Link

The magazine for people with Spina Bifida and/or Hydrocephalus

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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Call to join mass lobby of Parliament

A MASS lobby of Parliament to show opposition to the Disability Discrimination Act is set for 2 December – the day before the International Day of Disabled People's Human Rights.

Rights Now – a consortium of independent organisations campaigning for law to end discrimination on the grounds of disability – wants to gather as many people as possible outside Westminster on 2 December to lobby MPs.

On that day, the Employment section of the Disability Discrimination Act comes into force.

A Rights Now spokesperson said: "The more people who turn up to lobby their MP, the more effective we can be. It's hard to keep up the pressure now that the Act has been passed. Don't leave it to others. We need your help to show all political parties that the Act is totally inadequate. We need full and enforceable civil rights."

Set-down point for transport on the day will be St Stephen's entrance from 2.30pm. ***More details on 0171-250 3222.***

Our cover boy Joshua Porritt (pictured left) with his mum Stella and four-year-old sister Yasmin

JOSHUA PORRITT adorns the front of this issue of *Link* and this year's ASBAH Annual Report.

The three-year-old took his first steps in February after undergoing an operation in Sheffield to 'turn' his leg as his feet were pointing inwards. He topples over when he walks sometimes but he always gets up again.

His mum Stella, from Irton, near Scarborough, said: "I didn't know he'd be able to walk until he was 16 months old. When he was born I was given such a bleak picture – I was told he wouldn't even be able to sit up."

Other effects of spina bifida are he is doubly incontinent and lacks feeling down the backs and sides of his legs. He had a third shunt revision for his hydrocephalus in 1994.

Horse riding is a hobby shared by all the family. Mum owns a horse but rarely has time to ride these days. Joshua and sister Yasmin, aged four, ride on Mondays.

Both children attend playgroup once a week, plus 'Stepping Stones' where special needs children, their brothers and sisters are integrated with able-bodied children.

Joshua also goes to another playgroup once a week at a National Children's Home in Scarborough where one-to-one help is available. "He's come on no end since going there," says Stella.

Contents

ASBAH is a registered charity

Cover: Joshua Porritt is the cover boy on this year's ASBAH Annual Report as well as this issue of Link. Story on this page.

Staff news

What's in a name...

CHANGES in the job titles of key ASBAH staff have been introduced by our Executive Committee – but their work remains the same.

In future, fieldworkers will be known as ASBAH advisers, while disabled living advisers will be known as specialist advisers (with the specialism following in brackets – education, continence, mobility and so on).

The titles, particularly that of disabled living advisers, had been causing confusion outside ASBAH, and staff had requested a change.

At present, ASBAH has 38 advisers and 11 specialist advisers.

● SOUTH-East Region co-ordinator Gina Broughton left at the end of September after six years in the post.

Having completed a Management Certificate course, including a project taking a retrospective view of service users' training courses and making recommendations for change, Gina will be taking a couple of months off before deciding on her next career move.

During her 'time out' she hopes to do some training in alternative therapy, perhaps reflexology and aromatherapy, as well as pursuing another interest, photography.

Before becoming co-ordinator, Gina was a London fieldworker for six years.

She said: "I'm 50 next year and felt that if I didn't make a change now it would be too late. I've enjoyed my time with ASBAH and have been proud to be part of an organisation which I believe gives such excellent service to users. I hope to keep myself informed about the progress of the organisation and that I'll be asked to 'help' should the need arise. It has been a real experience getting the region off the ground and watching it take shape – I will certainly miss it. I've met some lovely people and made many good friends and I intend to keep in touch."

Interviews for a new SE Region co-ordinator were due to take place in October.

● ANN Wild, our part-time mobility adviser, left ASBAH at the end of August to become a product executive for Remploy, Britain's biggest employer of disabled people.

She had been mobility adviser for one year, but had been working for ASBAH before that as a London fieldworker.

Ann will now be involved in the design of wheelchairs as well as the usage, so her new job is a natural progression from the ASBAH post.

● ***Ann is captain of the British Women's Wheelchair Basketball Team – turn to page 8 to see how the team fared at the Paralympics.***

● SALLY Valentine, ASBAH adviser for the over-16s in East Sussex, left in August.

Sally made a valuable contribution to the South East Region team, focusing on the emotional, psychological and social needs of young adults, particularly those living on their own.

Former SE Region co-ordinator, Gina Broughton, said: "Sally left to concentrate more fully on counselling – a role she was not able to combine with being an ASBAH adviser."

Sally had been in the part-time job for one year. The vacant position is now being advertised.

New adviser for Lincolnshire

SUE Mason, the new part-time ASBAH adviser for Lincolnshire, started at the beginning of September.

The post is 100% funded by Lincolnshire County Council's Health and Social Services departments.

Sue was formerly employed by Lincoln NHS Trust for six years as a senior occupational therapist, based at Lincoln Hospital.

In the job before last, she worked for Social Services in Lincoln. Before that Sue lived and worked in Sheffield with all ages and types of disability, but mainly with the elderly and with people with learning difficulties.

As an ASBAH adviser, the mother-of-two is based at home in Welbourn, Lincolnshire – about equal distance between Grantham and Lincoln, and between Sleaford and Newark.

She said: "Two things attracted me to the job – the flexibility and the chance to get out and about in Lincolnshire and meet people with different needs."

Sue's ASBAH telephone number is 01400-272456.

Portrait of an Ordinary Hero **– Neil Bigwood – first published in *The Guardian,* starts on page 14**

A Wellcome gift from Glaxo

Dr Martin Bax, chairman of ASBAH's Medical Advisory Committee receives a cheque from Corinne Gordon, corporate communications executive, Glaxo Wellcome

A GIFT of £18,500 to ASBAH from Glaxo Wellcome plc will be used to fund a large study on the developmental progress of 100 babies with moderately swollen ventricles of the brain, from early detection in pregnancy through to the age of two.

The study will provide vital information on outcomes of pregnancies where hydrocephalus is suspected.

It will enable medical staff to give better informed advice to parents on whether the ventricles are likely to return to normal size before birth or whether and how the babies might be affected by physical and intellectual disability in their early years.

The condition affects about one in every 2,000 babies at birth.

Professor Stephen Robson, consultant in fetal medicine, and colleagues at the Royal Victoria Infirmary, Newcastle, are mounting the first full-scale study into mild and moderate forms of hydrocephalus in this age-group, where there are good chances of survival but less is known about life prospects.

Since October 1994, the Northern Region Fetal Abnormality Survey has been collecting information about swollen brain ventricles in unborn babies after routine scans taken between 18 and 20 weeks into the pregnancy.

The donation from Glaxo Wellcome plc will enable a paediatrician to undertake developmental assessments at the age of two on all the infants in the study, using recognised standard tests for physical and intellectual development. The funding will also pay the expenses of families travelling to Newcastle from as far afield as Cumbria and Durham.

ASBAH executive director, Andrew Russell, said: "This generous support from Glaxo Wellcome plc will enable our study to draw conclusions quickly. The results will be of immense value to the understanding of hydrocephalus in the early stages of development, and will help parents make better informed choices in pregnancy."

Officers & Staff

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ASBAH survey to help parents at a most difficult time

Funeral services for children

WHEN faced with such a sad time as losing a child, families are often too overcome by grief to be able to find the most appropriate funeral service, in terms of cost and service.

With this in mind, ASBAH Services Committee asked for a small survey of funeral directors to be carried out to see what was available across the country.

Our survey revealed that many of the large Co-operative Societies offer free services for children. The free service would give the 'basic' coffin or casket and a hearse – amounting to up to £500. If you want more than this you are likely to be charged.

In addition, the funeral director makes all the arrangements, such as contacting the priest or vicar, if wanted, the crematorium or arranging the plot for a burial, ordering the coffin or casket, arranging transport and bearers, buying the flowers, issuing the obituary notice and notifying the family of bereavement services afterwards.

However, the free service does not include paying for the 'disbursements' – that is, the fees to the local authority, minister, grave digger, organist, florist etc. which the funeral director usually pays on the family's behalf.

There are 26 independent groups of Co-operative Society funeral directors in Great Britain.

Those we spoke to – CWS (Co-operative Wholesale Society), with 400 outlets, and CRS (Co-operative Retail Service), with more than 100 outlets, give free funerals to children under 16. United Norwest Co-operatives, with 100 outlets in the North Midlands and North West, do not charge if the child is under 12.

All three groups are members of the Funeral Standards Council. This umbrella body was set up in 1993 by 25 co-operative societies and other independent companies after pulling out of the National Association of Funeral Directors. They made the change because the national association was unable or unwilling to police its code of practice.

According to Kate Edwards, administrator of the Funeral Standards Council, when a child dies, the hospital often offers to make the funeral arrangements but if preferred the family can do it themselves with the help of a funeral director.

She said: "Losing a child is particularly stressful and the funeral director is there to do everything for the family. A good one won't push the family into anything they don't want but will steer them through a difficult time."

The council's national premises officer, Bob Smith, added: "The Funeral Standards Council has a Code of Practice registered at the Office of Fair Trading, and our members have to abide by that code. The council is also responsible for setting up and financing the funeral ombudsman who is there to adjudicate when there is a complaint about a company."

