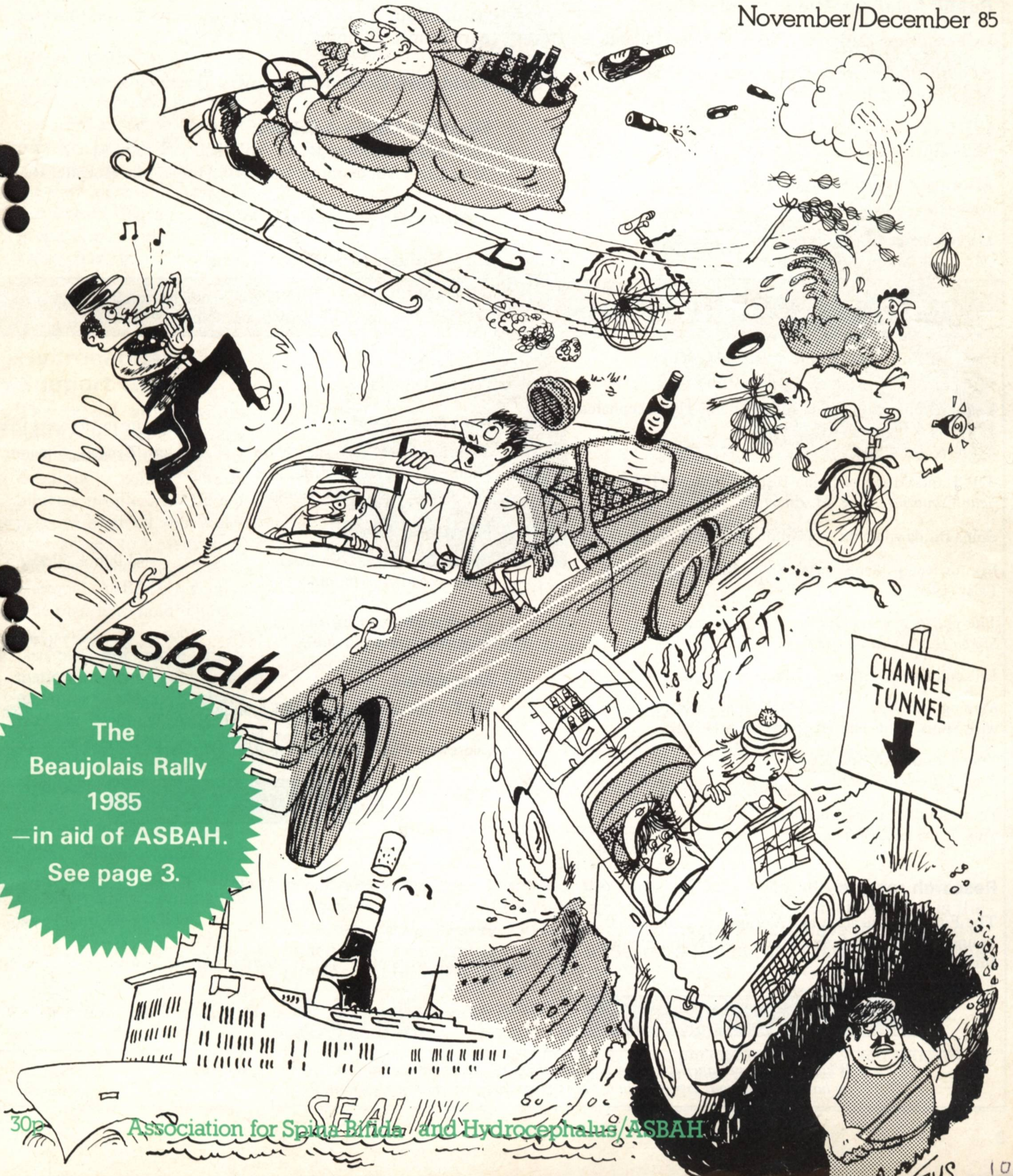
Link

November/December 85



The Beaujolais Rally 1985 —in aid of ASBAH. See page 3.

30p Association for Spina Bifida and Hydrocephalus/ASBAH

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Association for Spina Bifida and Hydrocephalus (ASBAH)

22 Upper Woburn Place, London WC1H 0EP

Registered Charity No. 249338 **TEL: 01-388 1382/5**

Patron: HRH The Duchess of Gloucester
Chairman: Mr D. M. Bryant **Hon Treasurer:** Mr A. K. Stewart-Roberts

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

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Administrator: Mr Paul Dobson, *BA (Hons)*

Link Editor: Mrs Susan Gearing

ASBAH Publications

All available from National Office.
Cheques payable to 'ASBAH'

Children with Spina Bifida at School (1985) *Ed. P. Henderson*	95p
Young People with Spina Bifida and/or Hydrocephalus — Learning & Development (1985) *Leonie Holgate*	£1.60p
The Handwriting of Spina Bifida Children (1979) *Joan Cambridge, Eliz. M. Anderson*	£1.60p
Spina Bifida and You — a Guide for Young People (1985)	£3.50p
Sex for Young People with Spina Bifida or Cerebral Palsy (1984)	£1.75p
The Nursery Years (1983) *Simon Haskell, Margaret Paull*	60p
Life and Death — thoughts on bereavement (1983)	75p
Making our Way — individual experiences of young people with Spina Bifida and Hydrocephalus (1984)	£1.20p
Your Child with Spina Bifida *Prof. J. Lorber (1981)*	60p
Your Child with Hydrocephalus *Prof. J. Lorber (1981)*	60p

Research reports

The Further Education and Vocational Training of Young People with Spina Bifida and Hydrocephalus *Hazel Benner (1984)*	£3.00pp

All prices include post and packing.

Leaflets

Lives in Question	30p

Fact Sheets

Fact Sheets	up to 10 copies free

Translations of fact sheets are available into Bengali, Gujarati, Hindu, Punjabi and Urdu, and into Welsh.
Please send at least 30p postage.

Films and Slides

Appeal for ASBAH (for hire) *16mm colour film (8 mins)*	£4.00p + 60p VAT
Living with Spina Bifida *Slide sets and notes (12 slides)*	£7.00 + 75p V[illegible]

Magazines

LIFT — for members of LIFT (young ASBAH)	Free
Causeway — *for contributors to ASBAH's work*	Free

LINK SUBSCRIPTION

UK	£3.30p
Europe and Overseas Surface Mail	£4.80p
Air Mail	£10.80p

For payments other than in sterling add the equivalent of an extra £3.

* *Except in the case of LINK all the above prices apply in the UK only. Overseas rates on request.*

Editor's Note

The late Autumn sunshine of October did little to dispel the shock and gloom of the surprise announcement by the Home Office that it was thinking of introducing regulations that would severely restrict the freedom of disabled people wanting to go to the cinema (see page 4). It seems to have been a very one-sided move on the part of the Home Office with little serious attempt to get the view of disabled people themselves. They are only proposals, as yet, so if you value your rights, please do make the effort to register your views.

The Hydrocephalus Support Group

The special group within ASBAH to cater for people with hydrocephalus only is definitely going ahead. Sixteen people in different parts of England and Wales have agreed to be 'contacts' and they met together at National ASBAH recently. The plan is to hold regional meetings as soon as possible. For more information contact the organiser, Mrs Barbara Hay, at National ASBAH. This is a good opportunity to point out that the Hydrocephalus Support Group is part of ASBAH and not a breakaway organisation which would only have the effect of splitting the effort and weakening the movement as a whole.

Sue Gearing, Editor

On the INSIDE

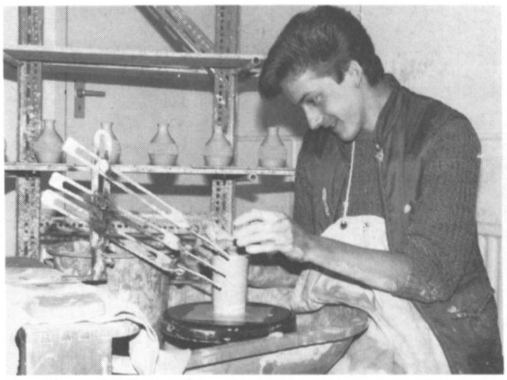
MAIN FEATURES

STARTERS

IN THE NEWS

Will this be a thing of the past?

LIFESTYLE



MONEY RAISING

PLUS

COVER PICTURE

Our thanks to Gus — formerly the famous Daily Mail cartoonist — for his imaginative portrayal of this year's Beaujolais Rally, from which ASBAH is the main benefitting charity. On November 20, over 100 cars leave the vineyard in Lacenas, France, carrying cargos of Beaujolais Nouveau. The aim is to find the shortest route to Margate.

