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JULY/AUGUST 1976 5p

Association for Spina Bifida and Hydrocephalus (ASBAH)

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

**Patron:**
**HRH The**
**Duchess of Gloucester**

Chairman:
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Hon. Treasurer:
**Mr. E. S. Gower,** FICS, FHA

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**Mrs. Kate White**

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

Link Editor:
**Mrs. Susan Gearing**

# Editorial

**This Link is a little out of the ordinary as it covers in some detail two important events in the life of ASBAH—the Annual Spring Conference, and the Tenth Anniversary Celebration.**

Link was there and in this issue shares with its readers some of the words of wisdom and atmosphere of both occasions.

Inevitably these two reports have taken precedence over some other stories but they will be carried in later issues.

Link began at the same time as the National Association and has grown with it. Now the stories and articles it carries not only concern spina bifida and hydrocephalic babies and children, but also teenagers and adults. It has been a natural growth, but this wider area of concern does mean that no one issue is likely to meet the needs of all readers. Over a number of issues, however, we try to make sure that coverage reflects the interests of different age groups. Only you can tell us if we have got it right.

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**With holidays just around the corner—or maybe already begun—now seems the right time to ask for your help. In fact, It's the Central Council for the Disabled that need your help in the form of comments—favourable and otherwise—on the accommodation listed in their annual Holidays for the Physically Handicapped Guide.**

Your experiences are much more helpful in giving a true impression of a place than any tape measurements of door widths, steps and so on. The Guide grows each year and there is a danger that quality may become secondary to quantity. Also let them know if you have found any nice accessible places not already discovered by the Guide, and which you don't mind sharing with others.

The CCD do an excellent job with this Guide and it would be a small return, and indeed in our own long-term interests, if we took the trouble to give them any helpful advice they need.

On the subject of holidays it is good to see that spina bifida youngsters seem to be spreading their wings more than ever this year and enjoying holidays in the company of others of their own age (see page 4). Link wishes everyone a very enjoyable holiday wherever it may be.

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## FRONT COVER

**The Association's Patron, HRH the Duchess of Gloucester talking to Trudy-Anne Bush of Surrey (NASBAH) who, dressed as ASBAH's Tenth Birthday Girl, won a first prize in the fancy dress competition at the Tenth Anniversary Celebration at Stoke Mandeville. (Full report of the Celebration on pages 8/9/10).**

**Photo: J & S Photos, Aylesbury.**

# News from all around

## More and more are going on holiday

Holidays for young spina bifida members of the Association, both on their own or with groups are becoming increasingly popular.

Mr Macfarlane, ASBAH's Liaison Officer told Link that this year he has helped to find suitable holidays for more young people than ever.

ASBAH has been able to fix up several children at the Children's Convalescent Home at West Kirkby in the Wirral where they should enjoy a very good holiday, as well as at the British Red Cross Challenge House in Nottingham and with Break Holidays in Norfolk. Quite large parties of children are going to holidays at Andover, Upper Woolhampton, Stonyhurst; to the Woodlark Camp Site in Hampshire and to Kent with the Young Disabled on Holiday organisation.

'The most thrilling of all, perhaps, is that two schools are taking parties—and ASBAH is helping with the cost—to the new Church Farm Field Studies Centre in Cornwall, and a spina bifida girl is also going there to join another group' said Mr Macfarlane. 'It will be interesting to see how they enjoy themselves'.

Other holidays have also been arranged with ASBAH helping both practically and sometimes financially too, and the first young members will also be going to ASBAH's own holiday centre—Five Oaks, the short term care home which will take children in August.

There is news that at least two older members are off on PHAB courses—Jean Slater (Trafford Association) is going to the USA and Carole Armour (Sussex) is bound for France.

Link wishes them all—and indeed all its readers—a very happy holiday.

## Special doll

Spina Bifida Associates of Southern California have come up with the idea of trying to produce a doll with calipers! They feel that the doll would help the self image of spina bifida children and serve as a teaching aid.

## Jacqueline helps out

In determined mood—eight year-old Jacqueline Turnley of Chipperfield, Herts—taking part in her own sponsored walk up and down the school gym, to raise money for the British team at the Montreal Olympics.

Jacqueline is a pupil at Sarratt Junior Mixed Infants' School and she and her parents are members of the Herts and South Beds Association.

Her mother tells us: 'Jacqueline loves school and the other children are marvellous with her and accepted her from the beginning.