Les Dean

Tribute to one who meant much to so many

A COMMITTED founder member and long-standing treasurer of a local association will be missed in so many ways by so many people.

Les Dean, aged 73, died in July after giving 31 years' service as treasurer to Wirral ASBAH and was a representative on the council of national ASBAH.

He and his wife Betty, now vice chairman, were founder members of the local association which was set up at a time when spina bifida and hydrocephalus were little known about conditions and a self-help group was desperately needed.

Their daughter, Carole, now aged 35, has spina bifida and hydrocephalus and lives at the family home in Upton.

Margaret Appleyard, secretary of Wirral ASBAH, knew Mr Dean for 20 years. She said: "He showed unstinting devotion to the Association. He worked tirelessly for the Association attending most committee meetings until ill health forced him to slow down.

"He'll be missed just for being him. The tributes that have been paid have been tremendous. He'll be missed by so many people in so many ways."

His wife, Betty, added: "He was a very, very good man."

Through his work in Wirral ASBAH, Mr Dean became an active member of other local groups including Wirral Association for the Disabled.

Find out about ASBAH's Clubability Challenge for young people next issue

Triple honours

THREE fellowships – one honorary – have been awarded by the Chartered Society of Physiotherapy to three ladies closely associated with ASBAH.

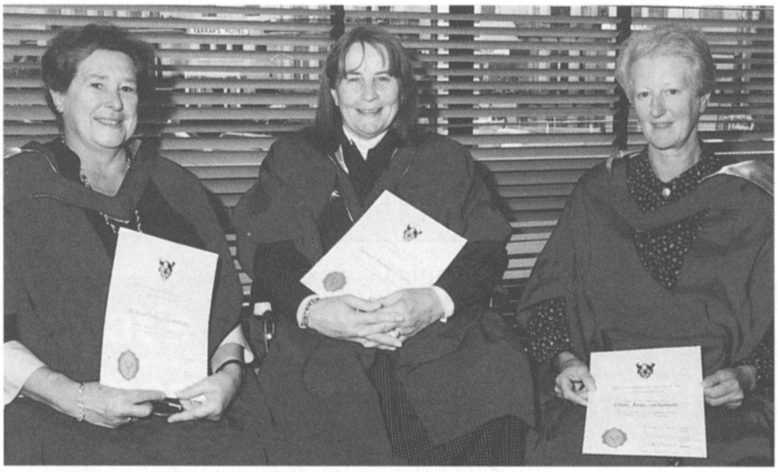
ASBAH vice-president Baroness Masham, Countess of Swinton, has been made an honorary fellow of the society.

Moyna Gilberston OBE, ASBAH executive director from 1977-91, and Carol Sobkowiak, a member of our Education Advisory Committee, become fellows for their contributions to physiotherapy.

All three received their awards at the society's Annual Congress in Eastbourne on 12 September.

As a result of a spinal cord injury, Lady Masham had first hand experience of physiotherapy and continues to support physiotherapy and physiotherapists in the House of Lords and elsewhere. Lady Masham was the first non-medical president of the society.

Miss Gilbertson was recognised for her work in the field of paediatric physiotherapy, particularly as superintendent physiotherapist at the Hospitals for Sick Children, Great Ormond Street.



Moyna Gilbertson (left), Baroness Masham of Ilton (centre) and Carole Sobkowiak with their honours from the Chartered Society of Physiotherapy

Carole Sobkowiak, superintendent physiotherapist at Darlington Memorial Hospital, received a fellowship for her work in the field of paediatrics and in particular for patients with spina bifida and hydrocephalus.

As a member of ASBAH, she was asked to evaluate the contribution of the Conductive Education approach to the treatment of children with spina bifida at the Peto Institute in Hungary and subsequently reported to the Department of Health.

Carole Sobkowiak has just become secretary of the Society for Research into Hydrocephalus and Spina Bifida – an organisation with an international membership.

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

London, Surrey, Kent, West and East Sussex

ASBAH South East, 123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (0181) 449 0475. Regional Co-ordinator: Gina Broughton, BA (Hons).

Lincolnshire, Cambridgeshire, Leicestershire, Nottinghamshire, Northamptonshire, Norfolk, Suffolk, Essex, Hertfordshire, Bedfordshire

ASBAH East, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.
Tel (01733) 555988. Regional Co-ordinator: Mary Malcolm.

Northern Ireland

ASBAH Northern Ireland, 73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (01265) 51522 Regional Co-ordinator: Margaret Young.

Northumberland, Durham, Cleveland, North Yorkshire, South Yorkshire, West Yorkshire, Tyne & Wear, Humberside

ASBAH North, Five Oaks, Ben Rhydding Drive, Ilkley, W Yorks LS29 8BD.
Tel (01943) 609468. Regional Co-ordinator: Joan Pheasant NNC.

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122 GREAT REASONS TO WAVE THE FLAG!

Marshall Thomas, Editor, Challenge (disability sports newspaper), swells with patriotic pride after Atlanta

TODD WARSHAW / ALLSPORT

Ann Wild punches the air in triumph after Britain's 46-42 win over Germany in the baskbetball

FOLLOWING a mediocre Olympic Games for British athletes, in August our Atlanta Paralympians put the 'Great' back into Great Britain with a superb 39 gold medals, 42 silvers and 41 bronzes to claim fourth place in the overall medals table behind the USA, Australia and Germany.

British athletes with spina bifida among the medals included this year's London wheelchair marathon winners David Holding and Tanni Grey, who were both multi-medallists on the track.

Holding (28) set two world records in two days in the men's T53 100m, streaking to victory in his semi-final before lifting his first-ever Paralympic title in a time of 14.45 sec. The Kettering book-keeper then added a bronze in the 200m behind Claude Issorat of France and Hakan Ericsson of Sweden.

Grey, a quadruple gold medallist in Barcelona four years ago, won gold in the T52 800m and silver in the 100m, 200m and 400m. Despite breaking the world record in all four of her events during the Games, the 27-year-old Cardiff athlete had her quest for another four-time gold medal sweep thwarted by 14-year-old American Leann Shannon. Shannon became Paralympic champion at the three shorter sprint distances, although many believe that – as a low lesion paraplegic – her spinal injury was not enough to see her competing in the same classification as Grey.

A third wheelchair track medallist was Tyne and Wear 17-year-old, Nicola Jarvis, who surprised even herself with two bronze medal-winning performances in her first Paralympics, finishing behind North American pair Chantal Petitclerc and Cheri Becerra in both the T53 100m and 200.

Jenny Booth (28), from Newcastle-under-Lyme, helped boost Britain's gold medal tally in the swimming pool, anchoring the team which took the spoils in the S1-S6 class 4x50m freestyle. Booth's swim ensured that she and team mates Jane Stidever, Margaret McEleny and Jeanette Esling not only became Paralympic champions, but also new world record holders with a time of 2mins 52.36secs. The same quartet added a bronze medal in the 4x50m medley relay.

More medals were to come in the equestrian sport of dressage, with 23-year-old Liz Stone claiming an individual silver medal in the Grade III competition and in the process helping Britain to the team gold.

Anthony Peddle, a bronze medallist in Barcelona four years ago, had to settle for the same medal again this time round. The 25-year-old Northampton sports development officer lifted 160kg to finish behind Korean and Nigerian athletes in the 48kg weight category, while Nick Slater, a medallist in each of the last two Paralympics, had to settle for fourth in the 100kg class.

On the basketball court, Jo Jayaratne was one of Britain's leading points scorers as the men's team took the silver medal, losing out to Australia in the finals. Meanwhile, Great Britain's women, captained by former ASBAH mobility adviser Ann Wild and also including Liverpool's Sue Conroy, improved their world ranking from seventh to sixth with a final match victory over Germany.

WE NOW HAVE OUR OWN INTERNET WEB SITE. PLEASE KEY INTO http://www.asbah.demon.co.uk/

Cuts to mobility component of *Disability Living Allowance*

What's happened and how the changes could affect you

MPS arrived back at the House of Commons from the summer recess with postcards campaigning for the re-instatement of cuts to the mobility component of Disability Living Allowance (DLA) on their desks.

New regulations reduce or take away £33.90 (higher rate) and £12.90 (lower rate) from adults who stay in hospital more than 28 days and for those living in NHS funded long-stay or residential care.

The government got them through Parliament on 30 July without any debate.

Mencap mounted a *Stop the Mobility Cuts* postcard campaign with a view to getting the regulations overturned.

But, even if the new cuts are kicked out this autumn, those people adversely affected in August and September by the benefit cuts are unlikely to have their money repaid.

Effects of the regulations include:

- If you go in to hospital and are there for more than 28 days you will cease to receive mobility component.
- If you have a car under the Motability scheme, go in to hospital and are there for more than 28 days your payments to Motability will continue to be made, but when the agreement ends you will not be able to enter in to a new agreement.
- If you have a car on order under the Motability scheme, go in to hospital and are there for more than 28 days you will not be able to take delivery of the car until you leave hospital.
- Your rights will not be restored until you are discharged from hospital and there will be no arrears payment for the period you were in hospital.
- People staying in a residential care home or nursing home whose place was arranged by the local authority will **not** be affected.
- Where the arrangements are made through the NHS the mobility component **is** likely to be affected in the same way as if you were in hospital. Seek advice if your mobility component is withdrawn or reduced while you are in residential care.
- The limit for adults is 28 days. For children under 16, it goes up to 84 days.

