

Link

APRIL 1991 NO 133

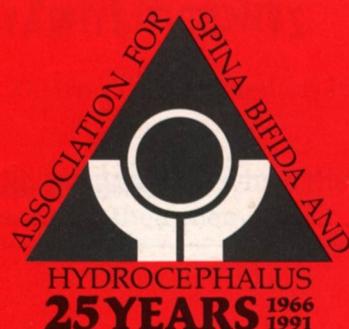
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APRIL 1991
ISSUE NO 133

This issue of LINK marks two significant points in ASBAH's history as April is both our silver jubilee and the month in which there is a change at the helm as Moyna Gilbertson retires and our new executive director Andrew Russell joins the Association.

Miss Gilbertson leaves at the end of the month after 15 years in post. Tributes to her work are covered in a special 12-page feature inside, where contributors chart the changes in ASBAH over the last quarter of a century, including personal views of the early days, the progress of medical treatments for spina bifida and/or hydrocephalus, the birth of LINK, and national's relationship with the local associations - with some questions on how this can be developed in the future.

One of the ways for local associations to communicate with each other, as well as national ASBAH and our many clients, carers, and professionals, is through the pages of LINK. We would welcome not only your views on matters raised in the magazine, but news of your group's activities, special achievements of individual members, success in fundraising etc, so why not write in and help us all to keep in touch over the next 25 years...

On the Cover



This month's cover shows Moyna Gilbertson cutting our 'birthday cake' at a London reception held to celebrate our anniversary and to thank the friends of ASBAH for their help and support over the years. Others in the picture are the mayor and mayoress of Peterborough and, from left to right, Peter Thurnham MP, Nicholas Scott Minister for Disabled People, Andrew Russell and Patrick Daunt.

Telethon cash for Lincoln

Lincoln ASBAH recently received £500 from ITV's Telethon 1990 appeal.

The local association is delighted with the donation which they will be using to sponsor driving lessons for their members.



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Miss Moyna P. Gilbertson, MCSP, FBIM

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Mr Derek Knightbridge, FCCA

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Mrs Teresa Cole, MICA

Disabled Living Service Manager:

Miss Rachel Stanworth, BA (Hons),
SRN, PGCE, MSc

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Mr Tony Britton

Research and Information Officer:

Miss Pat Corns, SRN

Regional Development Co-ordinator:

Mr Phillip Watson, BA (Hons), RGN

Five Oaks Centre Manager:

Miss Joan Pheasant, NNC

Appeals Manager:

Mr Roy Johnston

Off to a good start



Our Fund a Fieldworker campaign got off to a good start in Cambridgeshire with a £5,000 donation from Barclays Bank. ASBAH hopes to increase its fieldwork cover in the county to two full-time posts, costing a total of £150,000 over four years. Mary Castle, seen in the centre of the picture, is currently the only

Barclays' Peterborough Business Centre manager Brian Long, presents the cheque to Moyna Gilbertson, watched by Mary Castle and regional business executives Donna Treanor and Deirdre Pawsey.

fieldworker for the county, she is employed part-time and has to look after 117 families in Cambridgeshire as well as covering part of Norfolk.



Pedal Power

MADDIE BLACKBURN, who reported on ASBAH's research into the needs of young people with spina bifida and/or hydrocephalus in the last LINK, is putting action behind her words.

Maddie, a research health visitor, is planning a 26-mile sponsored bike ride for next month to raise funds for the educational section of the research project.

If you would like to sponsor the cycle ride contact her at Dept. of Children's Health, Westminster Child's Hospital, Vincent Square, London SW1P 2NS. Tel 081 746 8631.

Maddie on a practice run - getting a push from her colleagues.

New recruits for regional office

Recruitment for our new regional office in Northern Ireland is well under way after a week's intensive interviewing in the province in February. Staff for the Northern Ireland Disabled Living Services team were interviewed by, Assistant Director (Administration) Paul Dobson, DLS manager Rachel Stanworth and NI co-ordinator June Kerr with Pat Edser joining the panel for counsellor interviews and paediatric consultant Victor Boston sitting in on the selections for the other DLS posts.

Ms Stanworth was pleased with the good response for the vacancies "The applicants were

of a high calibre and we were impressed by their obvious enthusiasm and commitment". Those appointed to date are: part-time education co-ordinator Meta Harvey whose background includes both special and mainstream education; full time regional counsellor Julia Greer who has worked for Relate and been a family centre worker for Barnado's; and disabled living adviser Colin Robinson who has worked for Disablecare and is a wheelchair user himself.

Fieldwork Manager Teresa Cole also spent a week in Northern Ireland to select her new team of fieldworkers. Again the selection

board comprised Paul Dobson and June Kerr. Most of the fieldworkers will be starting their employment with ASBAH from the beginning of this month, though they will have an initial training period before establishing their own client groups.

The successful fieldwork applicants came from a variety of backgrounds, including nursing, social work, physiotherapy and special education. The two full-time fieldworkers are Mrs Margaret Young for the Ards Peninsular and Mrs Veronica Buckland for Co. Down. The other posts are for 17.5 hours per week and include: Mrs Barbara Hanna - Fermanagh, Mrs Alison McArthur - Antrim, Mrs Colette McCann - Tyrone, Miss Karen Moore - parts of Co. Down, Mrs Heather McKee - parts of Belfast, Mrs Fidelma Murray - Co. Londonderry.

Funds fly in

A staggering £20,000 was raised for ASBAH at this year's British Homing World Show of the Year. The show, which was held in Blackpool in January, is the pigeon equivalent of Crufts and it too has a Supreme Champion. Organised by the Royal Pigeon Racing Association, the show raises money for charities through its raffle and entry fees. ASBAH has been a

beneficiary for many years and the total raised for us to date is a massive £156,000.

Amongst the prizes donated for this year's raffle was a cake baked by the Catering Flight at RAF Wittering - not far from ASBAH's national office. The cake was won by someone in Wales which presented a problem of delivery until Hotpoint, another ASBAH

neighbour, stepped in and offered to deliver the cake personally. Other prizes included a holiday for two in Jersey donated by Travelsmith, a holiday in Legoland from Specialised Tours, a weekend in York from Rainbow Holidays, and a Fizz Wizz drinks maker.

Donna and Deirdre accept the cake from Warrant Officer Howard Inston.

Photo: Stamford Mercury



Appeals manager Roy Johnston, assistant manager Penny Hebblewhite and regional business executives Deirdre Pawsey and Donna Treanor with Mr and Mrs Alderson, winners of the Jersey holiday.

Five Oaks takes a tumble!

Washday blues are a thing of the past for our Five Oaks residents, thanks to a brand-new heavy-duty tumbledrier donated by Clugston Construction. The £800 machine was handed over to Joan Pheasant, manager of Five Oaks, in February. "We often have very heavy loads to put through the wash, says Joan, and Clugston's gift will make our job that much easier."

Michelle Hawley, Five Oaks resident, loads the new machine, watched by Joan Pheasant, Clugston marketing services manager Paul Goulard and site agent Graham Jagger.



Yoga and learning difficulties

Yoga as a therapy for people with learning difficulties is the basis of courses run by Maria Gunstone at the You and Me Yoga Centre in Lancashire.

The You and Me system of Yoga was developed after many years of studying the therapeutic use of yoga for those with mental disabilities, both in the UK and India, and using the feedback from physiotherapists, parents, teachers and carers in this country.

Ms Gunstone uses 20 basic movements which can be adapted for different degrees of ability. She says the benefits of Yoga include improvement in self-image, relationships, concentration, mobility, co-ordination and relaxation.

The Centre at The Cottage, Burton-in-Kendal, Carnforth, Lancs, offers classes for both pupils and teachers of Yoga. For more information on classes and teaching aids available contact Maria Gunstone on 0524 782103.