'She was determined to go to our village school to be with her brother Paul who is nine years old. It was that which spurred her on to walk with full length calipers at 4½ years so that she could attend school. She has gradually come down through different length calipers since then'.

**Photo: Watford Observer.**

# News from all around

## The long wait for calipers

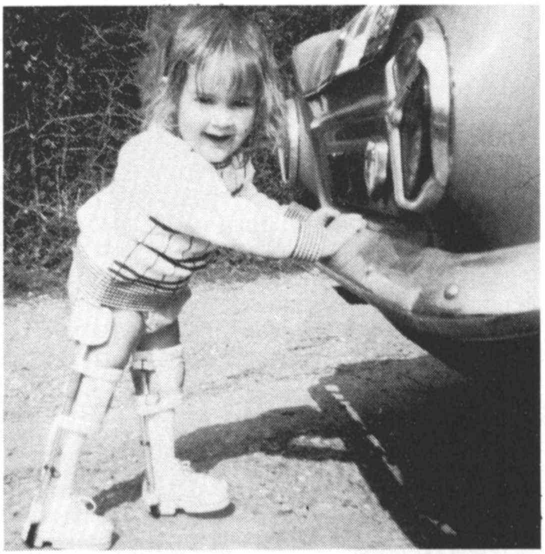
A little girl (right) in Kent, Catrina, happily trying out her new calipers. It's a photograph for which Catrina and her parents waited a long, long, time.

Her mother told 'Link': 'When we first asked the hospital about calipers we were told they like to get them fitted at normal walking age. Having two older children we thought this would be about 12-18 months. Catrina is now 3 years 9 months and has at last got her calipers.

'Various excuses were given when we asked about them, but eventually we discovered it was a matter of national economics. Appliance makers' wages were so low that no new recruits could be found—no fault of our own hospital, but a nation-wide problem . . . .

'The photograph doesn't really do Catrina justice. She has a personality I could not put into words, and after waiting so long for her calipers, she shows great promise. It's a struggle to get her out of them'.

**ASBAH has been working hard in taking up the case of caliper delay with the Department of Health, but can do little more without your help. IT MUST HAVE UP-TO-DATE EVIDENCE. If you have had troubles of this kind please do get in touch with the General Secretary, Miss Mary Oughtred. Every case will be dealt with in confidence and your child's name will not be used without your consent.**



## School raises £200

Pupils from Lindsey Comprehensive School in Cleethorpes proved themselves real friends of the Local Association last year, raising over £200 from various events.

Mrs Wyn Steele, Chairman of the N. East Lincolnshire and S. Humberside Association writes: 'One of the highlights of their fund-raising was a marathon table tennis match by four of the boys. The game lasted for 24 hours *after* they had completed a full day at school!

Messing about on the river . . . children of Stockport Association have had a great deal of pleasure from this dinghy which was presented to them by the Social Club at Robert Macard & Co.
Photo: Stockport Advertiser.

# News from all around

Mr Duncan Forrest opening the door of Surrey Association's new mobile home (see story below).

## Five Oaks opens

After many, many months of fund-raising, organisation, planning, redecoration the long awaited moment has arrived—the opening of ASBAH's short-term care home Five Oaks at Ilkley in Yorkshire.

Five Oaks—wearing its new paint, new furnishings, and recently adapted throughout—opens this month (July) and will start taking children in August.

Miss Gillian Harrison has been appointed Warden. She holds a Home Office Certificate in Residential Child Care and has many years experience of work with children.

The fee for Five Oaks is £50 a week, and it is hoped that local authorities will contribute at least a major part. No-one should hold back from applying through fear of the fee.

Children of any age up to 18 are welcome.

Bookings and enquiries should be made to the National Office, and a form of application will be sent to you.

Link hopes to carry a fuller article, and photographs of Five Oaks in the next issue.

## HMS Arrow promises help

**Sunderland and District Local Association has been 'adopted' by the company of HMS Arrow which has just been built on the Clyde and is being commissioned this month (July). The ship's company will raise money for the Local Association and take an interest in other ways. As a start parents and children have been invited to go aboard the day after the ship has been commissioned.**

## Surrey's mobile home is result of 10 years' hard work

Sunday June 13 marked the culmination of ten years' hard fund-raising by Surrey Association (NASBAH) when their new £3,800 spacious mobile home was opened.

It is situated on the Whitehorse Caravan Park Selsey, Sussex—next to Sussex Association's mobile home—and members and friends had gathered there to see Mr. Duncan Forrest perform the official opening.