Most people who receive the mobility component of DLA spend it on transport. They may buy or lease a car from Motability or use it to pay off a loan on a vehicle outside Motability.

If they are living in a residential home they will use it to go out for visits and appointments.

Ann Wild, ASBAH's mobility adviser until the end of August, said: "Cutting back on the mobility component of DLA is shocking. It's going to reduce people's quality of life to zero. Whoever thought this up failed to consider how much it will severely affect people. Loans for cars still have to be paid off whether or not you're in hospital."

Margaret Lavery, social security officer for RADAR (the Royal

continued on page 10

> *"It's not been thought out 100%. We're the guinea pigs."*

DOUGIE Shannon, from Bracknell in Berkshire, is a wheelchair user and depends on the mobility component he receives for getting into town by taxi. He is also putting some of the money aside for an electric wheelchair. He cannot drive for medical reasons.

As well as having spina bifida he has a bone infection in the pelvic area, and the treatment of this and other problems means hospital stays average six weeks.

He said: "It's a disgrace what's happening. It's not been thought out 100%. We're the guinea pigs."

Dougie lives in a warden-controlled block of flats in Bracknell and has help from care assistants every morning. He plans to move into a bungalow within the next couple of years.

"If the mobility component is taken away from me, it will ruin me until such time as I get it back and I assume it would take ages to get it back.

"It would be depressing to come out of hospital and not be able to go out."

Cuts to mobility component, from page 10

Association for Disability and Rehabilitation), is very concerned for two groups of people who will be adversely affected by the amendment – those living in NHS community or residential homes and those going into hospital for major surgery.

She told *Link*: "Those who have lived in residential homes and have received the mobility component for a year will have their existing entitlement reduced by half as transitional protection. This will seriously affect their ability to go out on trips and go to the dentist, hairdresser or see relatives.

"People who go into hospital for a major operation may have non-Motability finance agreements because Motability doesn't suit them or because they have an old car on the road. They will lose out and perhaps fall into arrears. It may also prevent carers from visiting.

"Those using Motability are protected, unless their agreement runs out while they're in hospital in which case they won't be able to renew it until they go home. This then may affect their rehabilitation."

She added: "The quality of life of all these people will be devastated."

A Department of Social Security spokesperson said: "The principal behind the change is to align the mobility component with the care component which is removed after four weeks in hospital. In addition, while people are in hospital the NHS looks after their basic mobility needs."

Mrs Lavery said: "Mobility component was the anomaly in the system and the new regulations are an attempt to even up the whole system and save money. We fear the next group of people to lose this benefit will be those living in all types of residential care and community homes."

- *If your mobility component is stopped while you are in hospital you will still be eligible to receive it when you leave. Tell the Disability Benefits Unit as soon as you know when you will be going home. Payments should begin again from the first pay day after the discharge date.*

"What would happen to my bank loan?"

TERRY Poole, secretary of Wessex ASBAH, and Dorset representative of National Association for Bikers with a Disability (NABD), is worried that his mobility component of £33.50 a week would stop if he went into hospital for more than 28 days.

He lives off his £75-a-week Disability Living Allowance and uses the mobility component and attendance allowance to pay back the loan on his bike.

His mum said: "When Terry buys his vehicles he always has a bank loan and, if he were to have an accident and be in hospital for more than a month, they would take away both the mobility component and attendance allowance.

"What would happen to his bank loan if he wasn't able to pay? The bank could call in the loan or maybe take the bike and sell it to get the loan back.

"There must be hundreds of people who don't get their vehicles from Motability and who, therefore, don't get protection against these new regulations while in hospital."

Date change for Leeds study day

THERE has been a change of date for a study day which was mentioned in the last issue of *Link*. The event called **'Sex, Relationships and You'** – being planned for young adults with spina bifida and/or hydrocephalus and, where appropriate, their partners – has been put back to **Saturday, 22 February, next year. The day will be open for people living in Leeds and Bradford only.**

The study day will be held at the **William Merritt Disabled Living Centre at St Mary's Hospital, Leeds, from 9.30am to 4pm.** ***For more information and an application form, please contact our northern regional centre, tel: 01943-609468.***

Your child's right to special education

FORTY of the most common problems concerning special educational needs are outlined in a new book for parents, teachers, advocates and advice workers.

Taking Action – Your Child's Right to Special Education also provides 40 cases which show how to solve these problems.

Produced by the Independent Panel for Special Education Advice (IPSEA), the book covers all issues surrounding the assessment, provision and courses of redress within the field of special education.

- ***Taking Action – Your Child's Right to Special Education* is available from Questions Publishing Company, 27 Frederick Street, Birmingham, B1 3HH. Credit card hotline: 0121-212 0919.**

***DARKE AT THE CINEMA* BY PAUL DARKE WILL RETURN IN NEXT ISSUE OF LINK**

NEWS ROUND-UP FROM NATIONAL SPINA BIFIDA WEEK 2-8 SEPTEMBER

Genetic study wins EU funding

A MAJOR study to identify specific human genes that may be susceptible to neural tube defects such as spina bifida has won funding from the European Union.

The study is being carried out by INTEGER – the International Neural Tube Epidemiology Genetic and Embryology Research – a consortium which unites four European research centres in Newcastle and London (England), Freiburg (Germany) and Nijmegen (Holland).

Heading up the consortium is the UK's Northern Region Genetics Service. Its director is Professor John Burn, a leading UK authority on spina bifida, who sat on the Steering Committee of the MRC Vitamin Study that showed folic acid supplements can prevent spina bifida.

Professor Burn said: "Research into the role of folic acid in preventing neural tube defects is ongoing and proving very complex. Studies are concentrating on the metabolism of folic acid. Research suggests that defects in the processing and metabolism of folic acid in the mother and foetus could lead to a susceptibility to the development of a neural tube defect. There are a large number of genes involved in the metabolic pathway of folic acid and it's possible that a number of them, if malfunctioning, could result in a neural tube defect (NTD)."

Before the EU agreed to fund the research programme, Newcastle did not have the resources to carry out the study.

Instead, it had been assisting researchers in Boston, USA, by providing British samples for use in the search for a gene that determines a certain hereditary form of spina bifida. The USA is unable to use its own people as samples because its gene pool is such a mixture of different races that it is almost impossible to identify similarities in gene patterns.

Two of these groups – in London and Freiburg – are attempting to identify all the genes in the mouse that could cause a NTD for, according to Professor Burn, the genetic structure of a mouse is considered remarkably similar to that of humans. Professor Burn's group in Newcastle and the group in Nijmegen will translate the information from the work on mice and attempt to test the importance of these genes in humans.

"Bringing the study home to Newcastle will allow us to broaden out the research," comments Professor Burn. "The UK offers a perfect pool of people who are descended from only a few races. We plan, initially to focus our investigations on one hereditary type of spina bifida, which may allow us to identify the pathways and processes that cause other forms of the condition.

"We are delighted that Europe has recognised the potential of this study and has chosen to award us funds. While we are still many years away from the possibility of being able to eradicate neural tube defects such as spina bifida, we are confident that slow steps forward will quickly lead to 'leaps and bounds'. Until then, my advice to women who think they might become pregnant – as soon as you even think about conceiving, start taking folic acid."

● If you are a couple who has a child with spina bifida you could help with the Newcastle research. This would involve giving a sample of blood or saliva from each of you and your child. This could be arranged through your own GP. Contact Dr Sally Ann Lynch on 0191-232 5131 ext 24631.

'Tell a friend or your daughter' – says Royal College of Midwives

'GET on the phone about folic acid' was the message that Caroline Flint, President of the Royal College of Midwives, wanted the nation to hear as ASBAH and the Scottish Spina Bifida Association launched their third National Spina Bifida Week.

"If every women who hears our call tells her friend – or her daughter – about the role of folic acid (folates) in preventing spina bifida when taken before conception and during pregnancy, and if they in turn tell just one of their friends, the message will spread like wildfire.

"I feel strongly that this message is as important as mothers telling their daughters about the need to have safe sex," said Caroline Flint.

If a couple has a baby with a neural tube defect there is around 2-5% recurrence risk for any future pregnancy. In 1991, a British study demonstrated that if these women took a folic acid supplement before conception and for the first 12 weeks of

continued on page 12

Rise in folic acid awareness among women – new survey reveals

EFFORTS to reduce the number of babies born with spina bifida have received a boost, as new research shows that three times as many women as last year now know about the importance of taking folic acid when planning a pregnancy.

The Health Education Authority (HEA) research measured changes in awareness and understanding of the importance of folic acid following the launch of the HEA's Folic Acid Campaign in February.

When prompted, two-thirds of the women questioned had heard of folic acid or folates (the name given to folic acid when it occurs naturally in food) and associated the words with pregnancy, compared with only half of those surveyed in 1995.

Encouragingly the findings show that women have a better understanding of why folic acid is important. Almost half of those women who were aware of folic acid (47%) knew that taking folic acid when planning and in the early stages of pregnancy protects against the risk of having a baby with spina bifida, compared with only 19% last year.

Campaign manager, Caroline Hurren, said: "All the hard work done to raise awareness of the benefits of taking folic acid are starting to pay off, but there is still some way to go. There is still some confusion as to when and why folic acid should be taken and how much is needed."