Link is published by ASBAH (The Association for Spina Bifida and Hydrocephalus)

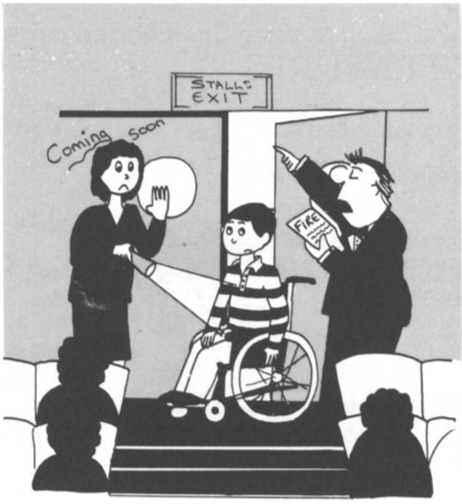
Contributions to LINK by way of letters, news, photographs, articles and opinions are warmly welcomed. The closing date for the next issue is December 5. Send to the Editor at National Office.

Proposals for cinema safety threaten the rights of the disabled

Film '85 might soon be the closest many people who use wheelchairs will get to the 'Big Screen' if the ridiculous proposals from the Home Office on the revision of the 'Cinematograph (Safety) Regulations 1955, are put into practice by Cinemas throughout the country.

They suggest that blind people and those in wheelchairs (unless they can walk to a seat) should always be accompanied by an able-bodied adult, groups of disabled people intending to go to the cinema, should seek the permission of the Chief Fire Officer, and that guides dogs ought not be allowed into the Auditorium. Haven't the people in the Home Office noticed that they are even allowed into the visitors gallery of the House of Commons?

The proposals according to the 'Access Committee for England', are confused, arbitrarily categorise people with disabilities into 'risks' and 'non risks', and concentrate too much on people in wheelchairs, forgetting or possibly ignoring the fact that other members of the public, who they are presumably trying to protect in the event of fire etc, may have invisible handicaps which could be equally awkward in a panic situation, such as a heart complaint, walking difficulties or even a nervous disposition.



A useful point that the Access Committee make in their response to the proposed revisions, is that means of escape in such places should not be seen in a purely physical sense but should also include a management system for assisted escape.

The Home Office proposals are not all negative, but the suggestions concerning accompaniment by an able-bodied adult could prove to be very restrictive.

It is also regrettable that only a handful of organisations concerned with disability were consulted regarding the revision. Of those that were, one has n[illegible] existed since the mid 1970's!

● These are as yet only proposals. You can register your complaints by writing as soon as possible to: *The Rt. Hon. Douglas Hird, Home Office, 50 Queen Gate, London SW1H 9AT; or contact me: Siobhan Rowe, Accommodation & Development Officer, ASBAH.*

"It's a hard struggle for families in the North"

LINK SPECIAL REPORT (Sept/Oct issue)

The LINK Special Report w[illegible] sent to the Director of Soci[illegible] Services for Cumbria inviting him to reply in this issue of LINK, as well, of course, as drawing his attention to the plight of the families.

Unfortunately his fairly lengthy reply was received on the very eve of going to press and so we are unable to reproduce it in this issue. We will do so in the January LINK.

Although the families mentioned in the Report have been visited by representatives of the social services since publication, it appears at present that their situation remains very much as described in LINK. We hope to be able to report some improvements next time.

Sue Gearing, Editor

Announcing two new ASBAH books . . .

Spina Bifida and You — a Guide for Young people

Written by Colette Welch; Edited — Sue Gearing; Design & Illustrations — Liz McQuiston

This thick (96 page) book is another in the Young ASBAH series and is full of illustrations, photos and easy-to-read text that will make it compelling and interesting reading for any young person with spina bifida/and or hydrocephalus from the age of about 12.

It tells young people all about spina bifida and hydrocephalus, the way in which their bodies work — the kind of information that parents may like to impart to their children but don't know themselves. For this reason parents will also find the book very useful.

There are sections on How the body works; Facts about spina bifida; The problems it can cause; Hydrocephalus; althy habits; Incontinence; and Going it Alone (independence).

ice: £3.50 (to include post and packing)

Young People with Spina Bifida and/or Hydrocephalus — Learning and Development

Written by Leonie Holgate

The hidden problems of young people with spina bifida and hydrocephalus have come to light in the last few years as a result of study, including that undertaken by Leonie Holgate as part of an ASBAH Research Project. This book has been written by Mrs Holgate following on her research, and looks at the development of young people and their problems in relation to training and gaining employment or meaningful leisure.

The young people looked at in the book are those who will not find paid employment even the sheltered type. But Mrs Holgate maintains in her book that it is possible for this group to lead interesting and fulfilled lives and to progress in their abilities.

Chapters look at the various problem areas; aids to learning and acquiring practical skills; problems with eyesight; and finishes with four case studies.

It will be useful to teachers and anyone concerned with this post 16 age group, including parents.

Price: £1.60p (to include post and packing). Both available from National Office (see p. 2).

Local Association Round-up

Northern Ireland

NORTHERN Ireland Association have given £5,000 to Parkenaur Training Centre for young disabled people for an 'Egar Suite' in memory of the former Honorary Treasurer of the N. Ireland Association, Mr Jim Egar, MBE who did so much to further the work in that part of the world. Mr Egar died last year. The money went towards refurbishing two bedrooms to accommodate two boys and two girls so that the centre could better cater for wheelchairs and severely disabled people. The bedrooms have shower rooms attached and are practically furnished to suit young people.

Sunderland

A PARTY of members went to Disneyland at the beginning of October — a holiday for which the association has been fundraising for a long time. Sunderland city's adopted warship, HMS Arrow has proved a good supporter of the local association, raising money in the West Indies, and recently from a 420 mile sponsored bath push from their base in Portland, Dorset to Sunderland.

St Helen's

TEENAGE members over 16 have started to be assessed for driving lessons, and so far the results have been encouraging. Four have passed their test — one only a week after his 16th birthday. Four more young people are taking lessons and two are awaiting assessment.

IN THE RECORD BOOKS. Meet a group who have now made it into the Alternative Book of Records. They are shown at the start of their sponsored wheelchair marathon (full marath[illegible] course) which they completed in a record 5 hours 3 minutes 40 seconds. The six young peopl[illegible] wheelchairs are members of Hull ASBAH, and they are being pushed by pupils of Kelvin [illegible]ll Senior High School, Hull — a school into which an increasing number of young people [illegible]h spina bifida are being integrated. The marathon took place round East Park in Hull and money was raised for the association funds.
Photo: Hull Daily Mail.

Marathon girl gets flying start

18-YEAR-OLD Sheila Gwatkins (right) of Lewisham, South London is determined to compete in next year's London Marathon.

Sheila, who has spina bifida and had both legs amputated when she was 12, needed a special lightweight sports wheelchair, costing £1,500, to give her any chance at all in the Marathon.

So she decided to raise the money for it herself with a sponsored swim at the local swimming pool. She rallied a host of friends to sponsor her, and the local paper carried her story inviting other people to back Sheila.

Local businessman, Peter Canham owner of a printing business in New Cross read about Sheila's bid for the chair, and reached for his cheque book.

He not only bought the chair for Sheila but said that his firm would give another £1,000 if she makes the finishing line in the marathon and another £500 if she is the first wheelchair entrant to cross it. Sheila is hoping to raise money to help other disabled youngsters through her Marathon attempt.

Sheila went ahead with her sponsored swim, and the money bought her a London Marathon tracksuit. She is now training for April. LINK will be routing for Sheila during the Marathon!

Local Association Round-up

Midland

A FEASIBILITY study on how to set up a sheltered workshop has been produced by this association drawing on its own experiences over the past two years in opening its own workshop, Court Enterprises. Copies are available from The Secretary, Midland ASBAH, 14 Court Road, Sparkhill, Birmingham 11. Tel: 021-771 0371.

Preston

CONGRATULATIONS to member, Andrew Hodge, aged 15 who is becoming an excellent competitor in wheelchair marathons and other races. He is so keen that he saved up and bought himself a new racing wheelchair costing £500. Recently he raised money from one of the marathons for his school in Ainsdale which needs sports equipment such as a snooker or table tennis table. Andrew won a gold medal and came first in the 1[illegible]00 metres at the National Games of the British Sports Association for the Disabled at Stoke Mandeville, earlier this year.

Sussex

ZEM RODAWAY, 21, of Haywards Heath in West Sussex has gained a B.Sc.Hons. Zem was at Southlands College, Wimbledon for three years taking Business Studies and Social Administration. Two photos of Zem were used in the very first ASBAH book about children with spina bifida at school, and she featured in LINK a year or two ago when she gained her Duke of Edinburgh Gold Award.

Beverley makes her way along the bar

SUSSEX association is becoming 'famous' for its activity weekends for its young adult members. One was held recently at Hindleap Warren in Surrey, and here's an article about it from Bev Harries, written shortly after she got back.

Activity course puts us to the test

THE GIST of it was that this was an activity weekend. We were at an activity centre and if we were to get the most out of it then, basically we should "go for it."

The first evening started reasonably quietly. We had a mini ASBAH meeting, and discussed our views on LINK and LIFT. It was considered fairly generally that LINK, although getting easier to read as we've got older, was still rather geared to families, especially parents, and LIFT covered a rather too wide an age range. There didn't seem to be much of a solution but I guess really the answer is with the readers who write in.

Another subject was fund-raising. It was thought that perhaps LIFT groups should find ways to raise money for their outings and such like, so that they didn't have to rely completely on ASBAH. So if anyone out there has any original ideas, make sure they are heard.