Tribute was paid to the fund-raising committee and to the numerous members and friends who raised money, in particular the Lions Club and Rotary.

It is a magnificent van—an adapted and enlarged version of the Charlie Chester Mobile Home—and will sleep seven, plus baby. It has been sensibly adapted and fitted out so that it is admirably suited not only for a family but also for any older spina bifidas who may like to 'get away from it all' on their own. They should have no trouble in being fully independent in the home.

## OCCUPATION AND EMPLOYMENT

# How we can help youngsters get the best out of life

**by Peter Johnston-Smith, Education and Training Officer, who wrote this article shortly before leaving ASBAH to return to teaching.**

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**It is relatively easy to produce facts and figures about the numbers of young people with spina bifida and hydrocephalus who are in open or sheltered employment, who attend day centres for the handicapped, who are unemployed or unoccupied. It is more difficult to interpret these facts in a meaningful way.**

Out of a group of just over 80 young people born with spina bifida between 1953 and 1958 I discovered that 17 were in open employment, 9 in secretarial or clerical jobs, 5 in factories, 1 in a travel agency, 1 working as a storeman, 1 in management training; 2 were with Remploy; 14 were in full-time further education or training (10 in special colleges, 4 in local colleges of further education); 5 were in residential occupation centres; 16 attended day occupation or work centres regularly five days a week; 8 attended day centres for three or less days a week; 4 were permanently at home or in hospital because of illness or ill-health; 18 were at home without occupation or employment, though some of these were waiting for a vacancy promised at one of the training colleges.

Which of these were adequately catered for? The short answer is, all those in open employment, in Remploy, in residential centres and the majority who attend day occupation or work centres.

**But such an answer requires careful qualification; for example, some of those in open employment might have been in more satisfying employment if they had received more imaginative and realistic advice and support at school or later. On the other hand, are some of those who are at home, as seems likely, satisfied because this is deep down what they and their families accept as best and what they want? Have many of these young people more potential than their home-bound position suggests: should their families perhaps have given them more encouragement to explore and use some of the facilities which exist?**

Whilst general unemployment among all school leavers has a very directly adverse effect on the prospects for handicapped young people, it does seem to me that good motivation and determination has a great bearing on finding and keeping a job, or sheltered placement. There is, therefore, a great need for parents and teachers to inculcate a sense of purpose in young people from the earliest days.

I also believe, however, that some of those seeking open or sheltered employment may not be being realistic, as day centre places with stimulating leisure-time activities may be more suitable. There is scope for more specialisation to meet the needs of the young handicapped in day centres, where programmes should include the encouragement of independence and an element of further education. From these beginnings progress to greater things may follow.

Here Local Associations, preferably working with other voluntary organisations and with Local Authorities, can do a great deal by making known the needs and potential of their spina bifida and hydrocephalic members.

There is a need to pool experience to get the best help for the individual. Social Workers, Careers Officers and Disablement Resettlement Officers may not have much knowledge of the medical aspects of spina bifida and hydrocephalus, and doctors and physiotherapists who know children are not equipped to give advice about training, employment or occupational placement, so sharing knowledge is vital.

We can all help for example by telling as many as possible of those concerned with jobs — both management and unions — the kind of assistance and understanding they can give.

This liaison work is something for which all Local Associations should plan, if adequate support and advice are to be given to our young people to enable them to live purposefully.

ASBAH

1966-1976

# WE'VE ARRIVED AN

**In May 1966 the first faltering steps were taken by a small group of people to set up a national organisation to look after the interests of those with spina bifida and hydrocephalus.**

Ten years later, no less than 1,200 people representing the Association in all parts of the country, gathered together under one roof to celebrate the first decade of ASBAH, and to prove once and for all that it was firmly established. From little acorns . . .

Some of the founder members were there—Professor R. B. Zachary, Mr Duncan Forrest, Dr John Lorber, Mr T. L. Williams, Mr Stephen Hinchliffe, Mr Ted Bartlett, and Mr M. A. Baldwin.

The Tenth Anniversary Celebration, was held at Stoke Mandeville Sports Stadium and among the special guests was the man largely responsible for the building of the stadium, Sir Ludwig Guttmann. People came from north, south, east and west—parents, children, young adult spina bifidas, professional workers, and some guests.

The Association's Patron, HRH the Duchess of Gloucester attended by her Lady-in-Waiting, Mrs Michael Wigley, arrived in a scarlet helicopter which landed on the adjacent sports field. They were met by Sir Ralph Verney, deputising for the Lord Lieutenant for Buckinghamshire who was ill. He presented one of ASBAH's Vice-Presidents, Baroness Masham, Countess of Swinton; the Chairman, Prof. R. B. Zachary, and Mrs Zachary; and the General Secretary Miss M. E. Oughtred.