The HEA campaign initially targeted women planning a pregnancy. The campaign now targets all women of child bearing age, their partners and families, to ensure that the message reaches women planning a pregnancy as well as those who may plan one in the future.

The HEA recommends three steps to increase intake of folic acid:

- Take a 400 microgram folic acid supplement. These are relatively inexpensive and available from most chemists.
- Choose foods fortified with folic acid, such as some breads and breakfast cereals. Check the label as the amount of folic acid that they contain varies.
- Eat more foods which are naturally rich in folic acid and avoid overcooking them. Green leafy vegetables are a good source.

But the findings show that women are still confused about whether they can get enough folic acid from a normal diet. Half had the wrong impression and believed it was possible, although 16% of this group felt it was difficult. Only 3% knew which foods fortified with folic acid were readily available and only 13% knew which foods were naturally rich in this B vitamin.

To ensure that women and their partners, relatives and friends have access to further advice and information, the campaign has arranged for the Health Information Service to provide advice on freephone: **0800 66 55 44.**

Tell a friend or your daughter, from page 11·

pregnancy it reduced the recurrence of spina bifida/anencephaly in their next pregnancy by 70%. Common sense therefore suggests that if all women took folic acid before conceiving, the incidence of babies with a neural tube defect would reduce dramatically."

Backing her appeal were: Professor John Burn, of the Northern Region Genetics Service and a member of the Steering Committee of the MRC Vitamin Study; Dr Lindsay Smith, the Royal College of General Practitioners' expert on maternity care; The Maternity Alliance, which works to make life better for pregnant women, new parents and their babies, and ASBAH.

Caroline Flint said: " Despite the campaign by the Health Education Authority, many women still need educating. Word of mouth is a sure fire way to ensure that every woman in the UK who is planning to become pregnant has the opportunity to act on this important information."

"General practice is the ideal place to get this message over as, every year, nearly all young women will see their GP or a member of the primary care team for one reason or another," said Dr Lindsay Smith of the Royal College of General Practitioners.

National Spina Bifida Week was organised by ASBAH and sponsored by Cantassium Micro Folic Acid from Larkhall Green Farm. Its aim was to focus public awareness on the role of folic acid in preventing neural tube defects and to increase support for people with spina bifida and/or hydrocephalus.

Tony Britton, of ASBAH, said: "We are delighted that The Royal College of Midwives made this appeal to women. Throughout the country, many of our members have had spina bifida babies and, after taking folic acid before a subsequent pregnancy, they have given birth to healthy babies. They are testament to the efficacy of this simple B vitamin."

NEWS ROUND-UP FROM NATIONAL SPINA BIFIDA WEEK 2-8 SEPTEMBER

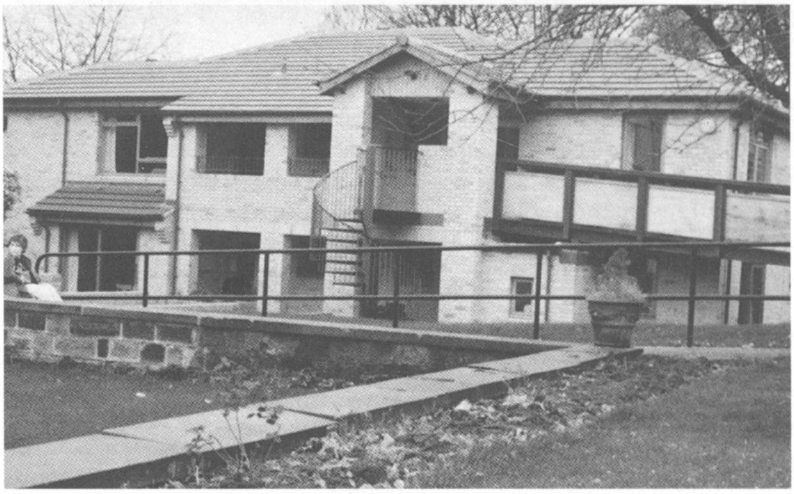
Future of Five Oaks flats secured

THE FUTURE of flats for 11 disabled people was secured in September with the official opening of the Five Oaks Housing Scheme at Ben Rhydding, Ilkley, West Yorkshire.

The two blocks of flats are next to Five Oaks House. The house is being sold by ASBAH after it was closed as a training centre two years ago when it became too expensive to run.

The flats – Denton View and Wharfedale *(pictured right)* – will be run as a partnership between ASBAH, Bradford Metropolitan Council and Sanctuary Housing Association. The scheme was opened by the Lord Mayor of Bradford, Councillor Gordon Mitchell.

It was formerly used exclusively by people with spina bifida and hydrocephalus. But, under the new partnership, tenants now have a range of physical and/or learning difficulties. Most of the flats are wheelchair accessible, with day-time support to tenants available in the week and an emergency alarm call monitoring system. There is also a community centre.



Wharfedale next to Five Oaks House – its future as flats for people with disablities is safeguarded

ASBAH keeps a presence on site through a small team of housing support workers. Bradford Metropolitan Council nominates people with disabilities to the tenancies. The buildings remain in the ownership of Sanctuary Housing Association, which collects the rents and carries out external maintenance.

Joan Pheasant, ASBAH regional co-ordinator, said: "We were particularly anxious to safeguard the future of both Denton View and Wharfedale as supported tenancies for disabled people, as this kind of accommodation is generally in short supply. We are pleased that the new agreement achieves this."

ASBAH is to move its Northern Region office from Five Oaks prior to the sale of the house. The sale was still being negotiated as this issue went to press.

Hospital parking pain

A MOTHER, who had to visit her sick child in hospital every day for five weeks, faced extra aggravation whenever she parked her car.

Julie Betts had to pay out a small fortune in car parking charges at the University College Hospital, Cardiff, to visit two-year-old Kirsty, who has hydrocephalus and cerebral palsy, and is recovering from meningitis.

When the day-time parking charge of £3 ran out at 8pm, she had to pay another pound or two to stay longer. "It's enormously expensive to visit Kirsty," said Mrs Betts from Cwmbran. "On top of the cost, there's the irritation of having to run out to the multi-storey car park to get another ticket, at a time when I should be helping to settle her down for the night."

Cranberry news

FIRST hand experience of the effectiveness of cranberry capsules in dealing with recurrent bladder infection has been highlighted by a member of the Spinal Injuries Association (SIA).

The member, known simply as Peter, reported great success when using the capsules in a recent issue of *Forward* – the official SIA newsletter.

He has since written a few more observations and a research article on the use of the capsules.

For a copy of the report, contact the SIA, Information Service, 76 St James's Lane, London, N10 3DF. Tel: 0181-444 2121. Fax: 0181-444 3761.

Gloves for wheelchair users

SPECIAL gloves for handling wheelchairs are just one of the items for sale in the 1996 catalogue of the Spinal Injuries Association (SIA).

The gloves have been developed in conjunction with Stoke Mandeville and a top sports wear maker. They are made from a special sports fabric, with strengthened stitching and carefully sited grip areas, providing comfort, protection and grip for self-propelled wheelchair users.

Copies of the catalogue are available from the SIA, same contact details as opposite.

This is the story of Neil Bigwood. A man who, with love, courage and determination, struggled to overcome his disability – and succeeded. Roy Greenslade celebrates his life and work. The Guardian ©

Portrai

EARLIER this year a remarkable man died. He was just 43 years old. Throughout his life he avoided publicity, insisting that I never write his story in a newspaper. He saw no reason for fanfare. It was not shyness but a deep-seated belief that he should not be thought any different from anyone else. In his eyes, it simply was not true, not relevant. He got on with things just like other people. So what if he was born with spina bifida?

In his eyes, that didn't make him special. Least of all would he have viewed himself in the guise of that absurd tabloid medical cliché: a hero.

But in this age of cheap celebrity, the story of Neil Bigwood's life and death demands to be told. Here is a genuine reason to celebrate a person. In one sense it is a tribute to the triumph in adversity of the human spirit. There is a wider context, too, raising questions about family and community values, about prejudice, society, about the National Health Service. Most of all it is a story about love, the love of parents for a child, the love of a wife for a husband, the love of one man for life. Neil, who despised sentimentality and self-pity, would not wish this on himself. Forgive me, Neil, but I must write. It is time. People should know.

Neil Bigwood was born in January 1953 to proud parents, Henry and Evelyn, working-class East Enders who, like so many, had moved out into Essex after the war. Henry, a painter on the maintenance staff at Hackney Hospital, and Evelyn – a dressmaker who worked from home – lived in a small flat in Barking and already had a five-year-old daughter, Susan. Neil's was a routine birth, carried out at home by the local midwife. He was a fine baby except for a strange growth on his back, the size of an egg. "It didn't seem like a problem at the time," recalls Evelyn, always known as Ev. "We thought it could be cut off." Ten days later they started to worry. Mother and child were taken to London's Great Ormond Street Hospital for Sick Children where a consultant told them that Neil had spina bifida. Ev can't remember him using the exact words but, even if he did, she wouldn't have known what it entailed. "In those days they didn't tell you much," she says. "Anyway, I was numb." She only found out later that it was a congenital defect, in which one or more of the vertebrae fails to develop completely, leaving a portion of the spinal cord exposed. In Neil's case, it appears he had a severe form known as myelocele.