At 8.45 next morning the great events started. We were split into two groups. One started with archery and we began with rifle and pistol shooting. Later we swapped activities. I never actually hit the target in archery, but I was assured that I deserved points just for my style!

After lunch came the obstacle course. We all gathered together for this and set out for the forest. The first obstacle was a wooden bar we had to crawl across. I tell you, there were parts of my body that hurt then that I didn't know I could feel! Still that didn't last long.

Next it was crawling under four alleys of criss-cross ropes. This was followed by a 15ft climb up the scramble net. It was absolutely exhausting but worth every breath.

Then came the dreaded tunnel. That was certainly an experience. I could have carried on with the obstacles forever. The feeling of being blissfully shattered and the pure exhilaration and sense of achievement was absolutely incredible.

After tea we had another little discussion about what we thought of the idea of a little book to be carried by people with spina bifida and/or hydrocephalus giving details of their disability and dates and nature of operations. This was considered by the group to be an excellent idea.

At about 8.30 pm we started out on a night walk in the forest. The only light was a torch carried by one of the instructors who was also reading a map. When we finally found our way out, there was a barbeque waiting for us.

When everyone was full,

Continued over page

Local Association Round~up

Continued from page 7.

the boozers departed to the pub and the rest of us sweet things sat outside and sang old guide and scout songs (those were the days).

Sunday started with the painful morning call at 7 am. It was our group's turn to do the washing up that day!

The morning's activities began with climbing a 20 ft wall. The harnesses we had were amazing. I volunteered to go up first and I was sure that they took longer to strap me than anyone else.

When I asked why, they informed me that I had been the guinea pig. Comforting eh?

After the tea break the final activity was orienteering.

Lunch was followed by a last group chat and we all set off for home about 3.30.

The whole weekend was absolutely amazing. The instructors were brilliant and even though I tried some pretty tricky things I never once felt unsafe. It just showed that where there's a will there's a way

Just one word of warning though. If you work, take the Monday off. I didn't and I can tell you it was a killer.

LINK Back issues

We have a selection of back numbers of LINK from issue 1-100. If you would like any of them, please contact Beverley Holland and she will see if we have the particular issue you are looking for. Price 10p each plus 13p postage. (We will invoice you for bulk orders).

Sue Gearing, Editor

Hello Sarah

WE'VE found "Saucy Sarah" the little blonde girl whose photograph with the Duchess of Kent was in the last LINK.

Liz Karney, Sarah's mother, rang from their home in Flitwick, Beds. Sarah is 4, and has spina bifida and hydrocephalus, and her 6 year old sister Donna is disabled, too, so Liz is kept very busy.

Sarah goes to playschool, and to the Child Development Centre in Kempstow. She's an active and happy 4 year old who can walk with the aid of calipers.

Cheers!

WITH Christmas just round the corner you may like to find out about ASBAH's New Wine Club. A variety of fine wines at highly competitive prices is offered to members in cases of 12 bottles delivered to your door. Each order produces a small donation to ASBAH.

Contact ASBAH National Office for a leaflet and order form.

Congratulations . . .

. . . to 20 year old Sean Alder from Middlestone Moor near Darlington who has been taken on under the You[illegible] Training Scheme by Sed[illegible]field District Council in th[illegible]r clerical administrat[illegible] scheme. Sean, who has spina bifida and is in a wheelchair, left sixth form college in Darlington with 'A' levels and a determination to succeed that impressed the council officers.

‘ The way in which it treats its disabled people is the hallmark of society ’

THIRD CONFERENCE: INTERNATIONAL FEDERATION FOR HYDROCEPHALUS AND SPINA BIFIDA

Over 170 delegates from 17 countries travelled to Manchester at the end of September for the third conference of the International Federation for Hydrocephalus and Spina Bifida. It was the first time that the Conference had been held in Britain, and it was hosted by ASBAH.

The Conference, held at the University of Manchester Institute of Science and Technology, was opened by the Rt. Hon. Mrs Barbara Castle, Member of the European Parliament for Greater Manchester West. Over lunch she had time to get to know some of the delegates, many of whom were parents of children with spina bifida and/or hydrocephalus and involved with associations in their own countries. Also present were several young adults with spina bifida and hydrocephalus, and members of the medical professions, educationalists and social workers.

In her opening speech, Mrs Castle said: “It is marvellous that you have all come together to share knowledge, and determined to make all the countries from which you come conscious of your rights to help, understanding and support”. She said it was essential to enlist the support of the social services, and it was necesary for all countries to mobilise together to strengthen international opinion.

Mrs Castle said: “The way in which it treats its disabled people is the hallmark of society”.

She said the fight for the disabled had started, and “we must fight and push all the time so that the tide doesn’t turn back”.


Mrs Castle at the Conference

Mrs Castle spoke of progress in Britain over the past few years, and on the international front, she praised the work done during IYDP (1981). She commended the Report to the European Parliament stating that it was time that Europe started thinking about the human needs of the disabled. It was a wonderfully comprehensive Report, she said, and as a result a European Bureau was set up working for the benefit of the disabled.

“It is a recognition of the problem and of a right. But its funds are minute. So long as the agricultural policy takes all the money it will continue to be minute . . . but the marker has been put up. The Charter for the Disabled has been set up and distributed. We should keep believing in it”.

Personal Perspectives

A young woman with spina bifida from Australia, travelling in Europe on her own for four months, a Norwegian kinder garten teacher, a student, an office worker and a freelance radio journalist were some of the young adults with spina bifida who were at the Conference. They spoke about their lives and feelings.

SARA Leaney, 22 from Adelaide, having completed a degree course in psychology was in Europe on her own for four months. She spoke of the independence that her parents had always encouraged and for which she was very grateful. “They tried not to spoil me” she said. The rough and tumble of family life with brothers and sisters did much to keep her on an even keel.

She said she still attended a children’s hospital where the doctors tended to treat her as a child and thought that when she got home she would probably go to a young adult clinic at a local hospital.

Sara hopes to get a job as an adolescent councillor.

She said she thought that the conferences for young people organised by LIFT were a great idea and she would pass the idea on to the association back home.

KRISTIN Zeiner-Henriksen from Norway spoke about the problems she had experienced through not being obviously disabled with spina bifida. She has spina bifida occulta, and felt she was very much an ‘in betweener’ — between those who are normal and those who are physically handicapped. She said she had a lot of hidden emotional problems as a result.

“If I was pregnant and had prenatal screening which showed that I was carrying a spina bifida baby, I would have an abortion. When I say that to my Norwegian handicapped friends they scream at me and are offended

Continued over page

saying 'Do you mean we are not worth anything?'

"Of course they are worth a whole lot . . . I know inside that, being honest, it's such a tough thing being handicapped, that it's not the way I would want a child of mine to live".

CHRIS Hopkins, 21, Chairman of the LIFT Working Party spoke about how upset he felt when having gone through ordinary school he applied and was accepted at a college of further education only to find that when he got there he had been relegated to the Work Orientation Department specially for disabled students.

"I caused a real fuss and in the end, despite the apprehension of the staff, they let me into the main college."

By the time he leaves college he hopes to have an Ordinary National Diploma in Business Studies.

PAMELA Cox, 27, feels that looking back she might have done better if she had been able to go to an ordinary school. She went to a residential college in Nottingham and then took a typing and secretarial course locally near home.

Bob Talbott, and Miss Sara Leaney, from Australia, take their turn at the microphone to sing a traditional Australian song, during a 'pub sing-a-long' evening. In the background is Brendon Scully, who was the MC for the evening. See Page 9 for Sara's 'Personal perspective.'

"I would have liked to pursue this as a career. I had lots of interviews but got nowhere . . ." Then out of the blue the Disablement Resettlement Officer contacted her, and with the sponsorship of ASBAH through the Sheltered Placement Scheme she became Secretary to the catering officer at a boarding school, where she is still working.

KEVIN Towner, 23, was one of the personalities of the conference.

"I have done bits and pieces voluntarily. Some have been very depressing, and sometimes I wonder if I will ever get a full time job, and be able to support a family. I accept that I should expect to be slightly worse off as a disabled person."

Kevin has been a fashion student, learning about design and art and in recent times has had quite a bit of success broadcasting with BBC local radio.

"I have worked as a teacher's aid with mentally handicapped adults and found it very useful and interesting . . . All these things have given me a wealth of experience which I would never have hoped to have had if I had gone straight into a job".

MAUREEN Wingrove is well-known at ASBAH because she is a lively member of the telesales department, but what some people didn't know is that really she would like to have been a traffic warden!

When she got to the interview, the interviewers appeared rather shocked and suggested that she was being disrespectful in applying for the job seeing as she was in a wheelchair.

Maureen said that she had found from interviews that people interviewing you were "either scared of you in your wheelchair, or didn't know how to deal with you".

There were a number of other young adults with spina bifida and/or hydrocephalus who had the opportunity of airing their views during informal and more formal discussions. People like Jennifer Nuttall, originally from Lancashire, and now a marine ecologist working in Scotland monitoring the effects of pollution.