FREELINE

Advice Line

A free, confidential advice line for questions about Benefits, Pensions and National Insurance is run by the department of Social Security - but is not linked to local Social Security offices.

Called 'Freeline', you can ring them on 0800 666555.

New Face at NICOD



MRS EILEEN THOMSON has been appointed Assistant Director of NICOD, the voluntary organisation which offers training opportunities and living options for people with physical disabilities (formerly Northern Ireland Council for Orthopaedic Development). A graduate of Queen's University of Belfast, Mrs Thomson has been with NICOD since 1984. The post of Assistant Director was created in direct response to the government policy paper 'People First' and Mrs Thomson will be responsible for monitoring quality assurance in NICOD services and promoting independent living opportunities for persons with a physical disability.

Working with new technology?

Disabled researcher Alan Roulstone, of The Open University, is doing a study on Information Technology and the Employment Experience of Disabled People. He needs to contact a large sample of disabled workers (and unemployed disabled people) who work, or have worked, with new technology in their employment. His research will use respondents' own reported experiences of the effects of new technology upon their employment.

If you would like to help in Mr Roulstone's research call him on 0908 274066 extension 3571 or 0235 527855.

Record attempt

The chance of a world record is spurring on Tony White from East Peckham as he trains hard for a marathon canoeing trip which starts this summer. Tony, who has spina bifida, is the only disabled youngster who will be taking part in the Rhine Challenge when he will canoe 709 miles down the Rhine taking him through four different countries. The going will be tough with 10 hours a day in the canoe to cover 30 miles and even then there's no soft bed to collapse into but a tent to pitch and supper to cook.

Tony is actually looking forward to this ordeal "The Rhine is one of the most fascinating rivers in the

world, we'll be going through cities, gorges and vineyards, and I'll definitely be taking my camera and loads of film. It's the trip of a lifetime and if I complete it I'll be a record holder - that's what's really spurring me on".

To prepare himself Tony is fitness training at home, doing press ups and sit ups, and taking part in training weekends every three weeks with the Kent Young Explorers who are organising the trip. The Rhine Challenge starts on 31 July and should be completed by 5 September. We wish them every success with the venture.

Picture: Courtesy of Kent Messenger



M O B I L I T Y M A T T E R S

We look at
the National
Consumer
Council's
report

FEARS for the future of wheelchair provision services in England were expressed in a report published recently by the National Consumer Council. The report paints a gloomy picture of thousands of people being virtual prisoners in their homes because they cannot get a powered wheelchair and have little say in the type of chair provided by a drastically under-funded service.

WARNING that the service, which is poor at present, could get even worse, the NCC urges that immediate steps should be taken to stop the service becoming the Cinderella of the NHS.

PROBLEMS are likely to occur, says the report, because the Disablement Services Authority is being disbanded and responsibility for provision of wheelchairs, and artificial limbs, will be passed to individual health authorities. The DSA was established five years ago after the McColl report produced a "damning indictment of the service to consumers previously provided by the Artificial Limb and Appliance Centres in England".

ASBAH gave evidence to the McColl committee on the inadequacy of government supplied wheelchairs at that time. It seems the situation has changed little since then - whatever new name the service is given.

FUNDING for the DSA was already insufficient, for instance, last year they estimated that another £53 million would be needed for wheelchairs alone and only £17 million was actually provided to cover wheelchairs, limbs and special seating. With the disbanding of the DSA their funds, albeit inadequate, will be earmarked for use for wheelchair and artificial limb provision for two years but after that disabled people will have to compete for cash with other areas of the NHS. There will no longer be any central body for disability organisations to deal with, to monitor needs and carry out research, as the DSA did. It is

possible that where a person lives could determine whether they are incarcerated at home, or have the appliances they need for mobility and therefore the ability to live an active working and social life.

WRONG provision of wheelchairs to individuals can lead to more pain and further disablement for the user, says the report. Making savings which condemn people to stay at home instead of being able to contribute to the community is also shortsighted according to the NCC.

Chairman of the NCC, Lady Wilcox comments

"This matter needs urgent attention NOW. Central Government must not shift the responsibility to health authorities, without providing them with proper resources."

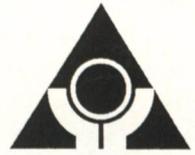
RECOMMENDATIONS by the NCC, to the Government, for improving the situation include:

- * increasing funding to allow a radical improvement in the provision of wheelchairs and both indoor and outdoor powered wheelchairs should be available in every region
- * the provision of wheelchairs and limbs should be determined by the needs of the users and people should get the chair best suited to their needs
- * health authorities should set up user groups to help monitor and develop the service and to offer information and counselling to individual users.

ASBAH's John Naude asks readers "As ASBAH's mobility adviser I'd like to be kept in touch with complaints that people have about supply of wheelchairs from the authorities. I am keen to know what information is given to individuals about their new wheelchair when it is supplied to them. Also, is the chair one which is suited to their needs and were any further adaptations offered to tailor it to their particular requirements". John can be contacted at National Office.



ASBAH



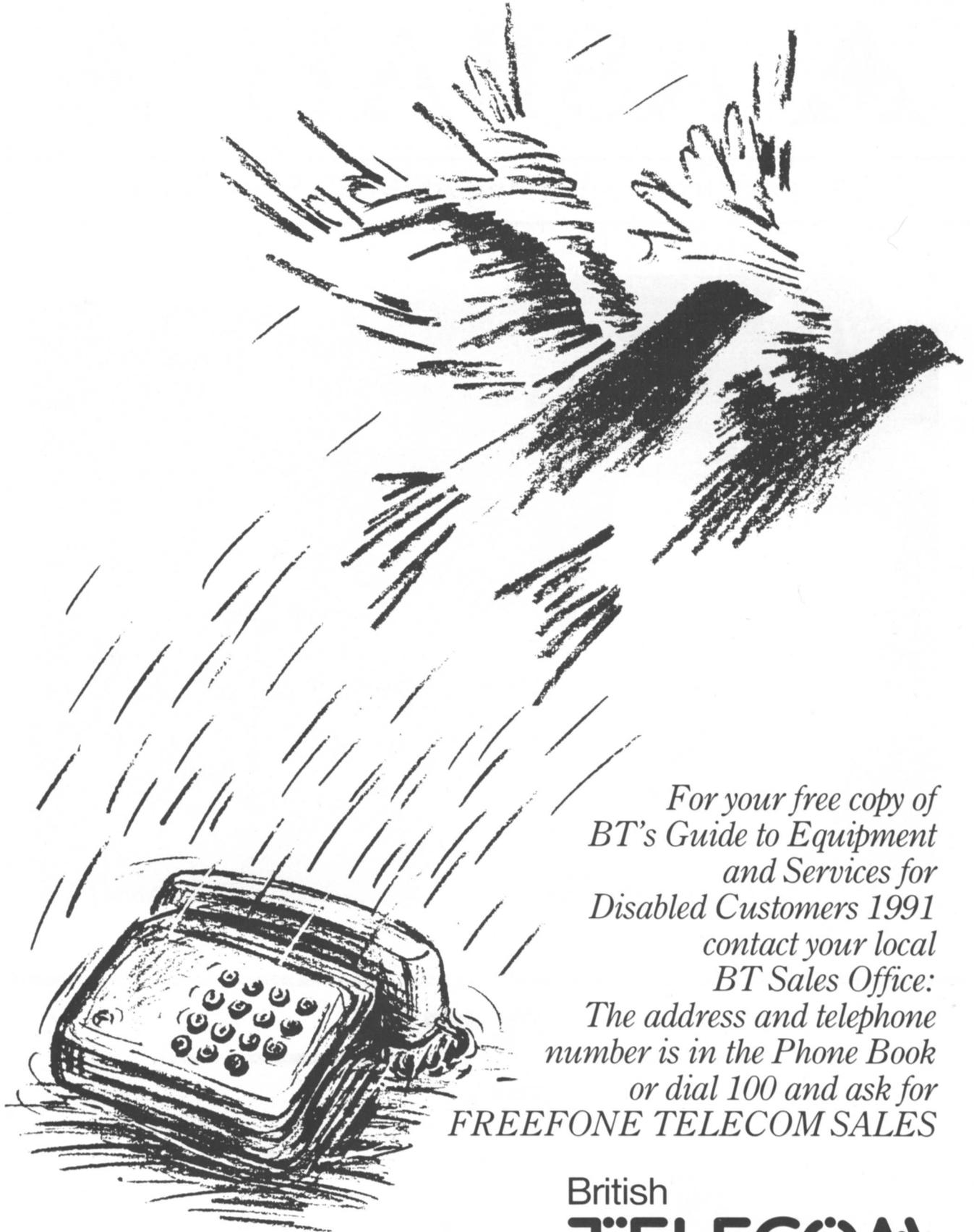
A 12-page feature marking ASBAH's Silver Jubilee