Myelocele is manifested not only through physical handicaps, such as partial paralysis of the legs, but repeated urinary tract infections which lead inevitably, and ominously, to kidney damage.

One bit of advice given to Henry and Ev by the consultant at that meeting was to remain with them for ever. "Your son is disabled," said the surgeon. "Take him home and bring him up as best you can." It may sound callous, but it wasn't meant to be. The doctor was giving a realistic assessment. It may even have spurred Neil's parents to make their best better than anyone could imagine.

Ev was given some cotton wool and a dressing which looked like half a rubber ball to bandage over the lump. At night Neil often woke screaming. Henry, who got up every day at 5am to paint hospital walls, would sit for hours cradling his newborn son because the pain subsided when he was held upright. Regularly, Ev would measure Neil's head to ensure it was not swelling. She had been told to watch for an abnormality, hydrocephalus, in which fluid flows to the brain, usually causing severe damage and retardation. Mercifully, this did not happen.

At five months, Neil had his first operation, the first of so many the family were to lose count. He could not walk. He had a club foot. He had bladder problems. As a "classic example of spina bifida" he was taken to a medical convention for students to view. His future looked bleak.

Barking's Labour Council provided one excellent piece of practical help. They offered the Bigwood family a house in a new block which had been set aside in a quiet road for children with medical problems. "It was very nice for Neil to have a garden," says Ev. She also found herself in a community where it came as second nature for people to help each other.

We need to cast our minds back to the 1950s. A working class child with Neil's disabilities had few options. The physically handicapped, regardless of their intellectual capabilities, were often lumped together with the mentally handicapped. Classed as "special", they were routinely sent to separate schools. As a young reporter, I visited such places in Barking. A caring but too often untrained staff developed children's vocational rather than educational skills. "He was heading for a life of basket-weaving," one relative told me.

Neil Bigwood

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School was a harsh test for the boy who spent long periods in Great Ormond Street undergoing a series of operations and who had to be wheeled to school every day. Boys can be very cruel to those they view different and Barking was a fairly tough place. Here was a lad who could hardly walk, heaving himself along with callipers. In the playground it was considered good sport to taunt him and push him over.

When he told Ev she did not complain to the school, but advised him to fight back. She laughs as she recalls telling him: "Grab them and bite them. They won't do it again." Neil's upper body strength was vastly superior to boys of his age and it must have worked. The bullying stopped. He even took part in school sports day, in the egg and spoon race. Of course he came last, shuffling across the line long after the next event had begun. But he finished, a sign of the grit he was to show ever after.

Soon he was able to pedal to school by himself on a specially adapted tricycle. This eventually gave way to a two-wheel bike, in which one of the pedals remained static while Neil turned the other with his "good" leg. He loved to propel himself down the stairs by swinging down the banisters. But he was able to walk, albeit for short distances.

He passed the 11-plus and went to Barking Abbey grammar school. He became a scout, went camping, visited France, learned to canoe, became a competent swimmer. He was about 12 when I first met him, after his sister and I became friends. Like so many of the able-bodied, I underestimated him. I was six years' older but he defeated me with ease at arm wrestling. He loved games and had a highly developed competitive urge to win. He beat me at chess. Most of all, he challenged my perception of normality.

He was a good-looking boy, with a mop of wavy fair hair, but he seemed out of proportion, with a big head and torso giving way to spindly legs encased in irons. He wore a huge built-up boot on one leg and to walk he had to clip the iron to clamp it rigid. His walk was ungainly and it caused him pain, but I never heard him complain. A broken body concealed a razor-sharp mind.

Do not see him as a saint. He could be obtuse. He was demanding. His sarcasm sometimes bordered on rudeness. But he also had a wonderfully dry sense of humour. He was not, in spite of his mother's best efforts, a terrific swot. Like other boys, he liked to do his homework sprawled in front of the television. He was about 13 when he announced that he wanted to be a doctor.

Even Ev, so keen to see her son live up to his potential, balked at the idea. "Henry and I tried to talk him out of it," she says. "We couldn't see him studying for six years. We thought he had set his sights too high." But Neil had learned much from his mother, a mixture of stubbornness and determination, and he would not be swayed.

He left Barking Abbey with eight O levels and three A levels. Top of his medical school list was Guy's Hospital which readily accepted him as a student. Lots of would-be doctors drop out along the way but Neil stayed the course and, in 1977, he became Dr Bigwood.

His first hospital was in Hove, and since I lived nearby I saw something of him. There was still a bit of the young boy I remembered (he talked a lot about war games) but he had matured into a witty, entertaining man. He had a way of addressing complex or sensitive questions in a flip way that somehow made everyone laugh. From there he went on to Great Ormond Street, returning as a junior doctor to the hospital

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PORTRAIT OF AN ORDINARY HERO – NEIL BIGWOOD *from page 15*

which had done so much for him in his first 18 years as a perpetual patient.

He would have liked to stay and help other children but his heart was set on surgery. While working at King's College he bought a house in south London. A friend told me he liked to entertain guests by reaching up to high kitchen cupboards with a stick to dislodge saucepans before catching them. Then came a spell at Mount Vernon's in Middlesex where Neil, the surgical registrar, found himself working alongside Mary Quigley, the medical registrar. It might sound like an episode from a hospital soap, but the two fell in love around the time Neil gained his fellowship of the Royal College of Surgeons. Just more than a year after they started seeing each other, they were married in the Roman Catholic cathedral in Mary's home town, Mullingar in Ireland. They would have been celebrating their 11th wedding anniversary on Thursday 30 May. As I listened to the mass, I thought back to the little boy I had known, the boy most unlikely to succeed. Who would have forecast marriage then? A year later came another joyous moment: Mary gave birth to their daughter, Theresa, who will soon be 10.

In his career, however, Neil had run into a buffer. He could not get a post as senior registrar in accident and emergency (A&E). "It was a traumatic, soul-destroying time for him," says Ev. "Nobody saw that he had something special to offer." What one suspects they did see were his disabilities and not his abilities. He was shortlisted, several times, always missing out, until he finally moved to Medway Hospital in Gillingham, Kent, where he was appointed as an A&E registrar.

After a few years, the hospital realised they had an extraordinary doctor. He was promoted to associate specialist. Prejudice still dogged him. He continued to apply for senior registrar posts but, misguidedly, he was considered physically unable to do the job. Instead, he trained himself, wrote papers and carried out research.

His supposed lack of mobility wasn't a problem. As Andrew Mason, the A&E's clinical director, says: "He moved around fast when he needed to. There were few quicker into the resuscitation room in an emergency." The man with the warped vertebrae proved to be the backbone of the team. "He was invaluable," said a colleague.

He also proved a superb teacher of junior doctors. "Hundreds of doctors owe their emergency training principally to Neil," says Mason. In January 1995, the hospital created a part-time consultancy and Neil was unanimously chosen by the selection committee. By that time, he had been working for five years while on renal dialysis. His one functioning kidney had finally given out, and both were removed so that he could take his place in the queue for a transplant. In January this year he was given a new kidney.

The omens were good. The transplant was carried out on his 43rd birthday at Guy's, the hospital where he had trained. In the first couple of months everything seemed to be going as well as expected. But the powerful drugs which are given to prevent rejection leave a patient open to infection. First, he developed a temperature. Then his toes turned black. His leg and foot swelled up.

The hospital, suspecting it was a virus, acted accordingly. But phlegmatic Neil, more knowledgeable than most about his own condition, knew he was in serious trouble when he began to lose his eyesight. Mary, a practical woman, by now a doctor in general practice, also grew concerned. Neil's mother and sister were beside themselves.

In situations like these, when people are focused on just one object, feeling impotent, suffering so much distress, it's not unusual for them to get angry and frustrated. Some of the family felt the nursing staff were inadequate to the task. It became clear that the ward was often partly staffed by agency nurses who, helpful as most might be, didn't have the skills to provide the intravenous injections many patients needed.

Here was a doctor suffering in bed with another doctor at his side. A doctor trained at Guy's. A doctor who had been made whole 40 years before by a fledgling National Health Service. Now an under-funded NHS was struggling to provide the proper level of care.

It is clear that the doctors did all they could. There was nothing wrong with their diagnostic approach. Only after Neil's death did they discover he died from an organism which according to Mary, is "as rare as hen's teeth." She also refuses to criticise the hospital. But, hearing from the family of those final days, the way it took ages to get any attention, the lateness of injections which could have relieved pain, Neil's agony as his sight faded, I have this nagging feeling that it could have been so much more dignified. He deserved better.

Not that Neil would have complained. He remained flippant to the end. When Mary asked him whether, if he did go under, he should be resuscitated, he replied: "Why not give it a whirl." That was just one of the memories we heard at his funeral. It was so well attended the chapel overflowed. When Neil made friends they lasted for life. One of them, Graham Shaul, told how at school they were asked to write a poem about their concept of death. Neil wrote: What is death? Death is a void. So avoid death.

One of Neil's last requests to Mary was to give their daughter a nice picture of him. Here is some kind of portrait, Theresa. Remember always. He had an iron leg and an iron will. And he lived for 43 triumphant years.