### DEBBIE'S DAY

Young Debbie Stenton from Pontefract, celebrating her own tenth birthday that day—had the honour of presenting the Duchess with a posy of lily of the valley and white roses.

Inside the stadium local dignitaries and the Chairman of each of the National Committees were presented to Her Royal Highness and then to a fanfare by trumpeters from RAF Halton the Duchess and her party took their places on the platform in the vast stadium hall.

Just to prove it really was a family day 26 young and very inventive competitors in the Fancy Dress Competition paraded in their colourful costumes.

The ceremony was opened by the charming Lady Masham who in her own incomparable way extended a warm welcome to everyone and wished them a very happy day.

### SPECIAL GREETINGS

It was good to know that many of ASBAH's friends were thinking of the Association on its tenth birthday, and the General Secretary, Miss Oughtred gave the greetings from a number of celebrities—Harry Secombe, Dora Bryan, Larry Grayson, Arthur Lowe, Jimmy Saville and the 'Magpie' team. Congratulations had also come from the Scottish Spina Bifida Association, and Miss Oughtred read a special letter of greeting from the Spina Bifida Association of America which spoke of ASBAH's role as the pioneer and paid tribute

**One young visitor enjoys a pony ride at**

# ID TO PROVE IT WE'RE HERE

t the 10th Anniversary Celebration

to its guidance and encouragement to other countries.

No national gathering of ASBAH could be complete without its Chairman, Professor Zachary, and the guests had the opportunity of a few words from the Professor who has been such an inspiration to the Association since its formation.

The highlight of the opening ceremony was the address by the Duchess of Gloucester who has proved herself a real and concerned friend in her three years as Patron.

The Duchess then performed the task of cutting ASBAH's Tenth Birthday cake.

## BIRTHDAY GIFT

Afterwards she presented the fancy dress prizes, taking time to have a few words with the winners.

Then came a very special surprise for Debbie Stenton, who was born on May 15, 1966, and so shared ASBAH's birthday. The Duchess, hearing of this had taken the trouble to bring a birthday gift which she presented to Debbie, and the pipers from RAF Halton played 'Happy Birthday to You'. Four other children from Local Associations whose tenth birthdays were in May—Jayne Dawson, David Bowcher, Jane Bryne and Stephen Williams, were presented with gift vouchers.

It was time for the afternoon's activities to begin and the Duchess and Lady Masham had the opportunity of mixing and talking informally with a great many parents, children and other guests.

There was a demonstration of wheelchair dancing by pupils from Coney Hill School, Hayes, Kent, and ever-popular Scottish Dancing by the Stoke Mandeville Highlanders. During the afternoon youngsters were able to have a go at a number of sports including table tennis when they met some of the Great Britain table tennis team for the physically disabled.

## SPORTS SHOW

There was a chance, too, to see just what makes Olympic swimmers when Great Britain's swimming team for the Toronto Olympiad for the Physically Disabled, 1976, gave a demonstration in the beautiful stadium swimming pool. Great Britain's archery team showed their skill on the sports field, in between squalls of rain, and indoors on the bowling green there was a demonstration of the art of bowls from a wheelchair.

The weather did not make life easy for members of Riding for the Disabled, or the Thames Valley police, but nevertheless displays of riding, and police dog handling did take place and proved popular.

Other attractions included the showing of the film about the 1974 World Games, a Punch and Judy Show, miniature railway and pony rides, and younger children were able to enjoy the Opportunity Playgroup.

After tea, the RAF Halton Apprentice Pipe Band Beat Retreat and the Duchess and her party departed by helicopter leaving behind guests who will long remember the happy day at Stoke Mandeville which marked the 10th birthday of the Association.

**Continued on page 10.**

ASBAH

1966-1976

# Now it's something people talk about

**Of the many interesting things that were said of ASBAH at the Tenth Birthday Celebration, perhaps the most unexpected was the reference to spina bifida as 'fashionable'.**

It does seem a strange way of describing a physical handicap, but as ASBAH's Patron, the Duchess of Gloucester pointed out, it indicates that ASBAH has been successful in getting its message and name across to the public.