25

YEARS

Action for Disabled Customers



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Happy Anniversary

Robert Zachary, founder chairman of ASBAH, sends his congratulations and best wishes from his home in Australia. This was his message:

"I was privileged to hold the position of chairman for 10 years, during which time I had the wonderful help of doctors, non-medical staff and parents who gave unstintingly of their time.

One of the most important lessons we learnt is that each child is unique; there is only one such person and whether he or she is small or large, with no paralysis or without movement in the legs, they are all worthwhile.

They deserve all the help we can give them to reduce the disability to the minimum and develop their capabilities to the maximum. They should not be discriminated against just because they are disabled; most of all, they all deserve to be loved.

It was only after the appointment of Mary Oughtred as permanent staff member that real progress was made by the association. That impetus has been continued in a most marvellous way by her successor, Moyna Gilbertson. Her influence on the development of ASBAH has been so enormous that its future is assured.



Sharing our birthday

Michelle Pearson, pictured on page nine, shares her 25th birthday with ASBAH, and as she's grown up with the Association she's been able to call on us for advice and practical help...

A new electric wheelchair made life a lot easier for Michelle - it meant that husband Alan no longer had to tow her up the hill when they went out!

Alan, who is himself disabled, used his electric wheelchair to pull her along the streets of Newcastle.

The purchase of the chair was made possible by a donation

from ASBAH, combined with fundraising within the couple's own community.

Advice on schooling, welfare benefits and even the chance of a



Michelle and Alan on their wedding day

specialist holiday in Florida assisted Michelle's parents to make her life a little more comfortable.

Michelle, aged 25, married Alan four years ago. He has severe arthritis and they met at a social centre for disabled people.

Alan takes up the story:

"Michelle used to have a really heavy old-fashioned wheelchair and could not manage the hills on her own. One day a police officer saw me pulling her along, and soon afterwards they bought me an electric chair."

Later, the landlord of a local pub 'adopted' Michelle and began to raise money to buy her a similar chair - since then they haven't looked back.

Throughout her childhood and teens, Michelle and her family gained valuable support and advice from ASBAH fieldworkers. In particular, there was lots of help when the couple met and decided to marry.

Sandra Wheatley was their fieldworker at that time and she helped them obtain an ASBAH grant for equipment. Sandra became 'one of the family' and the young couple have kept in touch even though Sandra is no longer actively involved with ASBAH.

Judith Wojtowiz

ASBAH's London Reception

THERE was real warmth in the welcome as, under the cover of the opening event in our silver jubilee celebrations, a reception held at Westminster by ASBAH last month turned into a tribute to executive director Moyna Gilbertson.

Miss Gilbertson, who retires at the end of April, found herself at the receiving end of kind words and a surprise presentation subscribed to by friends and colleagues in local associations and other organisations - a video and a cheque to go with it.

"I shouldn't be having prezzies at all because I have gained so much from ASBAH over the last years", she told the crowd of well-wishers at the Queen Elizabeth II Conference Centre opposite Westminster Abbey.

"Several times in recent weeks, people have been kind enough to comment on the professionalism I have brought to the job. That has made me very happy because I think it is so vital that voluntary organisations are seen to be what they are - professional.

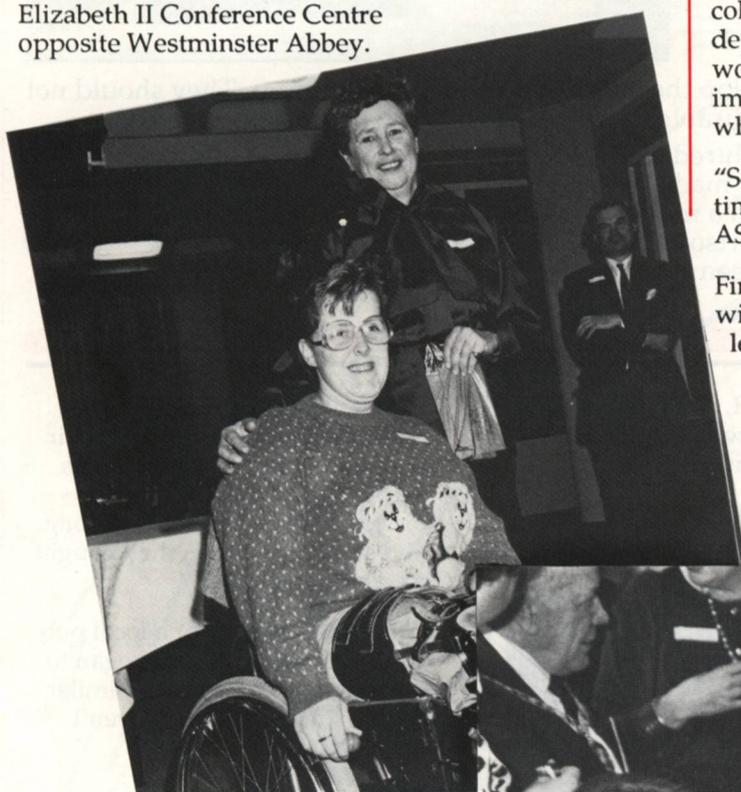
"But actually it was made easy for me because I have been working all the time with such professional people - ASBAH staff, you, my other colleagues in voluntary organisations and how vital that has been, particularly where we have stuck together through thick and thin over some rather traumatic patches.

"I have also been very lucky in finding so many colleagues in statutory authorities, government departments and both Houses of Parliament and in working with people who, in our terms, are the most important professionals of all - parents and people who themselves have disabilities.

"So you see, I have been receiving prezzies all the time, though some things I think I can leave with ASBAH.

First, my complete confidence in its future. I know it will go from strength to strength and its efforts will lead towards the comprehensive services to which we are all committed. I leave my enormous respect for its officers, committee members and staff. And, of course I leave my love.

"Thank you for all the support and friendship I have received over the years and for allowing me the great privilege of being



Trafford and Salford Association member Kay Burgin is greeted by Moyna Gilbertson.



Minister for Disabled People Nicholas Scott, centre, in conversation with Andrew Robertson a former member of the Prince of Wales Advisory Group, and Baroness Masham.

part of ASBAH."

The presentation was made by Peter Thurnham MP, with whom ASBAH has worked on a number of campaigns. Her strength of character was probably due to the fact that she had been a physiotherapist, he joked.

Beverley Holland, who was ASBAH's information officer for some years and now heads Southwark Disability Association, then spoke about the importance of ASBAH's work among people with disabilities.

A formal toast to ASBAH was proposed by Nicholas Scott, Minister of State at the Department of Social Security who has special responsibilities for people with disabilities.