30 YEARS AND COUNTING!

The second instalment about ASBAH's 30th anniversary conference, celebrating the empowerment of disabled people

Q E II CENTRE, LONDON – 6 JUNE 1996

TONY BRITTON reports on the highlights for Link

THE STORY SO FAR: The last issue of *Link* had a six-page special with reports on the first six speakers at our 30th Anniversary Conference. **TONY BRITTON** described how ASBAH's patron, **HRH THE DUCHESS OF GLOUCESTER**, opened the event. Reports followed on speeches from **CLAIRE RAYNER;** the Minister for Disabled People, **ALISTAIR BURT; STEFAN KRUSCHE** from German ASBAH; **RICHARD GUTCH,** chief executive of Arthritis Care and **SUE MACGREGOR,** presenter on the 'Today' programme. Now we bring you reports on the remaining seven speakers.

Hard work, but fun!

TANNI GREY, Britain's best-known wheelchair athlete, borrowed a *Daily Mail* headline over a story about her new biography for the title of her talk, 'Walking: what's so great about it?' which opened the afternoon session.

"I don't ever actually remember quite saying that but, as it was written in the paper, it must be true," said Tanni in the first of a number of amusing asides which drew laughter from the audience.

At the age of 26, she said she was constantly being asked when she would be retiring from athletics. That was not a question she was really prepared to answer before the Atlanta Paralympics. "Hopefully not yet, but I'll let you know at the end of the year!"

Tanni said, when she was growing up, nobody ever told her she had spina bifida and she could not remember when she found out about it.

"Certainly my parents were never told anything about it. They were told: 'Here's your child. She's got spina bifida.' My mum said: 'Thank you very much' and took me home, and spent the next few years in fairly blissful ignorance, mostly because my sister was very ill at the time, so they spent the first four years of my life worrying about her instead of thinking too much about me.

"Because of that, and because I could walk until I was about six years old, I don't think my experience of disability or being in a wheelchair is probably very typical.

"When I say I could walk until I was six, I actually used to wobble and fall more than walk, and still have the scars to prove it. But for me – at six and a half years old – having my first wheelchair gave me a tremendous sense of freedom, which I had not had before."

Tanni said she was useless at sport in school until she took up athletics. "I wouldn't say it has changed my life. It hasn't made me a better or worse person but it has added something to my life, and made it probably very different from what it would have been.

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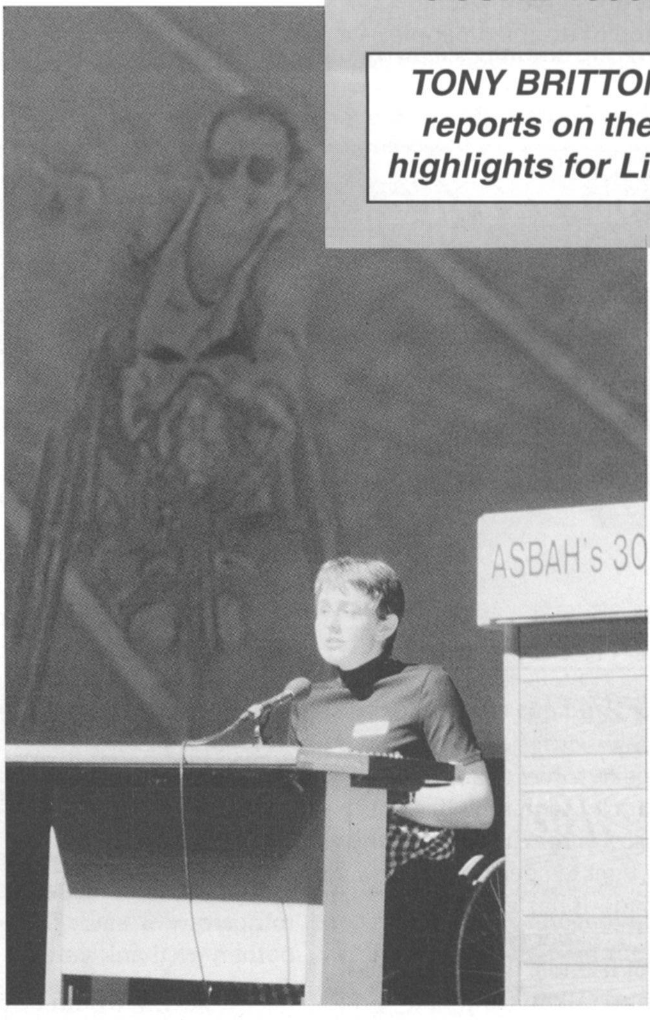

ANNIVERSARY CONFERENCE

Paul Darke

ONE problem in promoting positive images of disability is that they can exclude people who do not live up to them, film critic PAUL DARKE told the conference in a talk called 'Images of Disability on Film.'

"There is a bit of a problem in going too far with the positive image in that, as Tanni Grey was saying, it does give a wrong impression of disabled people as a whole.

It actually is much more dangerous than that because it actually demeans disability.

"There are those who fail to live up to a positive image – being fit, being a marathon runner or high academic achiever – because, as with many ordinary people, they don't have the desire to do that. They just want to get on with their lives, however they do it."

Much of Paul's presentation was given over to showing clips from four films, and a large number of slides.

There was never any problem from his perspective in finding images of disability in the movies because they were all-pervasive. The questions and the arguments arose in the interpretation of the film-makers' treatment of disability.

And Paul, film writer for *Link* magazine, seized the opportunity to be controversial. For instance:

'Young Frankenstein' (the Mel Brooks' version): "One of my favourite films of all time. It has a lot of images of disability and the monster has learning difficulties. A lot of people would say it is a deeply crass, offensive movie but I would argue the opposite – it is a glorious, politically-aware indictment of all the non-acceptance of difference.

"By going so far over the top, it undermines the very rigidity of the stereotypes and archetypes to the extent that Marty Feldman's hump keeps changing sides all through the movie. There's a parody of a scene with a hermit with a visual impairment; in the original, it's very patronising and it is crass because it creates a view of a blind person, which is sad, pathetic and lonely. The Mel Brooks' one parodies the original by undermining everything it portrays about people with visual impairment. What makes it funny is that you knew, all the way through, what was going to happen."

'Richard III' (with Laurence Olivier): "The publicity still shows how evil has been equated with

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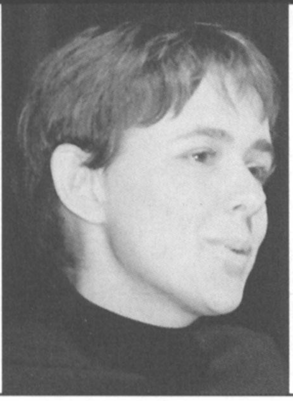
ANNIVERSARY CONFERENCE



Tanni Grey

From page 17

"It's given me huge opportunities, the chance to travel the world (I am very lucky with athletics, the track season is nine months of the year and I get to spend most of that abroad). It has given me tremendous experience, a huge number of friends, the confidence to come and talk in front of a roomful of people. I mean once you have competed in front of 65,000 people, you don't get scared by many things."

She was in a privileged position, but had to work for it. Daily road training produced a weekly tally of 140 miles, and there was sacrifice of personal life, which family and boyfriend could vouch for.

"People often make presumptions about you because of being in a wheelchair. You're either a role-model to disabled people or you're the poor little cripple who is having a go," said Tanni.

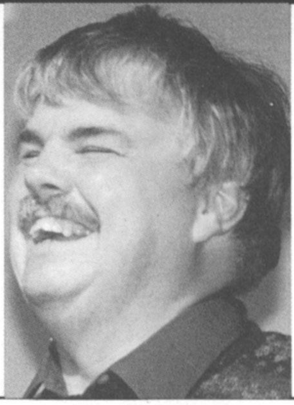
"I also find people are completely obsessed with walking and somebody said to me once: 'What would you do if they offered you an operation to make you walk tomorrow?' I said: "I wouldn't bother, no thank you!'"

"For a start, I would be anywhere between five foot and five foot six depending on which leg I was standing on and which way round you measured me. I'd have a limp and I'd be a hunchback, and none of my clothes would fit me. One of the great advantages of being in a wheelchair is that you can buy anything you like, tuck it up and it fits."

Tanni said that one of the downsides of the recent success of wheelchair sport is that too many people in wheelchairs get tarred with the same brush.

"One of my closest friends, who absolutely detests sport, hates going out with me because the first thing people say to her is 'So do you do the marathon?' She actually finds that quite hard to deal with, because of the presumptions that people place on her because she's a friend of mine. Her stock answer is 'No, I still have some brain cells left!'

ANNIVERSARY CONFERENCE



Peter White

SOONER or later in life, just about everybody was going to be disabled in one way or another, at least temporarily. "So it really is about time we stopped trying to portray it as rather extraordinary, exotic and tragic – almost as a sort of blurring of real life."

So said PETER WHITE, who became the BBC's first disability affairs correspondent in February 1995, when he spoke to the conference about his work.

"The object of the appointment, and the point of giving it to someone who does have a disability, is quite simply that we should change the voice and the way disability has been reported in the past.

"In the past, however well and however reasonably balanced a view is given of it, there has always been a sense that this is another group in society of which I am not a part. I might feel very sorry about it. I might be very admiring about it but it's nothing to do with me.