In her address the Duchess said a friend had described spina bifida as 'the fashionable disease'. The Duchess commented: 'It is not patients or doctors who make a disease fashionable, it is the pressure groups, fund-raisers and a large number of other people who have joined together. **'This Association, in its brief ten years, has by tremendous hard work made spina bifida and hydrocephalus well known, as something to be talked about. There is a goal to achieve and the best way of achieving it is to involve as many people as possible willing to give help and support.'**

The Duchess said she felt the Association had been particularly successful in three different fields— in publicising its needs, in providing help and relief for members and their families, and in financing research programmes.

The Duchess concluded: 'I am proud to be connected with ASBAH and I wish you all strength and courage to face the years ahead both as individuals and as an Association.'

ASBAH Vice-President, Lady Masham who is well known as a champion of the disabled spoke in broader terms of the need for better facilities for all physically handicapped people in this country.

'The 1970 Chronically Sick and Disabled Persons Act still lies untouched on the desks of some local authorities'.

She felt that the responsibility for seeing that changes were made, lay fairly and squarely on the shoulders of everyone interested in the welfare of the disabled.)

In his address, Professor Zachary said he was sure that not many of the people who met in Sheffield ten years ago and had been responsible for the founding of ASBAH would have thought that the 10th birthday celebration would be attended by so many.

He was full of praise for the work of the local associations as well as the national body, and he spoke of the importance of cooperation between the two. The main aims of the future were largely the same, namely, to identify the needs and then to decide how best they could be met through the combined efforts of national and local people.

He felt that the main challenge ahead was fully to prepare spina bifida and hydrocephalic youngsters for an independent life in the community.

It was a time for new initiative, and he hoped that in the second decade there would be the same sense of purpose and originality of ideas as there had been in the first.

**Debbie Stenton opens her present from the Duchess. Photo: Bucks Herald.**

# Thirteen to thirty

## Conference report

*In the last Link it was reported that ASBAH's Spring Conference this year on the theme 'Thirteen to thirty' attracted a record attendance. More than 170 people took part in the conference which was held at Culham College, Abingdon. Here Link reports in more detail . . . .*

**From being someone who knew nothing whatever about the disabled, Mr. Neil Marten, MP for Banbury, has become one of the leading parliamentarians with the interests of the disabled at heart.**

His address opened the Conference on a happy note because it indicated the concern within Parliament for the disabled.

Mr. Marten shared in the task of setting up the All Party Parliamentary Committee on Disability which was originally concerned with the problems of the disabled motorist but has now widened its scope. He emphasised the all-party make-up of the committee which was important because the problems of the disabled must never become a matter of Party politics. The Committee meets weekly, keeping in contact with the disabled and their problems. Questions are asked in the House, Ministers are pursued, debates initiated and eventually appropriate action may follow. The Committee for instance had played a vital part in bringing about the investigation into delays in the supply of calipers.

In defending integration Mr. Marten said it should not mean treating the handicapped like everyone else. 'We must recognise and acknowledge the differences and discriminate positively **in favour** of the handicapped so they have a head start'.

He felt that the disabled should increasingly get on to local committees and 'get into the fight yourselves.'

During question time Mr. Marten said that members of the Committee were urging the Department of Employment to look into ways of getting firms to employ the three per cent quota. One idea was a cash subsidy for the employer.

Mr. Marten gave a personal view that the Queen's Award to industry should not go to any organisation that does not honour the quota system.

He also said that there were likely to be questions about the disabled members of a household in the next general census—a valuable move in determining the nature and extent of the disabled community.

*Parents and young people from all over the country, and professionals of many different kinds met together at the Conference,—people who all too often find it difficult properly to communicate with each other. Over breakfast, in the bar, while queueing for meals—in these informal surroundings the 'them' and 'us' barriers start to crumble.*

*The 'fringe benefits' of a conference are very important—meeting new people, renewing friendships, sharing experiences—but to many the main interest centres round the speakers. And at ASBAH's fifth Conference this year the speakers, like the participants, were well mixed and had something to say that was worth hearing . . . .*

**Mr. M. P. Burnham**—Adviser for Special Education in Oxfordshire—and **Mr. A. Williams** who is a parent and member of Stockport Association, spoke on the 'Preparation for Life', and in particular the contribution that could be made by school, and home.

Both stressed the importance of the individual. Mr. Burnham felt strongly that every child must be given the freedom and the facilities to enjoy an individual education, whether at a special or ordinary school (or a combination of the two) which suited his own

**continued on page 12.**

particular attainment level and physical condition. Mr. Williams experiences with his spina bifida son showed the individual attention and special consideration that he had needed from his parents and schools to enable him to get a good education and one suited to his needs.