Patrick Daunt, ASBAH chairman, said in reply that it was important for the reception to be held at Westminster to remind Parliamentarians, Whitehall civil servants and heads of other charities that, despite the transfer of National Office to Peterborough last year, ASBAH was still in existence and still going strong.



John Lewis, Executive Committee member chats with Finance Director, Derek Knightbridge and Andrew Russell, Executive Director Designate.



Moyna Gilbertson with Nicholas Scott.



Chairman Patrick Daunt welcomes Rachel Hurst (British Council of Disabled People) and Baroness Masham, ASBAH's Vice President.



SPECIAL PEOPLE

Many special people have been involved with ASBAH during its first 25 years - parents, professionals and clients - but we've also had our fair share of celebrities to share our success.

Here are some of those famous faces who've helped ASBAH hit the headlines.



The Changing Medical Perspective

Mr Duncan Forrest FRCS, formerly on ASBAH's Executive Committee and the Medical Advisory Committee, looks back over 25 years



It is difficult to believe that ASBAH is 25 years old until one remembers the great changes that have taken place in the medical management of spina bifida and hydrocephalus over that period.

In the mid-sixties there was no pre-natal diagnosis, and so each birth was a terrible shock to the parents. Nevertheless, we had passed from a period when such a birth was greeted by despair into one where, in many centres around the country, doctors were hopeful that early, active treatment would be able to give a greatly improved outlook. Indeed, they were often over-optimistic and consequently, virtually every child was referred for treatment at birth. Those of us who had studied the problems in the Society for Research into Hydrocephalus and Spina Bifida were convinced that early operation to the back gave the best chances for improvement of movement and function in spina bifida, and we had seen the great benefits of shunting of hydrocephalus by the Holter and similar valves. The result of this increased interest, combined with something of an epidemic of births of spina bifida babies, was that there were suddenly far more survivors than in the past. It was the parents of this new generation who were responsible for seeing the need and setting up the infant ASBAH.

At first, nearly all the attention of the new Association was centred

on the problems of infancy and childhood. As new problems arose in the orthopaedic surgery and physiotherapy of the limbs, in the control of urinary incontinence and infections, and in maintaining the control of hydrocephalus, we had to learn new skills and techniques for the treatment of older children and, finally, of adults. Also, many other skills than the purely medical ones were brought in as our experience grew. The importance of educational, social and psychological considerations became more apparent.

As always happens, increasing experience led us to modify our early enthusiasm when it became clear that our policy of operating at birth on virtually every spina bifida infant not only had led to greatly increased survival but also that some of the most severely handicapped babies could never be much improved.

Fortunately, the natural incidence of spina bifida began to decline and the ability to detect spina bifida before birth by testing for alpha-feto-protein made for a rapid decrease in the number of cases being born.

Many of these developments were brought about or influenced by close co-operation between ASBAH's Medical Committee and the Society for Research into Hydrocephalus and Spina Bifida. Professor Robert Zachary, the first chairman of ASBAH, and

Professor John Lorber, who chaired the Medical Committee, for many years provided strong leadership and initiated many important projects. ASBAH has encouraged and often financed many of the research projects which have greatly improved our knowledge and ability to treat the very complex problems which have been thrown up by improved survival of children born with spina bifida. These studies have ranged from the most basic aspects of the development of the fetus and reasons for the abnormal development of spina bifida, the normal and abnormal flow of cerebro-spinal fluid and the development of hydrocephalus, to surveys of the late results of various forms of treatment, some of which profoundly influenced our management of patients. Probably those with the most fundamentally beneficial effect were those which established the maternal alpha-feto-protein levels as a reliable test for the presence of spina bifida, and the surveys which set out to establish whether or not folic acid has a truly preventive action. Dr Roger Bayston has been active, both in the Research Society and with ASBAH generally. He is the leader in the field of infection in hydrocephalus shunts, and has not only established reliable methods of identifying colonisation, but also devised methods of preventing infection in the first place. Carole

Sobkowiak has give detailed attention to many physiotherapy problems, notably an assessment of the Peto method of "conductive education".

One of the curious facts of the early days of the active treatment of spina bifida, at least in the UK, and of ASBAH was that most of the emphasis was on the infant and young child and most of the treatment was performed in children's hospitals. Consequently, when these children grew up they had to be transferred to adult hospitals, often with different consultants to look after them. These transfers were often traumatic because of the very different types of hospital. It is important, therefore that we understand and make provision for the growing number of older spina bifida patients. Dr Martin Bax has been studying the fate of adolescent and young adults in North London. The need for long-term follow-up is clearly shown.

Over the past 25 years we have seen many new diagnostic

techniques being developed. Notable among these is CT brain scanning which has revolutionised our ability, not only to diagnose hydrocephalus, but also to closely follow its progress under treatment and the onset of complications. Ultrasound scanning has become a very precise diagnostic tool. It is used routinely on pregnant women, not only to assess the pregnancy, but also to detect developmental abnormalities, including spina bifida and hydrocephalus. It is also used to study the brain in the infant after birth until the fontanelle closes. It has greatly improved our ability to diagnose hydrocephalus early and to monitor its early treatment.

Experience in the treatment of the deformities of the spine and lower limbs has greatly increased our understanding of the place of operative treatment and the role of physiotherapy, and new and greatly improved methods have developed over the years.

The management of urinary

bowel incontinence has also been much improved with better methods of training, the development of continuous and intermittent catheterisation, and new operations on the bladder and its sphincter. Parallel with these developments has been improved understanding of control of infections by free and healthy drainage of the kidneys.

What will the future hold? There is no doubt that in the next 25 years there will be many more improvements in our understanding and management of spina bifida and hydrocephalus as we continue to learn from the past. We know that expert treatment is expensive, and therefore, in a health service which is short of money there may well be battles to be fought for the resources that our patients need. We are fortunate that ASBAH has grown into an active and influential body well placed to ensure that the necessary research is organised and that the provision of good care continues.

LINK

Hundreds to Thousands!

LINK magazine, distributed these days to around 7,000 readers, has its roots in a local newsletter started by a parent in Sheffield, long before the Association was set up.

Stephen Hinchliffe, whose son Andrew was about two at the time, volunteered to produce a newsletter for a parents group formed locally in 1964.

"I'd dabbled with the church youth club newsletter, my wife doing the typing and copying," he recalled. The first edition ran to 200 copies.

When the national charity was incorporated, this newsletter

became Link, and Stephen its first editor. Before long, the original Sheffield branch newsletter had increased to 1,000 copies and took on a more professional 'look'.

Simultaneously, Stephen was heavily involved in the development of the national association, and it was inevitable that he would be asked to produce a national magazine.

"This was on a totally different scale, and would need to be professionally produced. I had ideas and ambition, but I knew I needed help; to make it fully national, we would need help from different parts of the country."

By chance, Stephen came across a journalist working on a national daily, whose daughter had hydrocephalus. Her husband was a sub-editor on another national newspaper. "They were both keen to help; while I provided the early ideas and looked after the publishing of the first few issues, it was their real expertise which

produced a readable and interesting magazine," said Stephen.

"I'll never forget that first issue. The printing was being done locally in Huddersfield, and we decided to be ambitious and go for 5,000 copies.

"Unpacking them on my living room floor brought the realisation of the scale of what 5,000 glossy 16-page magazines looked like! The smell of the print and the paper is what lingered most. But the size of the job we faced in posting them to various English-speaking parts of the world determined me to let the printer do the distribution from then on!"

In those early days, Link cost one shilling each, and the production team comprised members from as far as Scotland. Two years later, the editor's chair passed to Mavis Cotsford, but Stephen remained an active member of ASBAH, and a constant source of support to his growing son, Andrew.

LOOKING BACK

Alan Twyford pictured with his wife Margaret. Alan is a former executive committee member who has spina bifida.