The informal, social side of the Conference will be what is remembered most by those who were in Manchester. The chat over a drink, or at dinner, and the small discussion group sessions are always valued more than the official agenda and so it was this year.

Despite differences of language, people from each country were able to make valuable friendships and contacts with others from a different part of the world. The friendly atmosphere of this year's International Conference will long be remembered, and a good spirit of co-operation was evident and meant, for example, that access difficulties — which arose at the last minute at the Conference venue — were able to be overcome or dealt with!

ASBAH hopes that any international visitor in London will call into the National Office (open five days a week). A warm welcome will be assured. We are pleased to say that some of the delegates have already done so!

The sing-song on the opening night broke the ice as delegates from each country were 'persuaded' by MC, Brendan Scully to go to the microphone and give a rendering of a favourite song from back home. The next evening there was a choice of a disco, or a trip to see the Blackpool lights — and again it was an opportunity for people to get to know each other either round the bar, or on the journey to and from Blackpool. An official conference dinner and dance was held on the last evening, and there were several much more informal social get-togethers throughout the Conference which did much to further good international relationships!

The discussion sessions gave people the chance to air their views in smaller groups, and one of them on the subject of 'Problems facing Parents' — proved so popular that it had to be extended to another session. Parents were able to talk about what was troubling them and get the views and experiences of other parents from different parts of the world.

The next International Federation Conference is in 1986 and an invitation has been extended to America to be the host.

As soon as the venue and dates are confirmed we will let you have details, as we are sure than many of those who were in Manchester will want to renew friendships and book a place. LINK certainly hopes to be there!

Pre-natal Screening & the MRC Trial

Dr Howard Cuckle, the Medical College, St Bartholomews Hospital, London:

THERE had been a dramatic decrease of about 80% in the number of spina bifida births in the last 15 years in England and Wales. About three-quarters of this could be attributed to prenatal diagnostic techniques, and a quarter to a fall in prevalence due to environmental and genetic factors.

Ultra-sound techniques were not 100% accurate at present. There was a need for widely available sophisticated scanning facilities which would detect identical twins, dead fetuses, and gestation errors which at present could confuse a diagnosis of spina bifida and result in errors.

The MRC Trials — with which Dr Cuckle is associated — might establish positively, once they are completed, in about 3 or 4 years time, that one of the causes of spina bifida was a lack of essential vitamins in the mother from the start of conception.

Genetic Counselling

Prof. Kenneth Laurence, Professor of Paediatric Research at the University of Wales School of Medicine

PROF Laurence sees about 800 couples for genetic counselling each year. He said in this country counselling was 'undirective'. Couples were not pushed either way. A counsellor discussed the family history, and explained the risks in perspective, discussed the options which included the avoidance of pregnancy, or a good diet and the offer of amniocentesis and prenatal diagnostic facilities.

"I act as a sounding board" he said.

He felt that in future it might be more difficult for a genetic counsellor to offer accurate advice if it became possible to identify relatively mild spina bifida in the fetus. (At present only the more severe cases are detected).

Problems at Birth

Dr Roger Bayston, Lecturer in Bacteriology, Institute of Child Health, London

ABOUT 90% of children born with spina bifida developed hydrocephalus, but not all required treatment, he said.

The number of premature babies with hydrocephalus due to haemorrhaging at birth was giving cause for concern.

CONFERENCE REPORTS

Dr Bayston referred to one infection during pregnancy that could cause hydrocephalus in the baby — toxplasmosis, caught from domestic cats and by eating undercooked meats. But the figures were small — of 600,000 live births in Britain, 50 children were infected at birth and 12 developed hydrocephalus. The figure in other parts of Europe was higher.

Dr Bayston said that often it wasn't possible to say what had caused hydrocephalus to develop before birth.

Later Development

Dr Pat Tomlinson, Medical Officer and Dr Jane Lones, Senior Mistress, Lord Mayor Treloar College, Hampshire.

DR PAT Tomlinson said there were 81 pupils with spina bifida and or hydrocephalus at the college. They stood apart from the others, and seemed to have 'a spina bifida personality'. Staff at Treloar had found that any of the children with hydrocephalus could present with valve problems at any time. Evidence of valve trouble could be as simple as a change in behaviour, or a falling off in performance in the classroom. Parents should be aware of this and have the courage to insist that there was something wrong if that is what they thought. Dr Tomlinson stressed the need for more adult spina bifida clinics to keep an eye on the young people when they left school.

DR JANE Lones said, learning, spatial and perceptual problems were not just confined to those children fitted with shunts. Spina bifida pupils had many strengths as well as weaknesses. They did poorly at number work or in subjects where spatial perception was needed (such as geography). Typing and keyboard skills, which could be the most useful, proved difficult, and an early start and constant repetition was needed.

Those students trained in office studies who had been able to go straight into a basic office job had been quite successful, but if finding employment took time then it could be disastrous and skills were quickly forgotten.

The Youth Training Scheme, with its emphasis on a variety of tasks and change of environment, tended to confuse and muddle young people with spina bifida and hydrocephalus. Vocational courses sponsored by the Manpower Services were also, on the whole, unsuitable.

The students needed longer and more extended practice than the courses allowed.

Spinal Fusion

Mr P. Cheong Leen, Consultant Surgeon at Queen Mary's Hospital, Carshalton, Surrey.

MR CHEONG LEEN gave an illustrated talk about changes in treatment at St Mary's over the years. He said many children with spina bifida did not have spinal deformities at an early age, but very often severe scoliosis or kyphosis developed and there was usually a need for operation by the age of 10. He gave details of different methods of spinal fusion which had had varying degrees of success. Operation on severe kyphosis was often not very successful, and it suggested it might be better to save the children from painful surgery by making them happy and comfortable in a wheelchair with a specially cast seat moulded to their shape. He said there had been a dramatic increase in recent years in the numbers of spina bifida children going to St Mary's for operations.

Incontinence Problems with Spina Bifida

Mr S. J. Cohen, Consultant Paediatric Surgeon at Booth Hall Children's Hospital, Manchester.

MR COHEN spoke on the changes in incontinence management since the 1950's when the problems were first brought to light in any numbers. They ranged from ileal loop diversions, artificial sphincters to the current fashion for intermittent catheterisation.

He gave a word of warning about new ideas. They needed to be approached cautiously and tested over a number of years before they could be regarded as 'breakthroughs'.

Ileal loop diversions had been

Continued over page

thought to be the answer when they first came in and a staggering number of diversions were carried out particularly in America. All was well for a number of years and then problems started to present themselves as the patients grew up, and a large number had now gone through undiversions.

Enablement Technology

Dr Hugh Grenfell, Director of Enablement Technology, Port Talbot, South Wales.

MR GRENFELL said it was too early to say whether electro stimulation of muscles could be of any great use in helping those with spina bifida. Most of the work which he had done so far — outlined in a film that he showed to the conference — had been with people suffering from spinal injury after accidents. He was currently working with a spina bifida boy, and after many months of treatment there was now some movement of the hamstring muscles.

Employment Prospects

Mr N. C. Clegg, Principal, North Notts College of Further Education.

THE college had developed further education and training for disabled students. Mr Clegg said that the unemployment situation was affecting disabled young people more than their peers and prospects could be improved by better education, independence training, motivation and careers advice. He urged more colleges to respond to the Warnock Committee's recommendations. This, he said, could produce a major surge in assisting young people with special needs into employment.

The Youth Training Scheme should be extended for young disabled people to the age of 22, and schemes should go on for longer than two years, as appropriate.

There should be more relevant transition into work with organised support, and industry could help by providing more relevant work induction, adaptation to premises and equipment, and by the full take-up of the quota.

He called for the provision of more sheltered work schemes, and centres for independent living for the more severely disabled.

CONFERENCE REPORTS

Computers in Life

Freddie Green, Director of Education, The Spastics Society

MR GREEN spoke about the wide uses of computers in education and employment. He felt it was time that the special problems of those with spina bifida and hydrocephalus were looked at with a view to trying to solve some of them by means of a micro computer.

He said that computers could be invaluable, particularly in teaching those with special needs. "There are all those computers around, looking for problems to solve. We should use them more . . . unfortunately, there is an inertia in the educational system about computers and their possible uses".

* *Mr Green is the co-author of a book on the need to relate the use of micros to the curriculum "Microcomputers in Special Education" Longman Resources Unit £1.40.*

Fashion

Mrs Nellie Thornton, Director, Fashion Services for the Disabled, Shipley, Yorkshire.

"CLOTHING has a much greater effect on our lives than people realise" she said. It not only protected us and provided warmth but gave us a sense of belonging, confidence, and told people quite a lot about our personality.

"How do you project a favourable image of yourself when you literally have to wear what you can get into? How many disabled people never go out, simply because they have no clothing in which they feel socially acceptable? We know quite a number."

Fashion Services opened in 1982, with the aim of providing fashionable garments to meet individual needs and to give maximum independence. Disabled teenagers, disabled adults, parents, teachers, occupational therapists all came to the training centre for courses, learning to cope with individual problems, designing garments, making patterns, choosing fabrics. The workshop made individual made-to-measure garments for disabled customers.