Their talks emphasised the desirability of having a good and flexible choice of educational establishments to suit all handicapped children, so that no-one was condemned to work below their true potential.

The Careers Service is increasingly playing a significant role in helping young handicapped school leavers to decide what to do after school, and the speaker on the subject 'Follow on from School' was **Mr. J. R. Wood**, one of three specialist careers officers in Hampshire concerned with the handicapped.

Mr. Wood said that too many youngsters faced a confusion of well-meaning advice on what career they should follow—from parents, doctors, teachers, social workers etc. The Careers Service could play an important role as a liaison body, reflecting and simplifying these views for the young person. Mr. Wood and the next speaker—**Mr. C. J. Hartley** of Banstead Place Assessment Centre run by the Queen Elizabeth Foundation in Surrey—brought out the importance of letting the young person play the leading role in assessing himself and making decisions for the future. Mr. Hartley explained that Banstead Place coped with young people whose next step was in doubt and who, because of physical and emotional handicaps, had not been able to come to a decision and see the future clearly.

Both he and Mr. Wood felt the need for another reappraisal or reassessment at about age 23.

After the speakers on schooling and assessment, it was a natural step to turn to the question of employment. If all employers were like those at Rosalind Foods, Great Yarmouth, then it would seem there would be few problems for the handicapped.

**Peter Lowman**, Production Manager of Rosalind Foods impressed the conference with his description of the way in which his firm put themselves out to employ someone with a handicap, where they felt that person had something to contribute. Mr. Lowman said that once established in the company the handicapped person knew that he or she was not 'a passenger' and that work performance counted.

Rosalind Foods' experience shows what can be achieved in terms of employment where the management cares. In return the handicapped with the right training and back-up, can be as efficient and valuable employees as everyone else and can enjoy the social life of the company, too.

Speaking under the same heading as Mr. Lowman—'Working and Living'—was **Mr. Ronald Travers**, the dynamic Head of Counselling for the Cheshire Homes. He looked at the various residential care situations which were available. The present and future needs, he said, seem to be for more accommodation for married couples and also small units. He felt that domicillary care should be expanded, whereby a handicapped person lived at home but with a 'home help' coming in daily. This person need not be highly trained, but trained as 'a relative substitute' to help to run the home at the pace and in the way best suited to that family. He felt the scheme could do much to 'improve the quality of life' for the handicapped and their families.

*Relationships—our basic human need to mix with others and the way in which we relate to those around us—was the subject of the talk by Mr. W. R. F. Stewart, the much respected Director of SPOD (Sexual Problems of the Disabled).*

*Mr. Stewart held the attention of the conference and gave so much insight into out human behaviour that Link will be carrying most of his talk in the next issue to give all readers a chance of benefiting from his experience and views on this important topic.*

# Thirteen to thirty

For many people the highlight of the weekend at Culham was Saturday night when four older spina bifida members of the Association gave vivid accounts of their own lives and experiences.

Alan and Margaret Twyford—who were featured in the last Link— were the subject of a bright, original and heartening film 'Uphill Start' made by a friend. It was shot during a hot summer weekend last year at Tolworth where they live, and showed their everyday life ogether.

Faith Seward's talk which followed was unforgettable. Faith, who is now headmistress of 300 infants' at a primary school in York has a vibrant personality and a ready sense of humour. These and her determination to prove herself and to succeed in life helped her to overcome her handicap as well as the trauma of losing her mother when she was only 11

'I had to prove I was not just as good as everyone else, but better' she said. In so many walks of life she has proved this—by becoming headmistress of the largest infants school in York, by becoming an Advanced Motorist, and by gaining a BA in Education through the Open University, among other things!

It was a difficult task for anyone to follow such a speaker as Faith Seward. But Brian Worrall certainly managed it with great success. Brian, who is in his thirties, is now Design Engineer at a sheltered workshop in Wolverhampton.

He got there through his own efforts, spurred on, he acknowledges, by the support of his parents and bolstered by his sense of humour and optimistic outlook.

Brian, Faith, Alan and Margaret are all success stories, and are not as severely handicapped as many others who might not be able to achieve the independence and the level of attainment of these four. However, their determination, experience and sense of humour may inspire other youngsters to face the world with a little more confidence and will to succeed, so that they may, too, reach their own goals.