"I have been involved with ASBAH since an initial meeting in London in 1966 when it was a small organisation sited in City Road. At that time involvement of a person with spina bifida was somewhat unusual but a major change has taken place over the past quarter century with the growing participation of those with hydrocephalus and spina bifida as employees and members of local associations.

Over the years I have benefited from ASBAH in several ways. Initially, a local association provided me with a link with other families with children and gave me the opportunity to offer encouragement to some of them. In turn this increased my confidence in meeting people, public speaking and committee work. But the greatest advantage it brought me was to introduce Margaret into my life from 1968, when she wrote a letter printed in LINK, to which I replied. We married and settled in Tolworth in 1971.

The development of the fieldwork



service has been another benefit. Pioneered nationally by Mr Harold Macfarlane it has provided us with much needed advice and encouragement both personally and for local associations.

With the formation of ASBAH and its local associations (many of which are independently registered charities) the situation of those with spina bifida and/or hydrocephalus has changed greatly since Margaret and I were born in 1945. Then our parents had to contend with the statutory services which were far less developed and accessible than today. How useful it would have been to have had the benefits of Mobility Allowance, the 1981 Special Education Act and Attendance Allowance, let alone the support which parents have had since the early days of ASBAH when they could meet parents in a similar situation. And the instigation of independence training has given parents the

opportunity to realise how much physical and emotional support they are providing for their children and helped them to plan better use of their time and energy.

A recent development which would also have been so useful to our contemporaries is the professional counselling service provided by ASBAH. Mobility courses, advice on disabled living and on education and housing have all given help and encouragement to families. Whilst the staff concerned have also provided useful information to help influence government departments and local authorities in the provision of services.

One of the aspects of ASBAH which we have enjoyed being involved with has been in the writing and production of information leaflets and booklets which cover a wide range of topics. Many of these have been on subjects which had been neglected by similar organisations - such as personal relationships and bereavement. LINK and local associations' magazines have always been avidly read by us and will continue to be a source of much information and encouragement.

What of the future?

ASBAH has had an exciting and varied development and plans for regionalisation are a further mark in its life. My hope is that in regionalising, ASBAH will develop and combine the best advantages of both locally-based membership and the contact and strengths which a lively national office can bring".

LOOKING FORWARD

Future relationships

- ASBAH and the local associations

What should be the relationship between National ASBAH and local associations? David Bridge, a member of a local association raises some questions for discussion.

"What are the differences between the national and local associations? Could it be that most of the local association people have spina bifida and/or hydrocephalus, or are relatives of those with the

condition? Are most of these people working in a voluntary capacity to raise funds and provide help whilst having full-time jobs and families, whereas ASBAH employees are professionals within their field and perhaps don't have to juggle all these factors.

Perhaps we need to appreciate each other's role more, in order to serve better the spina bifida/

hydrocephalus community. I certainly feel we both need to be working together to overcome the hurdles of day to day living, encounters with local authorities, prejudices, non-awareness and so on. After all no one group of people is any better than the other, each is entitled to their viewpoint and we will achieve more from working together and listening to others' points of view. We must recognise, however, that some team members have more time available than others and that some have a more personal interest at stake.

I know from discussions with other local associations that some people feel that over the years ASBAH has

distanced itself from the grassroots membership but it is encouraging to know that the 'Fund a Fieldworker' campaign will be a joint approach with local associations to local businesses, only time will reveal how well we work together.

The expansion of the Fieldwork service should be good news for all of us but perhaps some might see it as taking over some of the contact which local associations have with the people, be they established members or new families. Are all local associations aware of every referral, so that local newsletters can be sent to new families to show them what local associations have to offer? Some families may not want contact initially but they may not realise the amount of experience and comfort available to them just from sharing personal experiences. This raises the question of where the line of confidentiality should be drawn, should all local secretaries be given the names and

addresses of every new referral to fieldworkers?

The recent introduction of the education co-ordinator is a step which, from personal experience, I do feel is extremely helpful to those faced with an intransigent education authority. It is also very useful to have the help of a professional who has experience of the Statementing process from the education authority perspective. In order to provide an adequate service throughout the UK for the future is it necessary for Regional Offices to have an educational co-ordinator?

How best should ASBAH and the local associations communicate whilst still keeping administrative costs such as printing, post and packing under control? I picked up several useful information sheets whilst at ASBAH House which I did not know existed. Should a list of information sheets be printed annually in LINK?

I hope that these questions have got you thinking, is so please send any letters to LINK".



Editor's note

In response to Mr Bridge's question on regional education co-ordinators we can say that we do recognise the need for more advisors and that this will certainly be reflected in the overall regional development. At this stage it is not possible to say if each region would need its own advisor, or whether, for example, an advisor could cover two regions adequately. What we can say is that decisions of this nature are based upon communications between central office, fieldworkers and the local associations.

With regard to information sheets, we will print a list of those available, in LINK, we already do this for other ASBAH publications as well as a LINK index to past major articles.

25 A joint celebration

Leeds and Bradford Districts ASBAH, like National, is celebrating 25 years of existence. There have always been very close links between the two and it has been like watching a family grow.

Looking back, the nature of the work of the local association has changed dramatically. We used to have a lot more direct personal contact with our members; there were regular meetings and activities, whereas now we are primarily a source of information.

There are many theories why these changes have occurred, such as better and informed support from the statutory services; more financial assistance; and ASBAH's fieldwork service advising and supporting families. All of these have come about as a direct result of the work done by ASBAH and similar groups in lobbying, educating, and training on a national scale. Locally good relationships have been established with education, health and social

services. And we've worked in partnership, with mutual benefits, with Five Oaks, which is in our area.

As we prepare for our own 25 year celebrations we'd like to share some of our reminiscences with LINK readers.

In the early days we had open meetings every month, with a creche provided, regular Saturday morning playgroups for the younger children and discos in the evenings for the older ones. We had Christmas parties - though when 500 children attended, one father who was also a fireman, would not come near!

Some members had difficulties arranging holidays and the children were getting bored in the school holidays. We gradually got two static holiday caravans and, although not the original ones, we still do have two holiday homes which are very popular with the members. To counteract the holiday

boredom some playschemes were started - again these were successful and the Local Authority took these over in conjunction with Barnardo's.

Austin Crowther from Calderdale ASBAH, together with his band of helpers, arranged holidays for youngsters. For many these were the first separations for the families - perhaps it's just as well that parents were unaware of some of the adventures!

As ASBAH has grown so have our own families. For our youngsters we have an active LIFT group and help and advice on independent living. The younger children no longer want the activities we used to have but we them and their families informed on new aids and developments, legislation, local activities etc through our local newsletter.

We've all made many friends through the ASBAH network and though we do get tired we enjoy the friendships and rewards of seeing youngsters develop into happy adults who are capable of directing their own independence. It has been a good 25 years for ASBAH - we all look forward to the next 25....

Jo Baxter.

Colourful Beginnings

A PROFESSIONAL belly dancer was one of the colourful characters who added 'a bit of spice' to the more serious work of ASBAH in its early days.

Soraya was the most charming wife of the association's first fundraiser, and it was inevitable that we coined the slogan 'dancing in the Casbah for ASBAH'!

A number of startling adventures followed the appointment of our official fundraiser, who came to us not only with his wiggling wife but a mobile zoo and a vintage Rolls Royce.

The mobile zoo presented certain problems, as it comprised a driver, and a van of doubtful parentage which tended to break down late at night on Salisbury Plain on the way from schools in Dorset on Tuesdays to schools in Yorkshire on Wednesdays.