From humble beginnings the movement for good fashion for people with special needs spread, and there were now about 12 similar workshops in the country, and other enthusiastic people hoping to start more.

Travel

Mr Terry Thompson, Director of PHAB

MR THOMPSON said PHAB international worked with travel agents, air lines etc and they were becoming aware of the needs of the disabled. They were becoming willing to open up programmes to disabled travellers . . .

He said we must also educate some of the disabled. Some of them had to be motivated, to be given the chance to see the opportunities that were there.

We still had the habit of isolating people, at least in their early years, so they were shielded and choice and travel were frightening and strange notions.

Realistic Goals

Paul Cooper, former LIFT organiser, and now Development Officer at Five Oaks.

PAUL COOPER began with some questions. "What about ability within the disability, the people who achieve more than their able-bodied counterparts? Why do they achieve when others fail? Is it the luck of the draw or is it down to their attitude to life?

"I believe it is down to attitude. I know there is a vast range of ability, but if attitudes improved there would be more of our young people higher up the ability scale . . ."

He suggested that one way forward would be the education of *all* people about the abilities of disabled people.

LIFT was based around achievements. If you did not try you would never succeed. If you failed at something try again. Everyone failed at something.

Detailed proceedings of the Conference are being published and will be distributed to all delegates. If anyone else would like a copy, please get in touch with Mrs Susie Dobson at National Office.

Why we have a role to play in street collections

I am writing in response to the letter 'Don't "Display" Our Children On The Streets' (Sept/Oct issue). There are one or two points Ms. Walsh seems to have missed.

- She claims that disabled people are being 'displayed' by collecting on the streets. I find this a particularly narrow-minded approach, particularly from someone who later goes on to bemoan the way 'our society thinks about and treats our disabled'. It is people like Ms. Walsh who breed this type of 'Superior' feeling over the disabled. Would you, Ms. Walsh feel [illegible]he same if you saw a parent doing the [illegible]me thing? I very much doubt it as [illegible]e/she is not disabled, you would not [illegible]nsider it as being 'displayed' more "collecting for those less fortunate".
- Ms. Walsh has a Spina Bifida child, and she wishes that her daughter should be — and I quote — 'independent, lively, sociable and fully integrated into our Society'. Money raised by collections are put, by local associations, towards such facilities so that these ideals may be met. Fine, I totally agree that disabled people should, indeed, be treated in such a way as Ms. Walsh wishes for her daughter. But, and let's be totally honest, many factors these days prevent this.

[illegible] Practical ideas put forward by such [illegible]sociations as those for people with [illegible]pina Bifida, are very often the only [illegible]y of such ideals being met. May I give the example of PHAB Clubs, whose sole aim is to enable disabled/able bodied people to 'mix'. They rely on funds, helped enormously by collections. Isn't this what Ms. Walsh wants for her daughter?

May I make one more point. As a disabled person myself (I too have Spina Bifida) I like to be as independent as possible, and agree wholeheartedly with integration of disabled/able bodied people. But let's not bury our heads in the sand, I *AM* disabled, and therefore there are a number of things I cannot do.

For her daughter's sake, the quicker Ms. Walsh realizes this, and cuts out the awful narrow-minded thought that disabled people should be labelled, the better. It is only by help from other people, who do not have this attitude, and local Associations, giving practical help, with money raised by collections etc, that her daughter, and other disabled people, can ever hope to have total integration, and thereby wipe out all thoughts of 'disabled' people being thought of as such.

Kim Egan
(Bristol & District Assoc)

Letters

How about a problem page and pen pal club

With reference to your article 'The Last Ninety-Nine, in the 100th issue of LINK requesting comments and suggestions on the future of the magazine, I think it may be appropriate to include a problem page for readers, who for various reasons may not be able to attend their local association meetings or for overseas readers, like myself, who may not be fortunate enough to have efficient associations.

No-one would dispute that the problems involved with spina bifida and hydrocephalus patients are multifold covering a wide area of the medical field and which in turn reflect upon the social and employment scene of the individual. As a recent subscriber to LINK and mother of a two-year-old son with spina bifida and hydrocephalus I find that problems or questions which crop up may have already been dealt with in previous issues and may not be due for further discussion for some time.

A problem page, or questions and answers page, call it what you will, will be useful to readers, enabling them to state their problems briefly and hopefully receive a competent reply from a member of the ASBAH team, or in certain situations, ASBAH readers themselves could intervene giving advice based on personal experience.

Having read that eight hundred copies of LINK per issue are sent overseas another suggestion has come to mind. Perhaps in the not too distant future a pen pal club may be set up either between spina bifida and hydrocephalus sufferers themselves or between their families, in cases where children may not be of an age to write.

I hope my suggestions may be of use for the magazine. Congratulations on having reached 100th issue I hope there will be many more, keep up the good work!

Susan Camassa
Milan, Italy

Editor: What do other readers think of these suggestions? If anybody has a specific problem they would like to see dealt with in LINK, we will do our best to respond. We are also ready to carry the names and addresses of people seeking pen friends.

Now, the first great granny?

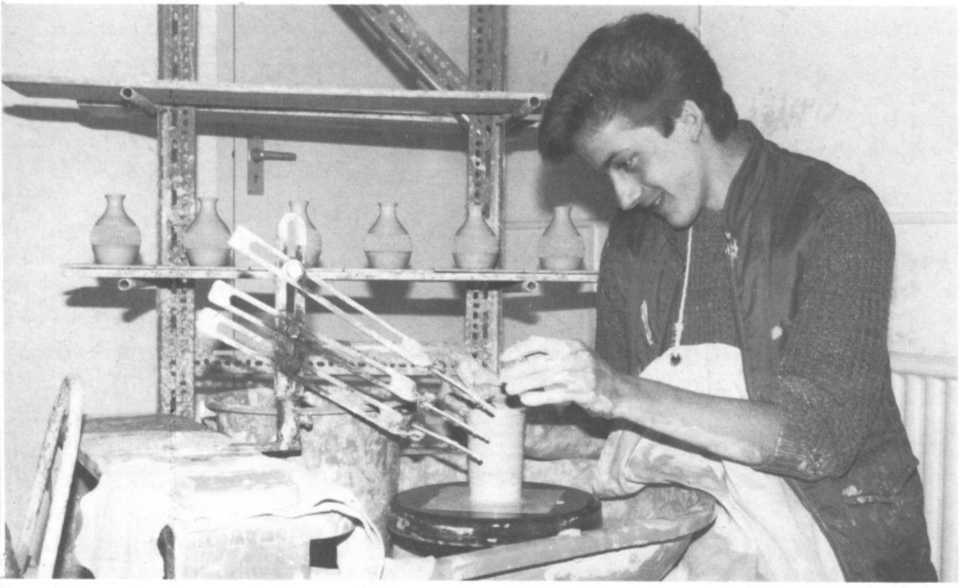
In our search for Britain's first spina bifida granny, we've now heard of a lady in Leicester who is a spina bifida great grand-mother.

I have five children, ten grandchildren, four great grandchildren, all in good health writes Mrs Marguerite Langman of Herle Walk, Leicester. The photograph (above) shows Mrs Langman who is able to walk with the aid of sticks. Mrs Langman suffers from spina bifida occulta which wasn't detected until she was an adult.

In fact, Mrs Langman doesn't quite qualify for the title of the first spina bifida granny because her eldest grandchild was 24 when she wrote, whereas Mrs Margaret Spencer of the Isle-of-Wight whom we announced as the reigning 'champ' in the last issue had a grandchild who was already 25!

It was close contest for that title and it now looks as if we have found the first great grandmother.

David works at the potter's craft



Eighteen-year-old David Wyke is on the way to becoming an excellent commercial potter.

David of Parkstone, Poole in Dorset is naturally artistic and good with his hands. He has been given the chance to work in a professional pottery and learn how to throw pots.

Purbeck Pottery, one of just two commercial potteries in the area, created the job for David, who has spina bifida, because in the words of Director, Gordon Ede: "We felt that just because he couldn't walk it shouldn't stop him from becoming a good potter".

David works full time at Purbeck Pottery under the Sheltered Employment Scheme. He is sponsored by the Community Employment Services in Bournemouth and gets the going rate [illegible] the job.

The Community Employment Services pay 50% of his salary, and the pottery pays the remainder.

David gained several CSE's and one 'O' level — in Art — at a special school in Wiltshire. It was while at a local day centre near his home that he had a go at pottery and showed he had what it takes.

On a good day he can turn out about 50 pots, but other times he finds it more difficult and it is this lack of consistency and concentration that David needs to be able to master if he is going to become a permanent member of staff.

"We are a professional pottery and need to make a profit. We are not running a charity and I am sure David wouldn't want that. He has the potential to be a good thrower. We hope he makes it" commented Gordon Ede.

Unfortunately, David works virtually on his own all day and this can prove lonely. Hopefully it may be possible for him to join the busier environment of the main factory a few miles away. And Gordon Ede has hopes that David will be able to be a demonstration potter for the public at Purbeck Pottery's large shop at Poole Quay.