# Conference report

**Dr. Esther E. Simpson, Principal Senior Medical Officer at the Department of Health and Social Security chaired the Conference throughout and drew together the thinking of the Conference in a masterly closing address, under the headings of Communication, Individuality, Personality, Parents, Attitudes and Government.**

## Communication

Mr. Marten, who opened the Conference, had shown himself to be a superb communicator, she said—a man of ideas who tests these out and then takes action. He saw that integration can be an empty idea and that discrimination **in favour** of those needing extra help is more realistic. It is acceptable in the family and necessary in employment, where allowance has to be made for those with physical problems. These allowances are based on communication—explaining disability and taking steps to ensure understanding where this is needed.

**Communication is vital to doctor-patient relationships. Dr. Simpson felt that doctors should seek to answer the unasked question; they should have this insight. Yet the training of doctors concentrates on treating and curing so that chronic conditions may be seen as a threat. To fill this gap doctors need to harness other sources of advice and help so that counselling may be available.**

Mr. Williams and Mr. Wood had both emphasised the need for continuity and co-ordination and Dr. Simpson hoped the Court Committee on Child Health Services will give a clear lead about this, when it reports.

## Individuality

Each of us is unique and our needs must be individually assessed and plans made accordingly and as Mr. Burnham had stressed, a firmly based plan made at an early age. Characteristics will change with the years and adjustments will be necessary. The voice of the young person himself must be heard in later stages.

Continued on page 14.

# Thirteen to thirty

**Personality**

Inseparable from the involvement of the individual is personality. The positive discrimination in favour of the disabled may well be supplied by the individual him—or herself. The quartet who had shared their experiences superbly and with such humour and personal insight on Saturday evening had shown this philosophy so clearly. But can we increase self-confidence? Can we change personality?

**Parents**

Mr. Stewart had emphasised, and the Saturday quartet had underlined the immense influence of the family on the whole of life. The need for continuing support to parents who have to face the trauma of having a congenitally disabled child cannot be over-emphasised. Help is needed to secure a balance between support (not over-protection) and the fostering of independence, and some achieve it better than others. Some young people refuse to be unduly protected; in others, the will to persevere may be easily eroded.

**Attitudes**

Ronald Travers had referred to the increasing awareness of the implications of disability, but such awareness must be matched by an allocation of resources.

Never must the needs of those not represented at the Conference, that is, those without family support, be overlooked said Dr. Simpson. They need someone to speak for them and to see that they, too, have a share in resources. The young may need a greater share of what is available at the expense of other age groups. Long-term care may call for a diversion of resources from dramatic, curative medicine. These questions need thought and attitudes need to be constantly considered, to get the balance right.

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**During the conference plenty of time was given for discussion. Link was there and sat in on many of the discussion groups, where it was clear that most people were taking full opportunity of these periods to exchange their view and share experiences.**

**Miss Felicity Birkett who was for three years ASBAH's very able and popular Appliance Officer has left the Association and is now following her career as a psyiotherapist in Hong Kong. Her regular column in Link has been very useful to so many, and Link will continue to carry news about aids and appliances.**

**A successor has not yet been appointed—this is, of course, at the time of writing—but National Office is continuing to answer queries and give advice about equipment and aids.**

## Aids and equipment

### Rotating seat helps you in and out of the car

**One very real problem experienced by those with any degree of paralysis in the legs is getting in and out of a car easily.**

Now a small firm in Accrington, Lancashire, has come up with something to make this everyday activity much easier—a rotating car seat.

The ingenious pivot device allows the seat to swing around and out beyond the doorway where it is readily accessible for sitting on. A touch on the release lever and the seat can be swung easily into the normal position, making it unnecessary to twist the body to get your legs into the car.

If you have a two-door car you can still get to the rear seats by swinging the rotating seat to its mid position. Tipping the seat forward is unnecessary.

The Elap Rotating Car Seat comes complete and costs about £70-80 depending on the mak of your car. Alternatively, conversion kits are available for over 40 different makes of car and cost about £30-£45. Fitting can be carried out by anyone who is competent at 'do-it-yourself' or by a local garage.

The firm which makes the seat—Elap Engineering—is now supplying them to the Department of Health and to many social service departments. If you want more details write to: Mr. E. Lord, Elap Engineering, 23 Lynwood Road, Huncoat, Accrington, Lancs. Tel: Accrington 36042.