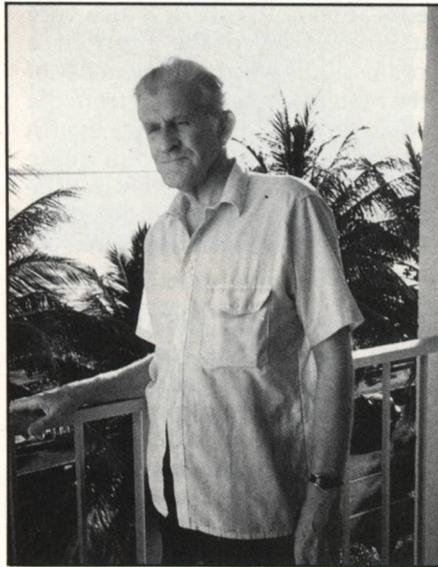
It seemed the bookings clerk had little knowledge of geography, or of the feeding habits of animals in captivity.

A scheme to sell the turf from Wembley Stadium seemed more promising but we had to store the turves in a hotel foyer somewhere and they proved difficult to send by post to willing buyers at £5 a time. This time, it was the worms which were not fed!

The final straw was letters to the Kremlin, the White House and No 10, proposing the sale of the Berlin Wall brick by brick in aid of spina bifida - a progressive idea and way ahead of its time, but nonetheless a great PR exercise.

Publicity was much needed in those early days, to support our fledgling organisation set up on behalf of the rapidly-growing number of parents requiring advice and guidance following the increased survival rate in the early Sixties.

Professor (then Mr) Robert Zachary



A lighthearted look back at our first 25 years by Frank Armour, the Association's first elected secretary.

and a small number of medicos saw the need and met with a few promising parents one memorable day in Sheffield to form a parents group. Within weeks, these pioneers were involved in the interminable business of creating a legal framework for the organisation.

Such were the delays that, before the first formal meeting could be held in Birmingham, a frustrated and vociferous bunch of parents were ready to overthrow these pioneers and elect a committee to 'get on with it'.

This was the hot potato I received, as the first elected Honorary Secretary. Mercifully, Robert Zachary, Duncan Forrest and John Lorber survived the upheaval to provide continuity and medical input to the new committee.

We had no name and no money. But with just £200 in the bank and

a lot of faith, consultants were appointed to publicise our cause and to raise money - lots of it. We prayed there would be money left over to continue the work at the end of their contract. Singer Harry Secombe launched the charity at a function in London in March 1968.

Our first full-time organiser was Mary Oughtred, who added a delicious sense of humour to her enormous determination and capacity for hard work in the less-glamorous fields of social work, welfare, educational advice, aids and appliances (how words do change their meaning) and more conventional fundraising methods.

The rapid expansion of our work under Mary and her successor Moyna Gilbertson, involving closer links with local associations and with legislators in Whitehall, the growth of the fieldwork scheme, the opening of Five Oaks and the development of Link and Lift led to successive moves to larger premises.

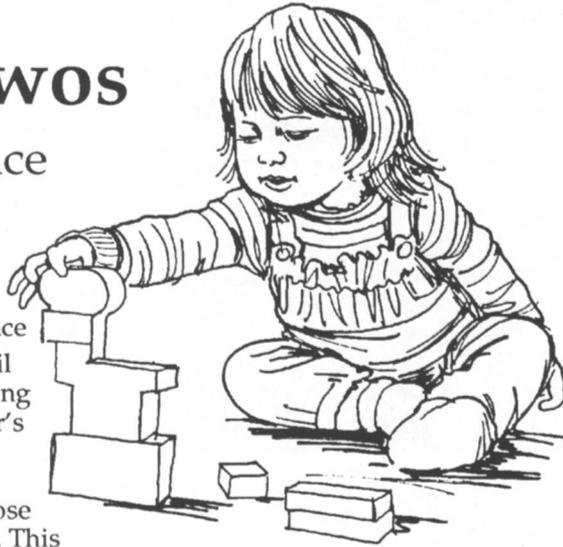
Each move brought its own trauma, engraved on the memories of those concerned. And one must not forget such heroes of those earlier times as the late Kate White, 'Mac', Olwen Nettles, Felicity Birkett, Judy Kay, Sue Gearing and a host of others without whom the work of today would have been impossible. And, of course, we should remember the equally tireless volunteers who gave so unstintingly of their time.

My lasting memory is of one friend who described us as 'We happy few, we band of brothers' who were infected with the urge to put our cause on the map in days when spina bifida was unknown to the public (it was even confused with famine-ridden Biafra), when parents knew more about it than their own GP, there was nothing in print and such things as a disablement allowance or an orange badge were unknown.

We did at least get 'spina bifida' into the Shorter Oxford Dictionary! Kate White would have called this a cause for 'modified rapture' - what more could we ask?

Under twos

- attendance allowance



The age two bar on attendance allowance which applied up to April last year is illegal according to a recent Commissioner's case. In the 1975 Act no power was given to the Secretary of State to impose an age limit for payment. This means a number of claimants, who were entitled to the allowance before their second birthday, may be due up to 18 months' payment. But establishing entitlement to claim could prove difficult for those for whom it is up to 19 years late.

If you originally made a claim which was refused on age

grounds by the DSS Adjudication Officer, you should appeal to a Social Security Appeal Tribunal giving the reasons why the appeal is late.

If you never had a decision from the Adjudication Officer but were only sent a leaflet to say the allowance was not available to

children under two, you should take one or both of the following steps.

- ☛ Ask the Adjudication Officer to make a decision now. If this decision is unfavourable you should appeal to the Social Security Appeal Tribunal.
- ☛ Ask for a previous claim for supplementary benefit or income support to be treated as a valid claim for attendance allowance.

Those who never made a claim should pursue both these actions to establish that a claim was made in all but name.

A pro forma is available from ASBAH to send to the DSS to register your claim. Copies are available from Mary Malcolm, assistant fieldwork manager, at National Office.

Training in Disability Benefits

The Disability Alliance is running several courses on benefits during the spring, mostly aimed at benefits advisers, they include:

2 May - Medical Appeal Tribunals and Social Security Appeal Tribunals. The aim of this course is to prepare advisers for representing claimants at both MATs and SSATs.

14 May - Attendance Allowance Reviews. A course designed to improve advisers' skills for challenging unfavourable attendance allowance decisions.

21 May - Incapacity for Work. To help advisers tackle reviews and appeals on incapacity for work issues.

11 June - Disability Benefit Changes from April 1992. A seminar which provides an update on new legislation due to come into effect next year. This day is not limited to advisers but participants should have a firm understanding of current benefits. This course will be repeated on 27 June.

Venue - The courses are held at 336 Conference Centre, 336 Brixton Road, London SW9, which is fully accessible. For more details contact Disability Alliance on 071 247 8776.

HALLIWICK COLLEGE

A ROUTE TO ADULTHOOD FOR STUDENTS WITH DISABILITIES

BASED in North London we offer a wide range of courses in Further Education for students of 16 plus with all types of disability.

Intensive independence and life-skills training in custom-built bungalows is supervised by a staff of specialist tutors, therapists and carers.

For further information please contact: Julie Durham, Manager or Marion Sampson, Assessment Manager, Halliwick College, Bush Hill Road, London N21 2DU, tel 081 360 2442 or send slip below:

Please send me a Halliwick College Brochure.

Name _____

Position _____

Address _____

Halliwick is administered by ICAN

LINK 4/91

A varied response

We have had a very varied response to the letter on conductive education published in our February issue. Not only did it produce further comments on Peto and conductive education but sparked off letters on the wider aspects of disability and independence. Christine Helliwell was moved to write about her fight for an independent lifestyle and Tracy Gates gives a personal view of the first stage of getting a child accepted for a course at the Peto Institute for conductive education in Budapest.

behind. "There you see, he stands", she said with satisfaction.

It may seem to some that she was trying to make a reality from an illusion and yet that single moment of having somebody else believe in his ability to stand was enough to make Samuel want to try it over and over again. "Up, mummy, up", has echoed through my ears several times a day ever since!