"The whole point is that I can use the word 'we' quite genuinely and without pretension. I can describe something as being not unusual, when it isn't, without any sense of being patronising and tell, and hopefully reflect, a genuine sense of identification with the issue involved."

Mr White agreed with Paul Darke that the issue was not about presenting people with a series of positive images.

"I don't think the positive image is any more justifiable in news terms than the negative image. The role of the disability affairs correspondent is that of every other correspondent and that is to present the truth.

"Now we haven't had the truth in the past about disability – not because people have deliberately lied but because they have put the spin on disability which has been put on it through films, through books, through people's fears, really since history began. And this is an attempt to present it in a completely different way as coming from the people who actually have the disability and might be in a position to know whether this is unusual or typical or atypical."

Mr White – who works across the spectrum of BBC TV and radio, in news and current affairs – said he would not be supplanting negative stories with positive ones.

"One of the things I want to do actually very much in the coming months and years is to see genuine debates about disability take place. I don't buy the idea that, for example as we have seem with some people who perceive themselves as minority groups, that they must never disagree in public. That is an extremely unhealthy way to look at things.

"I don't think there should be any no-go areas, genuine disagreements should be aired. We should have the confidence to say we are an enfranchised group of people: if we want to disagree with each other, we will. It only makes sense

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IMAGES IN FILM, from page 18

physical difference. It has been pathologised. It is quite amazing how crass many representations of disability can be in the sense that you'd think they would actually think while they were doing this, 'This is ridiculous', but it never seems to cross their minds."

'My Left Foot' (the story of Christie Brown): "Most images of disability are about people with acquired disabilities. Those that are about people with congenital disabilities, such as spina bifida, are always the more sad and tragic, or the super-heroic. There is no middle ground.

'Forrest Gump': "Disability is often portrayed as, if you want to overcome it, you can. This is a wonderful representation of that simplistic, naive idea in that he decides to run and his callipers fall off as he runs and he starts to walk and it is absolutely amazing. So, of course, once he has learned to walk, he has to befriend someone who has no legs. The crassness is just amazing.

'Mandy' (who is deaf): "All about how dreadful it is to be deaf and how wonderful it is to hear. Sign language is not even entertained as an idea and denigrated as a reality. There was a strong deaf culture at the time of 'Mandy' and it was just ignored.

"She is trapped in a desolate wasteland of hopelessness. Obviously, when she learns to talk and lip-read, they put the lawn down, and so another way of denigrating disability is by showing it and then paralleling it with normality – in this case hearing – and getting the disabled character to pass themselves off as normal."

'The Men' (starring Marlon Brando): "One of his best films, but is all about the only good cripple is one who can pass himself off as normal, which is all very well for those of us who can but, by its very process, is demeaning of those who can't and we shouldn't put too much weight behind the idea of the positive image.

"I am not saying we should go around asking for negative images, but for a multiplicity of types of images."

ANNIVERSARY CONFERENCE

Tracey Proudlock

TRACEY PROUDLOCK put charity representatives at the conference on notice that the era of user-participation and user-control had arrived.

"Disability charities of the future must ultimately place power in the hands of disabled people. The argument that disabled people are not capable of running their own organisation is becoming a little threadbare," she said.

"It must be understood that disabled people are coming from an historical background where non-representative able-bodied people have spoken on our behalf. Therefore, I believe it's quite natural that there be a backlash, perhaps even a knee-jerk reaction, where we insist on speaking for ourselves and running our own organisation, even if you think we can't."

In a talk entitled 'Look who's talking now!', ASBAH executive committee member Ms Proudlock said: "I do believe that disabled people and non-disabled people can learn from each other. The key issue which must be understood, of course, is that disabled people must direct the change.

"Perhaps a fault of mine and others within the disability campaign movement is not recognising how to utilise non-disabled allies. Non-disabled people in the audience and outside this room can be strong allies within the disability campaign movement but they have to recognise their place and then have their backsides kicked when they step out of line."

Other people labelled militant or radical sometimes found her involvement with ASBAH somewhat surprising, she said.

"Why should I want to be involved with ASBAH? It is still a parent-dominated organisation, and people often think I mustn't have enough problems dealing with my own parents since I volunteer my time to work with other disabled people's parents. The answer really is quite simple: ASBAH has proved itself time and time again to come up with the goods to support and enable disabled people, struggling to reach their potential and to take their place in society.

"I am working in partnership with ASBAH parents to develop services that will enable and empower young people, although I do have to warn that people like myself do have designs on those parent-seats of power. I am sure I don't need to tell the committee that."

Ms Proudlock welcomed ASBAH's commitment to the campaign for disabled people's full civil rights, but said she refused to be drawn into 'a futile debate' over how things have improved over the last 30 years.

"People often want to talk about how improvements have come about but I haven't got the time for that. After all, I am a mother-of-two and I'm a carer-of-three because I have got a vegan husband who needs attending to, and I also have to write speeches for ASBAH.

"Correct me if I am wrong but that last I heard is that rights were either something you have or didn't have and there can be no half-measures."

She asked how she had rights of access to enter a cinema, shop or restaurant and expect equal treatment with non-disabled customers when there was a law which stated that she can be excluded from these venues when her inclusion was too expensive?

How could there be equality when she had to pay more for everyday services like insurance, although she did believe there were measures to draw the insurance industry into the Act, by hook or by crook? How could there be equality when she was excluded from her children's playgroups and schools?

"The well-intended public should know that disabled people do not have automatic rights to anything: access usually has to be bargained for or negotiated."

She closed by paying tribute to the early founding-parents of ASBAH. They wrote letters, they pestered the authorities and the medical profession and all to secure better education and facilities for the inclusion of their children.

"Many battles have been won but we have a long way to go before disabled people have true equality. People with spina bifida and hydrocephalus need ASBAH, but ASBAH needs us. Thanks in part to the medical profession, we can now expect to outlive those parents and therefore we will inherit the Association and we will carry forward the Association's work."

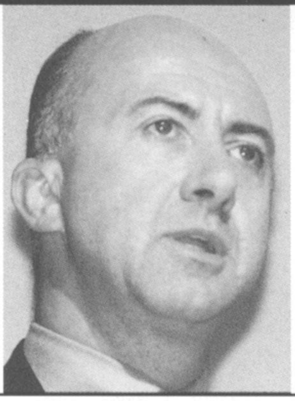
PETER WHITE, From page 19

to show a united front when you are genuinely united.

"Frankly to show a united front all the time seems to fall into the oldest trap of all which is to say that we are all the same. Clearly, we are not."

Mr White gave out his work phone number, 0171-765 3833, saying he wanted people to have a better opportunity of getting their views across to the BBC. "I am always looking out for perspectives on disability stories."

ANNIVERSARY CONFERENCE



David Grayson

THE NEW National Disability Council (NDC) had enormous tasks ahead – not least, said chairman DAVID GRAYSON, in overcoming the inertia in the non-disabled community to the idea that disabled people are being discriminated against.

"It's just five months ago that the Council was established and we have been concentrating on trying to make sure that we were listening and trying to canvass some initial ideas.

"The first thing that strikes me is that people who are not themselves disabled don't really believe that there is actually discrimination against disabled people. They very often can't imagine that somebody could be refused service in a pub or in a restaurant. Yet, if you look at the Scope survey from not too many months ago, just over one-third of disabled people said they had experienced such a refusal to be served. That figure rises to 46% if you are in a wheelchair."

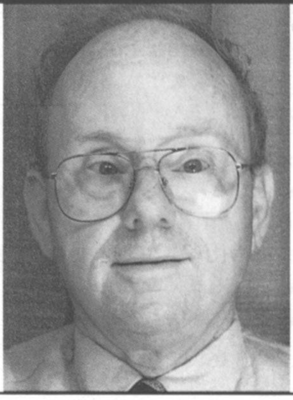
Mr Grayson said legislation could never provide the complete answer but it should be part of the response, and new rights of access will come into force on 2 December this year. The accompanying code of practice will be easy to understand for disabled people and providers of goods and services, particularly smaller businesses.

"From 2 December, if a waiter in a restaurant says 'I won't serve you because you've got a facial disfigurement as it will upset other people in the restaurant' or 'you can only eat if you sit behind that screen or in the area by the alcove' that will become illegal.

"Similarly, if somebody tries to charge you a higher deposit on a holiday or on a rented TV because

continued on page 22

ANNIVERSARY CONFERENCE



Alan Twyford

THERE was a very real welcome for people with the disabilities to become more involved with ASBAH, both nationally and locally, ALAN TWYFORD told the conference in his speech called 'Adding a new dimension to policy'.

Mr Twyford, vice-chair of the Your Voice in ASBAH user forum and standing in for Terry Denyer who was recovering in hospital after an operation, said a core group of disabled members had taken root, after a number of day conferences attended by people from throughout the UK.

Initially, working with the publicity manager as facilitator, the group had monitored the image of disabled people, inside and outside ASBAH, and sought membership of the charity's executive committee.

Nominations were obtained from YVIA who now had four places on the executive, alongside others with spina bifida and hydrocephalus who had served for many years. YVIA was also taking up places on other main committees.

"It is good to be able to put the user perspective and join in debate. It was clear that training in committee skills and in disability equality was wanted by many people wanting to take part in YVIA and, for this reason, we were able to undertake a pilot course over one weekend a few months ago. This was very successful and will help to shape further courses."