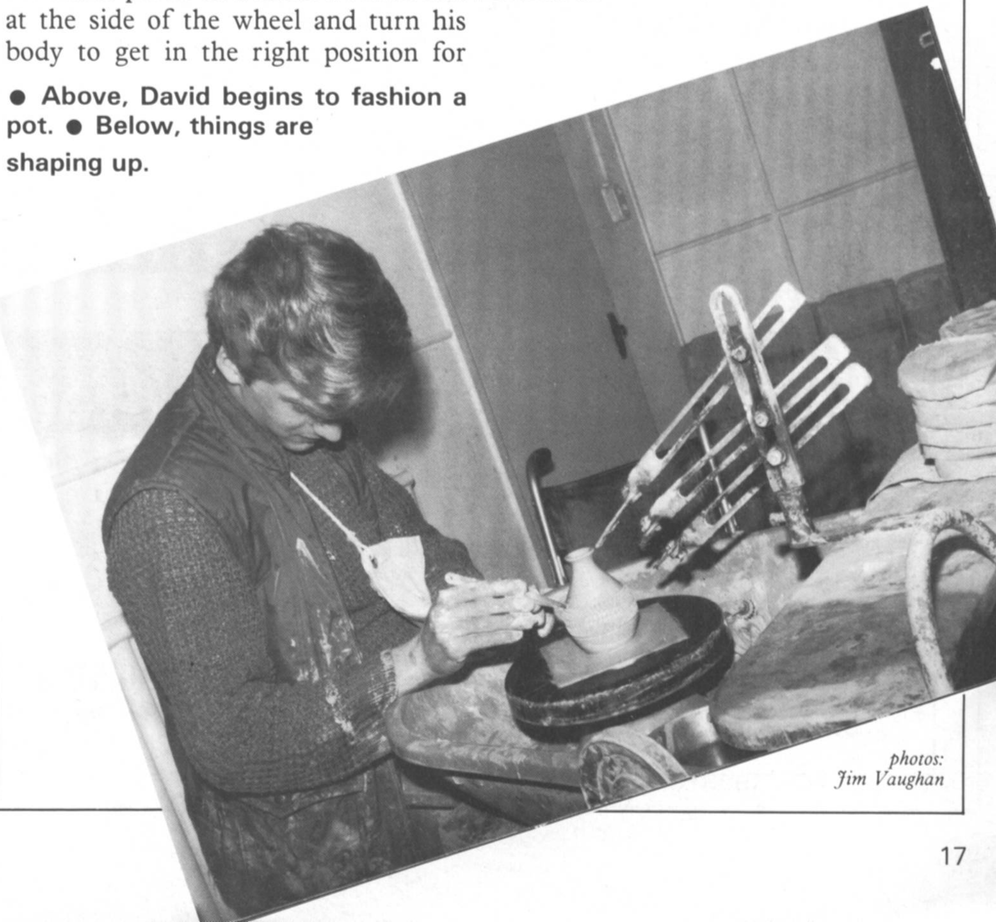
At present it is easy working where he does because his father is able to give him a lift to work. However, David has passed his driving test and is hoping soon to get a car of his own. This would give him much more independence and flexibility.

One problem at the moment is that David can't work from his wheelchair. He has to perch on a small wooden seat at the side of the wheel and turn his body to get in the right position for throwing pots. Working for long periods in this position is very uncomfortable and gives David back and neck ache.

Maintenance Engineer, Jim Vaughan at Purbeck Pottery has spent a good deal of time designing a special wheel assembly that would enable David to work from his chair. He has produced a model and the Manpower Services Commission have taken it away — hopefully to build the real thing for David.

David has been given this opportunity to learn a valuable craft and to learn how to do it in a commercial and profitable way. It will take determination on his part to succeed. There are plenty of people who are hoping he makes it.

● Above, David begins to fashion a pot. ● Below, things are shaping up.



photos: Jim Vaughan

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2 new schemes — South Wales and Manchester

A home of your own

Since September, ASBAH has rented a two bedroomed wheelchair accessible flat from the United Kingdom Housing Trust in Cwmbran, South Wales. The flat is amidst a scheme for young single people, and includes a communal room and a community warden. UKHT have included nine wheelchair standard homes in the scheme, which is close to Cwmbran's very accessible town centre.

Our flat is intended for the use of people with spina bifida and/or hydrocephalus (or other disabilities) to use on a short term basis, to try living in a place of their own. The people that have shown interest so far have varying reasons for [illegible]oing so, which include the desire to assess what sort of [illegible]ptations they may need, the amount of practical help that will be required and to work on household and domestic tasks before moving into permanent accommodation.

There is no formal assessment by ASBAH, and applicants can refer themselves. A home help from the Social Services has been allocated to the scheme and users can make use of this service if they wish. ASBAH's Fieldworker in the area is also available to give advice and support, as necessary, if this is requested.

ASBAH pays the rent monthly to UKHT and then recovers it from the occupant, who if on a low income or in receipt of Supplementary Benefit can claim Housing Benefit which meets almost the full cost of rents and rates.

We hope this will be a useful project. Though it is primarily intended for young people in South Wales we welcome enquiries from elsewhere.

More information from Siobhan Rowe, National Office.

[illegible]fter much hard work Trafford and Salford ASBAH, [illegible]ve finally secured the land for their Housing scheme in Stretford, Manchester.

Working with the Manchester Methodist Housing Association, it is intended to build 12 flats, four of which will be wheelchair accessible, 2 single person, one bedroomed units and 2 two person two bedroomed flats. There will be a communal laundry on site.

The scheme is intended for young people with spina bifida and/or hydrocephalus and it is hoped that they will stay for a couple of years, and then move on to other accommodation.

The site that has been chosen is very close to a local Arndale shopping centre, and other local facilities. The tenants will make use of the local community services like district nurses and home helps, for assistance in their homes.

The major costs of the scheme will be met by the Housing Association, via a grant from their funding body, the Housing Corporation, Trafford and Salford will fundraise for certain furnishings.

If anyone would like further information, please contact the Secretary of Trafford & Salford local association, Mrs J. Robinson, Moorfield Annexe, Council Offices, Crofts Bank Rd., Urmston, Manchester M31 1UD. Tel: 061-748 4000 ext 293 (mornings).

Three views of the Cwmbran housing scheme: front, rear and kitchen

Siobhan Rowe,
ASBAH's
Accommodation &
Development Officer.

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The Green Paper, 'Reform of Social Security' has provoked such a negative response from those concerned with the disabled that the Secretary of State, Mr Norman Fowler has agreed to think again. That's the good news. What's not so good is the way the Green Paper emerged in the first place and the fact that it did nothing to improve the position of people with disabilities. Here then is an outline of a Green Paper and its likely consequences which left many people seeing red.

GREEN PAPER: REFORM OF SOCIAL SECURITY

It's bad news for disabled people

by Beverley Holland, Information Officer, ASBAH

The proposed changes in social security as outlined in the Green paper "Reform of Social Security" would do nothing to improve the position of people with disabilities, many of whom are likely to be reliant on benefits for all or most of their income. It is clear that the needs of disabled people were not considered in detail in preparing the review.

The proposed abolition of State Earnings Related Pensions (SERPS) would have a detrimental effect on invalidity pensioners and put a further strain on carers who would feel obliged to carry on working whilst providing care. The proposals for private pension schemes would mean that many disabled people might not be able to get cover as insurers might consider them a bad risk.

It is suggested that Supplementary Benefit could be replaced by Income Support with a new system of 'premium' payments based on age, marital status and client groups, giving little regard to individual needs. Although figures are not available it is strongly felt that the 'disabled persons premium' would be insufficient to cover individual needs, such as special diets, heating additions etc.

The full extent of the proposals for change in supplementary benefit can only be guessed at due to lack of precise details of structure or clarity of qualifying conditions. Given the present Government's commitment to reduce spending on supplementary benefits this can only mean that large numbers of people would not only lose considerable sums of money, but would also fall further into the poverty trap as they would never know precisely how much money they had each week.

The abolition of single payments and weekly additional payments would mean an effective drop in income for some disabled people of up to £40 a week, thus bringing many people to or below the poverty line. The proposed replacement of these allowances by the Social Fund is the most invideous of all the proposals. Administered by local DHSS offices, cash limited, discretionary, with no right of appeal and possibly in the form of a repayable loan, it would hit hardest the most vulnerable members of society who would be forced to beg for payments they desperately needed, thus stripping away any legal entitlement to payments which in the past disabled people have had as a right.

Replacement of the Death Grant by means-tested help with funeral costs would bring hardship to many families who might not be entitled to Income Support.

It is suggested Family Income Supplement is to be replaced by Family Credit, paid through the husbands wage packet in two-parent families. This would mean that benefits to meet the needs of children would no longer be payable to mothers and could lead to serious financial difficulties if the husband is less than generous in his contributions to family income needs. It might also be seen by employers as an inducement to lower already inadequate wages, confident that Family Credit will top them up.

The proposals to make Housing Benefit claimants pay 20% of their rates and to implement a 70% taper for withdrawing benefit would seriously affect disabled people, many of whom are represented in the ranks of the low paid, poor and unemployed.