At the end of the assessment Samuel was offered a place at the Institute and we hope he will have started by the time you read this.

My view of conductive education is that it's not just about teaching a child to walk. It is a way of life, it is an attitude - a positive belief that you are capable of more than the narrowmindedness of society's expectations would have you believe you are. It is about learning what you want to achieve. It is not the place to go if you are looking for a miracle - Peto does not deal in the business of miracles, but in results borne out of long hours of dedicated persistence and sheer hard work.

Even from the glimpse I had, I could sense that the atmosphere is positive, the aim is achievement and the outcome is success. The conductors do an incredible job. Not only are they involved in extremely demanding physical work every day from nine to five, they are also not afraid to be involved emotionally. There is evidence of such feeling and humanity that is sadly lacking in modern medicine.

I didn't come away a 'convert' or narrowmindedly blinkered. I did see evidence of quite pronounced physical deformities that may well be attributed to the absence of any orthopaedic appliances. I saw exaggerated lumbar lordoses that may well have developed from the sheer strain of using joints that are congenitally weak. It raised the question, in my mind, as to how long some of those children would be physically capable of standing

Assessment for Peto

// Samuel was born on 20 December 1987 with spina bifida (lower lumbar region), hydrocephalus and severe talipes. Three years on, he is a vibrant, noisy, shrewd child with perfect hearing and eyesight. But for many long months we struggled against the bleak prognoses and the negative influence and prejudices of society until the lack of willingness of anyone in authority to give us any sense of hope began to pull me down.

And so, after much soul searching and repeated swings in my decision making, in the summer of 1989 I wrote to the Peto Institute in Hungary, requesting that Samuel be considered for an assessment.

I did my research thoroughly - I spoke to teachers, physiotherapists, doctors and parents of Peto children. I wanted to be clear in my mind what CE was offering. As both a medic and a mother of a child with spina bifida I felt I could judge reasonably objectively how and if Samuel would benefit.

I had to turn down the first assessment offered by Peto when our orthopaedic surgeon decided major surgery was needed on Samuel's right hip and feet followed by three months in plaster. I was torn between Hungary and surgery but I couldn't gamble with Samuel's future. I was forced to trust

professional judgement - Peto had to wait.

A year later we got our second chance and flew to Budapest on 25 September 1990.

The conductor who assessed Samuel spoke good English - not always the case - and having obtained background information from me on the pregnancy and birth she turned to Samuel. I was thankful that he answered all her questions correctly and did all that was asked of him without fuss or tears. I kept wanting to tell her all the things that he could do and elaborate on his strong points, knowing that 30 minutes was all I had to influence her decision. But it became increasingly apparent that she was looking for specific things in Samuel, and assessing his general potential and not just his present capabilities.

There came a point when she asked Samuel to stand up and I explained that he couldn't stand without his callipers. She asked again and I began to feel that there was a language problem arising and insisted quite emphatically, "No, he cannot stand at all!". She simply replied, "Oh, I think so".

With this, she sat him on a wooden stool in front of a ladder-back chair and got him to 'crawl' up the chair as far as he could pull his body weight. She then held his knees locked from

before their vertebrae literally 'gave up'. And yet how are we to know, if we wrap our child in cotton wool and give them the 'comfort' of a body brace or a wheelchair from the word go, that we can protect them from secondary scoliosis, lordosis and the like. And if they have only a few years on their feet that is an experience which, in itself, will teach them a great deal about achievement, independence and self-confidence.

Conductive education is not the answer for everyone. Some people move on, looking for something else, but for Samuel I believe that Peto will provide the opportunity to learn the true extent of his capabilities without being limited by the negative expectations which arise from scientific technology. I am fully aware of the value of modern medicine - without it, Samuel wouldn't be alive. And yet I am also aware that so much time,

effort and money is spent on what can be done surgically that not enough value is placed on what can be done for the person. A person is more than a collection of two arms, two legs, a spine and a brain. The achievement of a child in his formulative years is largely determined by the degree of encouragement from his peers. It is in this area that the concept of conductive education scores top marks. //

Winning the fight for an independent life

CHRISTINE HELIWELL is now 44 years old and an analytical chemist she wrote to tell us how, helped by her parents, she has achieved success.

"I am writing this letter having read an article about the Peto Institute in LINK.

I am a spina bifida. When I was born my parents, like many others, were told there would be little hope of me having a very good life. But they fought very hard to make me independent even though a large number of people were against their attitude.

I attended a baby clinic and then the school clinic as they managed to get me walking. It took a lot of hard work and patience but because they encouraged me to do exercises and spent time with me I can now walk without any aid of any kind. This is in spite of nerves being damaged to one set of muscles in my leg. As soon as she could, my mother let me travel on the bus to and from the school clinic on my own.

Around the time I was born it was expected that disabled people should be hidden away and that they were unable to benefit from a normal education. From the age of six my parents managed to persuade the education authority to provide a retired teacher for me for two hours a week. They fought continually to get me into a normal school and, at the age of

10, I was accepted at Parkinson Lane Junior School, from there I went to Haugh Shaw School. I started at the bottom of the bottom class and worked my way to the top of the middle class.

Another turning point in my life was when I joined the Brownies, at the age of eight, I saw other children achieving things and wanted to do the same. I fought hard and even though it did take longer sometimes, I did almost always achieve the same as the other children.

In my teens I became a Sunday school teacher and a playgroup helper. Before I left guides I was made a guide assistant and then a brownie leader. I am now assistant to the local association for the disabled.

After leaving school I studied for my GCEs at night school, and worked at a printing firm making hand-made carrier bags. I now have a degree in chemistry and am an analytical chemist for an agro-chemical firm in Bradford.

I have my own home, I do not have a home help and do manage to do all my own cleaning, washing and shopping myself as well as working full time.

My bladder and bowel have been



badly affected by spina bifida but I now do intermittent catheterisation and manage to keep dry most of the time.

I often travel on my own on weekend coach trips to London to see the big shows - I have seen Cats, Phantom of the Opera and Aspects of Love this way. I always travel on holiday on my own and have spent many weeks in Scotland.

In many ways I have had a more worthwhile life than many able bodied people. I have never regretted attending a normal school or learning to walk. I have reached total independence, only asking for help when I am too ill to cope on my own, which is almost never. When my parents are no longer around I know I will be able to manage. Many more spina bifidas, if encouraged in the right way, could lead a very full life".

Problems with schooling

"My son Lynton was diagnosed as having hydrocephalus at the age of three months and a shunt was fitted. The reason I write is to tell you of the problems we experienced during the first few weeks of his schooling.

Before Lynton was due to start school he was seen by an education psychologist and it was agreed that he should attend our local primary school. We were overjoyed at this and it seemed that all our hard work pre-school had paid off. I made an appointment to see the headmistress with Lynton and explained his condition, in depth, and the problems which might be encountered.

The first day of term arrived and Lynton went to school with no reservations whatsoever. But our joy turned sour just a few days into the term. Lynton became withdrawn and quiet, which was totally out of character. The school asked to see me and I was told my son was a disruptive influence and was uncontrollable - characteristics we had never encountered. As time went on the situation did not improve and eventually the headmistress told me the situation was intolerable and another school would have to be found.

I was devastated but agreed because Lynton was not the

The difficulties which may be faced by a child with hydrocephalus starting mainstream school are highlighted in this extract from a letter which was sent to HSG News*. Peter Walker, ASBAH's education co-ordinator echoes the sentiments expressed by this father at the end of his letter and asks parents in a similar situation to contact ASBAH before their child starts school so that any such potential problems can be averted.

same little boy he had been a few weeks earlier. A tutorial unit was found a few miles away but I was very apprehensive. This is when I contacted my local ASBAH. Our fieldworker came to the new school and asked questions I would not have thought of as she toured the unit with myself and Lynton. She was impressed with the answers and thought it would be a good idea for Lynton to attend. He only stayed a short time and was soon back in mainstream education at a nearby school. My son is now eight and holding his own at a junior school a few miles away.

