse circumstances, the Stomahesive wafer makes possible a leak-free attachment of appliances to the skin thereby providing a unique degree of comfort free of irritation and soreness often associated with ordinary adhesives.

Surgicare™ System 2 takes full advantage of these benefits which are particularly evident in the management of urostomies.

generates confidence

During the post-operative week the patient learns firstly how simple it is to replace pouches, then with growing confidence learns how to prepare and apply the Stomahesive™ Flange.



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Adverts for the next LINK (Jan/Feb) should be in by December 10. 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 Road, Kenton, Harrow, HA3 0NH. Tel: 01-907 8526 (2-7 pm).

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London Holiday Flat: London, N4.

Motor Caravan: First season 1981. Can be hired for one or two weeks, and driven anywhere in Gt. Britain. It has tail lift, special wheelchair W.C./Shower unit, and other modifications. Black & White T.V. and Radio.

For further details contact: John Grooms Holiday Department (Ref. L1.), John Grooms Association for the Disabled, 10 Gloucester Drive, London N4 2LP. Tel: 01-802 7272.

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

FOR SALE

Leisure Wear: White cotton Tee Shirts with green Family symbol and words 'Support Spina Bifida' £1.60 each size 22"-30"; £2 each small, medium, large. Also quality Sweat Shirts with reverse colours in all sizes including extra large adults. All at £4.50 each plus postage. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

Batric three-wheel electric car. In need of some attention. For details tel: David Hiam 05476 246.

Local Association Secretaries

THE following changes of Local Association secretaries have taken place since the last issue. A full Directory of associations will appear in the next LINK.

Bedford & District

Mrs S Shere
29 Ridgeway
Eynesbury,
St Neots, Cambs.
Tel: Huntingdon 72454

Darlington & District

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

Salisbury & District

Mrs J Renshaw
1 Philip Court,
Coronation Road,
Salisbury SP2 9DA

ASBAH booklets etc...

<i>Your Child with Spina Bifida,</i> by J. Lorber, MD, FRCP	35p
<i>Your Child with Hydrocephalus,</i> by J. Lorber, MD, FRCP	20p
<i>Children with Spina Bifida at School,</i> Ed. P. Henderson, CB, MD, DPH	30p
<i>The Care of an Ileal Conduit and Urinary Appliances,</i> by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
<i>Aids and Equipment</i>	60p
<i>Sex and Spina Bifida</i> 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

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 15p per booklet.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida 30p

The Spina Bifida Baby 30p

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).

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All available from Appeals Dept.—postage extra.

Film 'Appeal for ASBAH' 10 mins

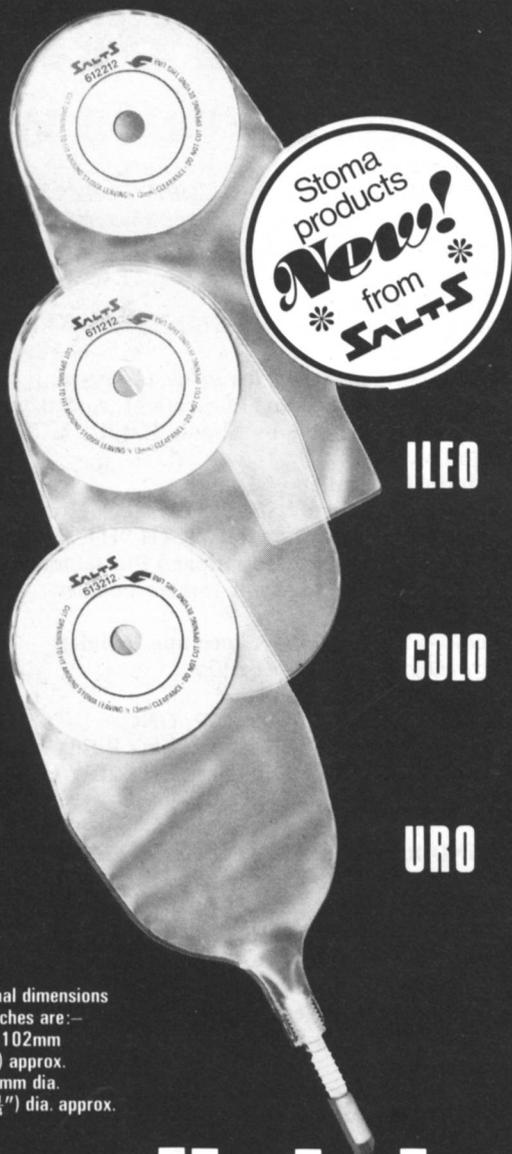
16 mm Colour/Sound £4 Hire

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

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

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THE DISTRICT Advertising Company of EMI Elstree Studios, Shenley Road, Boreham Wood, Herts. WD6 1JG, offers a special service to Charities. They produce Telephone Address & Notebooks. These are a unique way of raising funds, also Fundraising Charts with Socks attached for Donations. These also help promote your cause and recruit new members, and are displayed in public houses, restaurants, on factory notice boards and other prominent places. Calendars, Diaries and Programmes for Fetes, Donkey Derby's, Bazaars, Charity Football Matches, etc., can also be obtained, all completely free of charge. For further information contact: Mr J. A. Alter at the above address or tel: 01-953 1600 Ext. 171.



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The external dimensions of the pouches are:-
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Flange 82mm dia.
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paediatric

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LW URINARY POUCHES

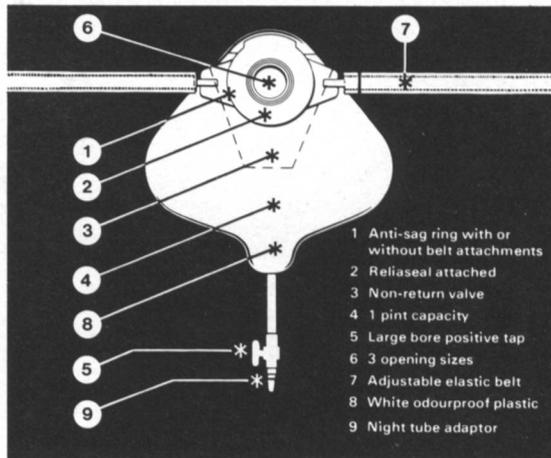
are complete appliances and can be worn without any additional accessories, though some ostomists prefer the added feeling of security which LW accessories can provide.

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 $\frac{1}{2}$ ".

* Now available in Small capacity size



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.

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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 $\frac{1}{2}$ ".

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