Taken as a whole the proposals spell out bad news for disabled people, many of whom will find themselves drawn even further into the poverty trap. ASBAH is therefore pleased to learn that as a result of the negative response to the green paper, Norman Fowler is looking again at his proposals. Let us hope that this time he consults the right people, those who are going to be most affected by the changes.

Copies of ASBAH's response to "Reform of Social Security" can be obtained from Beverley Holland at National Office.

New from the DLF

Clothes sense for Disabled People of all Ages.

Peggy Turnbull, and
Rosemary Ruston.

THIS up-dated book is a mine of practical information on all aspects of clothing and dressing, both for those who need assistance to dress and for those who can remain independent if they choose their clothes with care.

The book looks at choosing suitable styles and fabrics, dressing techniques and aids, reinforcement and repairs and also how to adapt clothes.

This new edition includes details of the clothing problems of disabled children. It is an easy-to-read publication with clear line drawings.

Price £9 inclusive of postage and packing. Available from the Disabled Living Foundation (Sales) Ltd., Book House, 45 East Hill, Wandsworth, London SW18 2QZ.

Clothing for Wheelchair Users: an Information/ Training Pack

THIS package was assembled as an information/training resource designed mainly with a view to helping handicapped adults, needing to use a wheelchair for either all or part of the day, to cope with any problems relating to clothing (including footwear) which might arise.

It consists of slides and lecture notes together with illustrated sewing hints on useful adaptations, illustrated suggestions of alterations to paper patterns, names of suppliers, and a list of DLF books about clothing.

An optional extra is a boxed small collection of clothing with examples of certain items and photographs of others.

Further information from: Mrs E. M. Turnbull, Clothing Adviser, DLF, 380/384 Harrow Road, London W9 2HU. Tel: 01 289 6111.

Newslines NEWSLINES Newslines

Pupils of Dorin Park School, Upton, Chester enjoying the sun during their week's camp at Perros Guirec in North Brittany this year. The site is especially suitable for the needs of campers in wheelchairs.

Mr C. W. Owen from the school writes: "The social and practical experiences that the children gained were numerous and could only have been proved by such a camp . . . The pupils and staff would like to thank ASBAH for the generous financial assistance which made this venture possible".

- FORD carried out a survey which revealed that too few disabled people are taking advantage of buying their own cars through Motability because of ignorance and fear of red tape.

Only two dealers, according to the survey, supplied more than 100 cars to the disabled last year. Way out in front is Trust Motors in Scotland who put almost 600 cars for the handicapped on the road from their Glasgow and Motherwell centres. A spokesman for Trust said "I think a lot of people don't realise they could qualify for the Mobility Allowance . . . "Documentation and exemption certificates for tax are handled by the dealer. All the disabled customer has to do is sign the forms. We're now processing 30 applications a month, but it's just the tip of the iceberg."

- A COMPREHENSIVE programme to tackle the problems of Britain's 5.5 million disabled is promised by the Labour Party in a book recently launched.

In "*As of Right*" Labour promises to review all benefits, to increase allowances where necessary. The Party will also consider discrimination against the disabled and barring contracts to companies which discriminate.

Labour is committed to improving access to public buildings and to helping them convert their homes. More jobs and housing are also promised.

"*As of Right*". Available from: Mr Michael Meacher, MP, House of Commons, London SW1 0AA. Price 95p.

- HORTICULTURAL Theraphy, the national charity for disabled gardeners, has a new Director. Miss Alison Ryan took over in the Autumn from Chris Underhill, who founded HT in 1978. HT is based at Goulds Ground, Frome, Somerset BA11 3DW. Tel: 0373 64782.

- MOBILE ACCESS Services has self-drive vehicles for hire which take several wheelchairs. Vehicles have electro-hydraulic tail-lifts and anchorage fittings for wheelchairs.

Details and sample hire rates from: Mobile Access Services, POB 213, Winslow, Bucks M18 1NX. Tel: 029 671 3169.

- CONQUEST — the Society for Art for the Physically Handicapped is staging an Exhibition at the Stock Exchange in London, Monday, December 2-23, 10am – 3pm.

Details: The Secretary, Conquest, 3 Beverley Close, East Ewell, Epsom, Surrey KT17 3HB.

- THE DISABLED Travellers Club Ltd has been formed to provide travel information, and organise holidays for disabled people. The Club hopes to be able to arrange discounts on travel and on some goods and services. Membership is £2 per year with an entry fee of £3.

Contact: Mr H. Wilson, 28b Leys Avenue, Letchworth, Herts SG6 3EW.

- THRESHOLD Travel's new 1986 holiday brochure is available. This year activity holidays for the disabled are featured — a Judean desert safari, a Kenya wildlife safari, or scuba diving and deep sea fishing in the Red Sea. The company which specialises in holidays for the disabled has opportunities ranging from individual holidays to coach tours, fly-drives and lots more in all parts of the world.

Brochure from: Threshold Travel Ltd., Wrendal House, 2 Whitworth Street, West, Manchester M1 5WX. Tel: 061 236 9763.

MEETING POINTS

COMPUTER CONFERENCE

The Computer as an Aid for Those with Special Needs. April 15 – 17. Sheffield City Polytechnic.

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ANNUAL MEETING

THE 19th Annual Meeting of ASBAH was held in September at the Westminster Cathedral Conference Centre. It was opened by the President, The Rt. Hon. Lord Maybray King in his usual inimitable style.

Mr Dennis Bryant, Chairman of the Executive Committee, referred to ASBAH's move during the year to new offices in Woburn Place. They are just across the road from ASBAH's old home, Mr Bryant said that it was hoped to install a lift before too long so that all of the office was accessible. He also mentioned the new style Annual Review which was an attempt to put across the scope of ASBAH's work to a wider audience.

ASBAH's emphasis during the year, he said, had been on international activities as well as on those in the UK. "We have to recognise that in the world today international co-operation can bring a greater impact and force. We should be concerned about joint activity in the common market which can give greater recognition of our aims and alternative sources of funding."

★ *Warm thanks were given to Mr Howard Smith who resigned as Honorary Treasurer of ASBAH after three years. Mr Bryant said he had been a good friend to the Association for many years.*

SUMMING UP

In her Report to the Annual Meeting, ASBAH's Executive Director, Miss Moyna Gilbertson referred to the Association's participation in International Year of Youth (IYY).

"It will probably come as no surprise to you that during the planning for this year . . . the needs of and the involvement of disabled young people in the year seemed to be neglected. It was certainly in our view inadequate. It was for this reason that DISPART was formed."

DISPART — Disabled Participation — is a consortium of charities, PHAB, the Muscular Dystrophy Group of Great Britain, The Spastics Society, Spinal Injuries Association, Handicapped Students Bureau, SPOD and ASBAH. The idea behind the formation of the consortium was that young disabled people should themselves have the opportunity to participate in events of the year.

"ASBAH's particular contribution has been to organise a Study Day on Independence Philosophy and to take part in the organisation and participation in a work camp which was held in Werkenrode, Holland at the end of July. Our involvement here was considerable."

"About 25 people were recruited and in total the party consisted of almost 100 people. The group was a mixture of people with disability and able bodied and as far as we were concerned each delegate went on an equal basis paying the same fee.

"To me there were two very significant factors — first of all that there was a strong LIFT representation including the Chairman Chris Hopkins and Philip Brown who is, of course, also a member of the Executive Committee . . . and secondly that the young people were all very anxious to be involved in

Continued over page

★ *A galaxy of celebrities has agreed to support ASBAH as Vice Presidents, it was announced at the Annual Meeting. They are: Michael Aspel, Barry Cryer, Moss Evans, Thora Hird, Esther Rantzen, Claire Rayner, Jeffrey Tate, and Shaw Taylor. They have already helped ASBAH in the past, and in this way can now show their support officially.*

Their backing is a sure sign that ASBAH is now recognised as a nationally important voluntary organisation.

FINANCES

There's need for caution

***MR A. K. Stewart-Roberts,* who has been Hon Treasurer since April 1 was welcomed to the Association, and gave the financial report for the year. Some of the main points of his report are given below:**

- **The original forecast of a deficit for the year of about £35,000 seems to have been pessimistic. The deficit was about £6,700. There will be a full review after six months of this year.**
- **We must be careful not to be over-optimistic and increase our services too ambitiously. There could be no signal for unbridled spending. "Careful stewardship of our resources must be the watchwords".**
- **Income from legacies showed a substantial increase and the trend was continuing in the current year.**
- **The office move at the end of March 1984 — mainly in order to expand the telesales department — cost nearly £14,000. Much of the money went on rebuilding to satisfy fire regulations.**
- **ASBAH received about £115,000 from ASBAH Trading during the year.**
- **Five Oaks was a drain on resources. The emphasis is now on short-term stays and courses which, it is hoped will help to increase occupancy.**
- **Micro-computers have been installed at national office. "The use of computers in invoicing enables us to keep tighter control on debtors and improve cash flow.**

★ *Copies of the Annual Review, and of the official Annual Report and Accounts are available from National Office.*

Continued from page 25.

the management of their own affairs. Some of them were very angry and it seemed to me that augurs well for the future."