If only I had contacted ASBAH before he started school, all that unnecessary heartache could have been avoided. My advice to any reader whose son or daughter is about to start school, whether special or mainstream, is to involve your fieldworker or ASBAH representative, they will prove invaluable."

Name and address supplied.

**HSG News is a quarterly newsletter for members of ASBAH's Hydrocephalus Support Group. Membership of the group is free and is open to all interested individuals and/or families. To join write to Lynn Thomas, Disabled Living Services at National Office.*

PRODUCT NEWS

Coloured wheelies

Red, blue and yellow tyres now available from GBL services could give your wheelchair a facelift. The tyres are available for wheel size 24" by 3/8" at £12.00 per pair plus £1.99 p&p. GBL claim the quality is that of the grey continental tyres currently available on the private market.

For more information contact GBL Services on 081 569 4195.

Reducing pressures

A new cushion designed to reduce both pressure and shear forces on the skin has been designed by Charnwood Surgical Ltd and incorporates a liquid displacement cell (LDC) within a sandwich of fire retardant foam.

Priced at £85 plus VAT, the LDC cushion is available for adults, small adults and children and the company will consider making cushions for those who need special adaptations. For further information telephone 0664 411311.

Footwear Catalogue

A new made-to-measure footwear catalogue has been produced by Remmedi, the medical division of REMPLOY. The colour brochure enables you to choose your style and leather before the footwear is made. More details can be obtained by telephoning 0272 277512.

Unless otherwise stated, the items in Product News have not been tested by us.



Mobility Roadshow

THE BIGGEST show of its kind - Mobility Roadshow 1991 - opens on Friday 21 June and runs for three days. The show promises opportunities for seeing and test driving a wide range of the latest adapted cars (*providing you hold a provisional or full licence*). All the test models will be fitted with dual controls and visitors will be accompanied by an experienced driver when trying vehicles on the test track and private road system at the show.

But there's more to the show than just cars - many other mobility aids will be featured from wheelchairs to tricycles, and caravans to minibuses. Accessories are not forgotten either, seats, hoists and harnesses will be amongst the many items on display. Many organisations which provide services, advice and insurance will also be at the show to offer specialist information.

Facilities on the site include extensive car parking, refreshments, volunteers to push wheelchairs or assist in other ways, ample toilet facilities and, on the Saturday and Sunday, a professionally staffed creche.

How to get there

The Mobility Roadshow is being held at the Transport and Road Research Laboratory, Crowthorne, Berkshire and will be AA signposted from both the M3 and M4. Those travelling by train are advised to go to either Wokingham (from London Waterloo) or Reading (from London Paddington) both these BR stations are wheelchair accessible and there will be a frequent accessible shuttle bus service from these stations to the show. The organisers are hoping to run an accessible bus service from King's Cross and Euston to the venue. For further details on travel and accommodation for the show telephone 0344 770463 or 071 276 5252.

Reduced Rates for AA

Special terms have been agreed with the Automobile Association for disabled motorists, whether they are joining for the first time or are already a member of the AA. The scheme organised in conjunction with RADAR allows Orange Badge holders a 12.5% discount on comprehensive membership - which covers Roadside Assistance, Relay (taking you to your destination after a breakdown or accident) and Home Start (for when your

car won't start at home.

For an application form write to The Manager Group Membership, Membership Division, AA, PO Box 50, Basingstoke, Hampshire RG21 2BR, stating that you wish to join the RADAR scheme.

Last Call for Sweden

LINK readers from America, Italy and Britain have contacted us for more information on the 1991 conference of the International

Federation for Hydrocephalus and Spina Bifida (IFHSB) since we featured it in our last two issues. The conference is being held in Sweden, in August, and those wishing to attend the conference itself, or the Family Week or Young People's Programme, are reminded that fees must be paid before 31 May.

If you would like further information about the conference or the activities based around it contact Teresa Cole at National Office.

Call for new initiatives from the tourism industry

THE HOLIDAY CARE SERVICE is hoping to focus the attention of the tourism industry on the largely ignored market of six million adults with disabilities in the UK. The HCS points out that this is obviously not a minority market and that the industry should be trying to meet people's needs not out of philanthropy but for sound commercial reasons.

Following last year's launch of the 'Tourism for All' campaign, the HCS would like to see holiday companies and accommodation providers develop this market and they are calling for new initiatives from the industry: "We can help the industry to develop their services to disabled travellers and can promote their initiatives to the thousands of enquirers we hear from each year".

Let's hope that more companies will take up the challenge so that

disabled tourists can benefit from more accessible facilities and staff trained to be more aware of their requirements.

The HCS offers free information and advice to anybody looking for holiday information - both providers and customers. They publish 240 factsheets covering holidays in the UK and abroad.

For more information contact: The Holiday Care Service, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW. Telephone 0293 774535.

A new hotel?

St Margaret's Nursing Home in Louth, on the edge of the wolds, is considering using the premises to create a two star hotel offering holidays for disabled people. Before they go ahead with the venture they need to establish the demand for the facility and are asking interested parties to complete a questionnaire on likely requirements of their clients. For a copy of the questionnaire contact Mrs Would on 0507 605005.

National Key Scheme

RADAR has published a National Key Scheme Guide listing accessible toilets throughout the UK for disabled people.

Compiled by John Stanford this is a useful reference book for keeping in the car or taking on holiday and costs £3.00 and is available from RADAR at 25 Mortimer Street, London W1N 8AB.

On the move

Disability Alliance has moved to:

Disability Alliance ERA, 1st Floor East, Universal House, 88-94 Wentworth Street, London E1 7SA. Their new telephone numbers are: 071 247 8776 - public line - 071 247 8763 - rights advice line.

Banstead Mobility Centre has also moved to Damson Way, Orchard Hill, Queen Mary's Avenue, Carshalton, Surrey SM5 4MR, telephone 081 770 1151.

Diary Dates

7 May - RADAR training seminar from a series on 'Community Care and the Contract Culture', this one will be Budgeting for and Negotiating Contracts and will be held at RADAR's London office, 25 Mortimer Street, W1. Tel: Rachel Scott, Conference Officer on 071 637 5400 ext 339 for more details.

11 May - ASBAH General Study Day, St Austell, Cornwall, including mobility and incontinence management. Contact Trish Jones, National Office for more information.

13 May - RADAR training seminar, as for 7 May, this time at The Dene Centre, Newcastle. Contact: As before.

18 May - STEPS Conference, 'Preparation, Surgery & Aftercare for Children with Lower Limb Problems', including: The role of NAWCH, Anaesthetics for children, Care of a child in hospital and the community, Indications for physiotherapy. From 10.00am at Nissan Play Centre, Worthing. Admission £6.00, STEPS members free. Telephone 0925 757525 for more details.

28 May - Parents, Families and Professionals - one day seminar on joint initiatives and working together - Castle Priory College, Wallingford, Oxon. Telephone 0491 37551.

28 May - Yoga for Young People with Special Needs - at Castle Priory College - for teachers, parents, care workers etc. Fee £39.

29 May - ASBAH study day in Manchester, 'Incontinence Management' for individuals and parents but professionals welcome. Details: contact Trish Jones, National Office.

8 June - Activity Day at Castle Priory College, Wallingford, Oxon. A shared learning experience for children and adults with disabilities, their families and friends. Cost £7.50 adults, £2.50 children. Telephone 0491 37551.

26 October - ASBAH's AGM will be held at the Royal College of Nursing, Cavendish Square, London. Full details to be announced later.

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Small adverts for the next issue of Link (June) should be submitted by Friday, 10 May. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

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