# ASBAH booklets . . . leaflets . . . posters

| | |
|---|---|
| *Your Child with Spina Bifida,* 3rd Ed., by J. Lorber, MD, FRCP | 20p |
| *Your Child with Hydrocephalus* by J. lorber, MD, FRCP | 15p |
| *The Nursery Years,* by S. Haskell, M.A., Ph.D., and M. E. Paull, Dip. Ph.H. | 15p |
| *Children with Spina Bifida at School.* Ed. P. Henderson CB, MD, DPH | 30p |
| *The Care of an Ileal Conduit and Urinary Appliances* | 15p |
| *Clothing for the Spina Bifida Child* by Barbara Webster, SRN, RSCN | 15p |
| *Equipment & Aids to Mobility* by O. R. Nettles, MCSP, ONC. | 25p |
| Information leaflets | 100 for £1.30 |

All available from ASBAH, 30 Devonshire Street, London W1N 2EB. (Special rates available to Local Associations.)

**Scottish Spina Bifida Association booklets**

*The Spina Bifida Baby* . . being revised.
*Growing Up with Spina Bifida* . . 20p. both by O. R. Nettles, MCSP, ONC.

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

## Fund raising and publicity material

**Posters**

| | | |
|---|---|---|
| Best Foot Forward | 20 x 30in. | — 10p each. |
| Best Foot Forward | 15 x 10in. | — 10 for 40p. |
| For local publicity | 15 x 10in. | — 10 for 40p. |

**Car Stickers** 5p each.
**Cards for Notice Boards** 10 for 10p.
**Flag Day Emblems** 1,000 for 70p.
**Plastic Lapel Badges** £2.10 for 100.

**All available from Appeals Dept.** — postage extra. Full list on request.

**Spina bifida badges.** 25p each, postage extra. (for one badge enclose s.a.e.). Bulk orders particularly welcome. Available from: Mr K. McKenzie, Salisbury & District ASBAH, 111 East Gomeldon Rd, Gomeldon, Salisbury SP4 6LZ.

# Films about spina bifida and hydrocephalus

**What is Spina Bifida?** Black/white. 16mm. 25 mins.
**A New Lease of Life.** Colour. 8mm. 25 mins.
**Like Ordinary Children.** Colour. 16mm. 30 mins.
**Growing Together.** Colour. 16mm. 40 mins.

All may be hired from Concord Films Council, Nacton, Ipswich, Suffolk.

The Mansfield Association film "**What shall we do tomorrow?**" Colour, 16mm. 22 mins, may be hired direct from Mrs Freeman (see p.16).

# Holiday accommodation for spina bifida families

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

**Christchurch**, Dorset, Hoburn Farm. 6/8-berth caravan, 1 mile from sea, near New Forest. Further details: G. R. Large, 89 Duchess Way, Queensfield, Swindon.

**Easington**, Withernsea. 7-berth caravan on [illegible]l-equipped site by sandy beach. Details: Mr A. Clark, 3 Leys Close, Carleton, Skipton, N.Yorks, BD23 3EW.

**Golden Sands**, Voryd, Rhyl, N. Wales. 8-berth caravan, mains water, electricity, gas, shower and T.V. Every facility on site, right by the sea. Enquiries to Mr. Adams, 58 Strathedan Road, Bradeley, Stoke-on-Trent.

**Great Yarmouth**. Caister Beach Caravan Camp — 6-Berth caravan. Details: Mrs E. N. Barefoot, 23 Marlborough Road, Southall, Middx. Tel. 01-574 5067.

**Haggerston Castle** (5 miles south of Berwick-on-Tweed): 8 berth caravan. Details: Mrs Connolly, 103 Raby Rd, Oxclose, Washington, Tyne Wear.

**Looe.** Millendreath Holiday Village. Two bungalows. Details: Mr Keith Jackson, 202 Exeter Street, Plymouth, and Mrs Cook, 19 Winslade Road, Harestock, Winchester.

**Mablethorpe.** Two well-equipped self-contained chalets, 6-berth, at Golden Sands Estates. Details: Mr K. Hall, 17 Walhouse St, Cannock, Staffs.

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

**Prestatyn:** The two caravans usually advertised are fully booked for this year.

**Selsey:** New well-appointed, self-contained 16ft. x 30ft. six-berth mobile home. For details send s.a.e. to Mr R. V. Taylor, 3 Dickins Way, Horsham, Sx, RH13 6BQ.

**Winterton-on-Sea, nr. Great Yarmouth** — new well-equipped 6-berth chalet. Indoor swimming pool, shop, and play areas. Details: Mr R. Morris, 127, The Pastures, Downley, High Wycombe, Bucks. Tel: H. Wycombe 32184.

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

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Printed by David Green (Printers) Ltd, Kettering, Northamptonshire