Miss Gilbertson mentioned changes in overall structure and redevelopment at Five Oaks, which she hoped 'heralds an exciting new phase'.

"We have now held one driving ability course and one driving assessment course at Five Oaks. Members will recall that this proposal was discussed at Council and did appear to us to meet with univeral approval of local Associations. It is however, a very expensive course for young people because paying for a concentrated series of driving lessons costs a considerable amount of money.

For this first course we awarded bursaries from the Professor Lorber Bursary Fund which was inaugurated last year with the result that there is very little money left for the award of further bursaries. We do most strongly commend to local associations the importance and usefulness of these driving courses and hope that the bursary fund will receive large injections from you or alternatively that local associations will consider sponsoring young people.

"Our Annual review mentions the paucity of Fieldwork cover which we are able to provide in many areas. Cumbria was a particular cause for concern and we decided to reallocate some hours which for various reasons were not being taken up and I am pleased to be able to report that Sandra Wheatley, Fieldworker in the North is now employed on a full-time basis."

On the subject of research, Miss Gilbertson said lack of money was still a problem, but in the last few months funds had been allocated to three research projects:

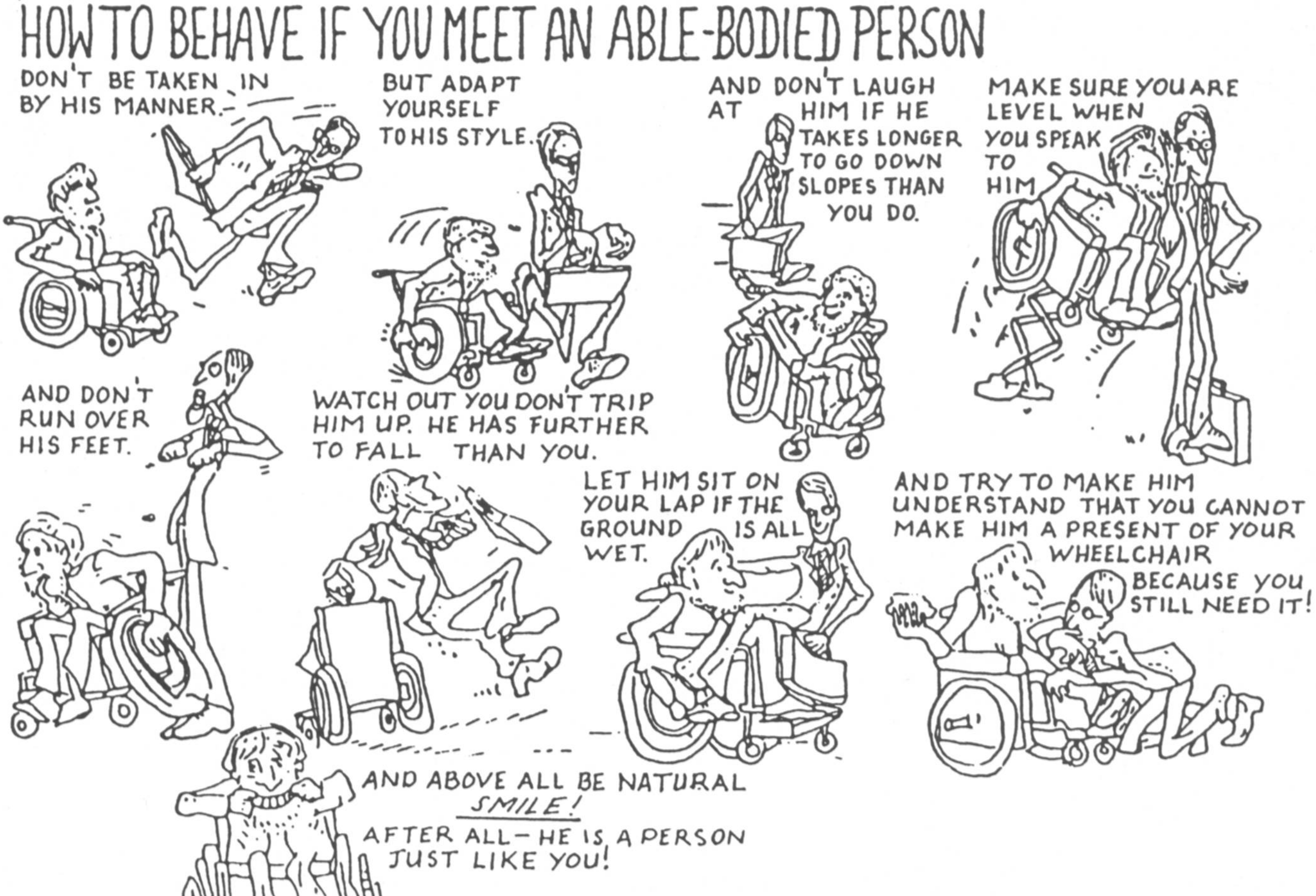
- A study into Cerebrospinal Fluid flow under normal and hydrocephalic conditions — by Dr Paul Brown at Frenchay Hospital Bristol.
- The Health and Social Needs of Physically Handicapped Young Adults in the London area — Dr Martin Bax, St Mary's Hospital Medical School.
- Effects on families of Spina Bifida babies deemed unsuitable for surgery and a comparison of home versus hospital care — Dr Janet Goodall, Stoke-on-Trent.

All three are very important and ASBAH would be delighted if any local association was interested in earmarking donations for any of the projects.

Miss Gilbertson thanked the Executive Committee and other ASBAH Committees who had worked so hard during the year, and paid special tribute to Lady Jean Mackenzie whose work with ASBAH will have to decrease because she has become Chairman of the Royal United Kingdom Benevolent Associaton.

★ "A Home of My Own" *was the subject of the talk given at the Annual Meeting by Mr Charles Moore, Director of the John Grooms Association for the Disabled. LINK will carry a report in the next issue.*

★ *Three very valuable and har working members of ASBAH's Executive Committee retired at the Annual Meeting — Mrs M. Clarke, Mrs H. Payne, and Dr Adrian Stokes. Mr Bryant, Executive Committee Chairman paid particular tribute to the work of Mrs Clarke and Mrs Payne over a great many years.*



Reprinted from the Bulletin of the International Cerebral Palsy Society, author unknown.

Young Yachtsperson of the Year, Pete Joscelyne of Knutsford, Cheshire, helming a GP 14. Crewing is fellow competitor Mike Gregory who won the Theory Trophy.

This nationwide competition organised by ASBAH reached its climax with the finals at the RYA National Sailing Centre on the Isle of Wight in September. The 26 finalists who had got through the preliminary stages in regional heats earlier in the year, competed for the title during two days of competition.

Each youngster who took part also raised funds through sponsorship on a per points basis.

Prizes were given in Seamanship, Racing and Theory, as well as the main prize for the Young Yachtsperson 1985. They were presented by Chay Blyth at the Southampton Boat Show.

Organiser of the event, Sue Stamps said ". . . this is only the first year and we have made many friends who are urging us to organise the competition again for 1986. But ASBAH really needs a sponsor so that the event can grow, and raise more funds for disabled youngsters".

The sporting and beautiful support ASBAH

HRH The Duchess of Gloucester, ASBAH's Patron talking with Karen Terwee from the Netherlands who is staying at Five Oaks while studying conversational English. In the background (left) is Mrs Yvonne Cox, Chairman of Five Oaks House Committee and the Gala Committee, and (right) Joan Pheasant, Manager, Five Oaks.

The occasion was a Gala Evening at the Majestic Hotel, Harrogate in October in aid of ASBAH, with international fashion for autumn and winter presented by Crofts, the leading Harrogate Fashion House.

It proved a spectacular show based round the season's colour combinations of cerise, fuschia, black, navy and white, and was devised and directed by Peter Teverson, Crofts' director.

The celebrity team which took part in ASBAH's second golf tournament at the RAC Country Club, Epsom in September — Desmond Lynam, Richard Kittar, Roger de Courcy and Robert Powell.

Twelve teams took part — the other eleven came from companies, and Gareth Hunt and Kenneth Wolstenholm lent their support as members of one of the company teams.

A good day's golf was enjoyed in dry weather, and a video of each competitor's swing was taken and analysed at the end of the day. One celebrity flatly refused to watch his own swing!

After dinner in the clubhouse, ASBAH's Executive Director, Moyna Gilbertson presented the prizes.

Footsore, but triumphant — one of 96 teams that took part in Mountain Express over the Brecon Beacons this Summer for ASBAH. It has been described as 'Britain's toughest walk for charity'.

Given 24 hours to complete the gruelling 40 mile walk, each walker used compass and map and carried a 40lb pack (30lb for women). The winners completed the course in only 8 hours 32 minutes with the last checking in 17 hours later.

The whole event was organised by ASBAH and raised almost £20,000 through sponsorship.

Presenting prizes over a celebratory breakfast, John Powell, Chairman of the Sport Council for Wales said "I heartily congratulate all participants . . . and well done to all those who completed the tough course. You need training to take on the Beacons, but you have done a fine thing for charity and made this part of Wales a happy place indeed, but look out there'll be a Sports Council Team taking part next year!"

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