The regular staff link person was now the senior services manager, and this had resulted in close contact with the delivery and content of ASBAH's services – something very important to all members of the group.

"We are pleased that there is harmony between YVIA, the executive committee and all the staff, which will help us work together in the future."

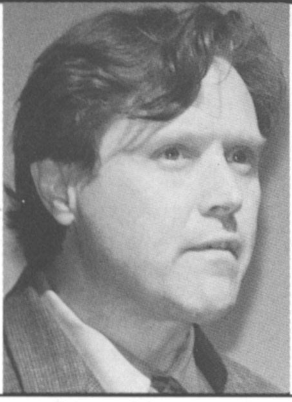
One major activity spread among YVIA was representing ASBAH on outside bodies. Another was responding to government consultations, as with the Disability Discrimination Act.

"We are aware of the complex and varied needs of our particular group of users. Whilst this makes representation complicated at times, I am certain that the varied skills among the members of the forum help us to ensure that sight is not lost of any amongst our group.

"I began by saying that ASBAH is able to be responsive to changing needs. As a growing part of ASBAH, we are determined we should, by careful planning, tackle the kinds of subjects most sought after by those with our conditions.

"This will happen I am sure in future years, alongside the ASBAH regionalisation which has happened in some areas and will continue to happens in other parts of the country, and so there is a lot to do."

ANNIVERSARY CONFERENCE



Pierre Mertens

FINAL speaker of the day was PIERRE MERTENS, the newly-elected Belgian president of the International Federation for Hydrocephalus and Spina Bifida, which has member organisations in over 30 countries, across every continent.

Formed in 1981 by 20 countries meeting in Dublin, Mr Mertens said the IFHSB had a unique network of experience and knowledge about the two disabilities. The member organisations had seen an important shift from institutional care to real help in the community – in the home, at schools and at work.

The focus of these changes had been to allow people with disabilities to take their place in society and stretch themselves to the limits of their wishes and talents.

"These organisations are still important to give people with hydrocephalus and spina bifida a voice. Health care is a delicate and a complex undertaking and effective evaluation of a good functioning health care can only be done by the so-called chronic patient, because only he knows."

The IFHSB's next international conference would be in Bonn next year, with the title 'It's about me! Return to dignity in rehabilitation.' He said the work had to be reclaimed from the big institutions, divorced from reality.

"Of course, medical help is important at many times in the life of all of us but everyone should have the opportunity to choose to be as independent as they wish.

"Community-based rehabilitation is an important approach for the care of people in developing countries, too. Worldwide, one person in 10 has to cope with a disability. Four to five of these people living in developing countries with a disability are handicapped twice – by disability and by extreme poverty."

To fill gaps in knowledge about spina bifida and hydrocephalus, the IFHSB was working with the World Health Organisation on a manual for mid-level rehabilitation workers in Kenya. The IFHSB also had a pilot project in Kenya: an expert on the disabilities was spending six months teaching mid-level workers throughout the country.

"This is just a start. Solidarity with people with hydrocephalus and spina bifida in developing countries has to come from people with hydrocephalus and spina bifida over here,"said Mr Mertens.

DAVID GRAYSON, from page 21

you are disabled, that too will become against the law. Those are the first of the new rights."

The NDC had a wider remit, of course, and that was both to advise ministers about the operation of the law and generally on the removal of discrimination against disabled people.

Mr Grayson warned: "We mustn't fall into the trap of imagining that lots of other parts of our society even know there is such a thing as the Disability Discrimination Act, warts 'n' all. We have got to raise it up the agenda of some of the people who can most affect change for the better.

"We have got to make sure that they understand their obligations if they do not make sure that their own staff are trained and so on, as well as seeing that there are some enormous positive benefits. By one calculation, the market as far as disabled customers are concerned has been put at something like £33bn."

Mr Grayson said the NDC did not have the right to take individual cases through the courts. It did not have enforcement powers. It could not adjudicate on individual cases.

"What we can do is track the cases that are being raised, either formally through the courts or indeed through any conciliation service that may be established this year. Where we see general issues emerging, for instance in relation to any particular industry or type of company, then we can investigate such issues.

"I have no hesitation in saying here and now that, if we find that there are general issues coming up, that we will go to the organisations concerned and be asking them some very searching questions about what is happening and why these kinds of issues are emerging."

NDC research would identify good practice and get that more widely understood and shared around the country. "I want to see a competition in this country in the business community not to be the last, to implement the very minimum, to conform with the letter of the law but a competition to be the first, to accede and go way beyond the minimum in terms of developing a way of doing business that is good business sense, but which is also open and responsive as far as disabled people are concerned."

Finally, Mr Grayson invited ASBAH to work closely with the NDC on common programmes in the coming years. "While it may be very good for you to celebrate 60 years, I hope that we will long since have done ourselves out of a job because, with your help, we have made a very different kind of society for the future."

LOCAL ROUND-UP

Please send your news items to: Liz Cawthorne, Link Editor, 42 Park Road, Peterborough, PE1 2UQ

THEY said it with flowers, and photographic mementos, when two veterans with almost 42 years' service between them retired from a local association recently.

Liz Selby, secretary of North Hampshire, West Surrey and South Berkshire ASBAH for nearly 27 years, and Ray Miles, their honorary treasurer for 15 years (pictured above)*, were honoured at the annual meeting in Farnham.*

Mrs Selby, who had run the office from a room in council premises in Guildford, said: "After so long, I'm going to miss ASBAH and all the families. It will be a wrench but I'm handing over to some lovely people. I hope to keep in touch." Her job will be split between three members of the committee.

Mr Miles, who travelled to the presentation from his home in Somerset where he has been living for the past couple of years, has been succeeded by Mary Bellairs.

Member David Peters said: "We were sorry to lose them."

AUTUMN BOOK SALE

	Normal price (inc p&p)	Sale price (inc p&p)	Numbers ordered
The Handwriting of Spina Bifida Children by Dr E Anderson & Joan Cambridge	£1.60	£1.00	
Young People with Spina Bifida and/or Hydrocephalus – Learning & Development by Leonie Holgate MCRP SRP	£1.60	£1.00	
Spina Bifida and You – A Guide for Young People by Collette Welch	£3.50	£2.00	
Sex for Young People with Spina Bifida or Cerebral Palsy – Ed ASBAH	£1.75	£1.00	
Making Our Way – Ed ASBAH	£1.20	0.50p	
Life and Death – Ed ASBAH	0.75p	0.50p	

Please send the above order to:

YOUR NAME ____________________

ADDRESS ____________________

____________________ POSTCODE ____________________

Send completed forms to: *Information Officer, ASBAH, 42 Park Road, Peterborough, PE1 2UQ.*

Cheques payable to 'ASBAH.' Prices apply in UK only. Overseas prices available on request.

LOCAL ROUND-UP

Another 30th anniversary

THE Bristol & District Association, like ASBAH, is celebrating its 30th birthday this year.

The Sun Life Challenge West project accepted a challenge by us to put on a party for our members.

On 5 July, more than 50 members and friends went to Sun Life Sports and Social Club in Patchway to a disco with a really great buffet and a birthday cake.

The team presented a cheque for £150 to be used for the local Welfare Funds.

Gordon Egan, who was a founder member of the Bristol Association and has been an officer for the last 30 years, and his wife Sheila were presented with a bouquet and bottle of liquor by Julia Hall on behalf of the members.

We now thankfully have our fieldworker, Julie Knight, and hope she will have a long and happy stay with us.

In May, a party of members had an enjoyable evening bowling at the recently opened Hollywood Superbowl. A special 'cradle' was available for the disabled bowlers and proved very successful for them.

A boat trip was organised on the Sharpness Gloucester canal on Saturday 29 June for a party of members. They had a good time although the weather was not too great.

Bristol & District Association sends best wishes to ASBAH members everywhere.

Family event forges new links

ASBAH notified local group secretaries that Contact-A-Family, which provides support to families with a member who has any kind of disability, wanted to raise awareness of the needs of such families.

ASBAH-Surrey, covering Croydon, Merton, Kingston, Sutton, London Boroughs and Boroughs in South East Surrey, decided to fund a children, adults and parents afternoon on 9 June.

This was held at St Faith's, a family centre in Leatherhead, run by Surrey Social Services.

The centre is bright, new and fully accessible and has a safe play area where the group was able to erect a hired 'bouncy castle' and a ball pit, as well as having activities with water.

Fortunately, it was a really sunny warm day! Whilst the children played, parents were able to get to know each other better and to compare notes.

All have indicated that they want the link to continue and will be encouraged in this by the ASBAH-Surrey committee. Tea was provided which was much appreciated by all.

The preparation for this event and later tidying up was completed mainly by members of the ASBAH-Surrey committee, led by Sandra and Ian Cole, whose daughter Elizabeth, has spina bifida and hydrocephalus.

Wedding bells for Carolyn and Tim

ROMANCE blossomed for ex-local association secretary Carolyn Merry after finding her husband-to-be through a *Heart to Heart* column.

Carolyn phoned Tim Morris after reading his ad in the local paper more than a year and a half ago. They first met in a local pub.

Tim moved in with Carolyn in May last year, and then proposed to her as they watched the sun go down behind the sea at Hunstanton, Norfolk.

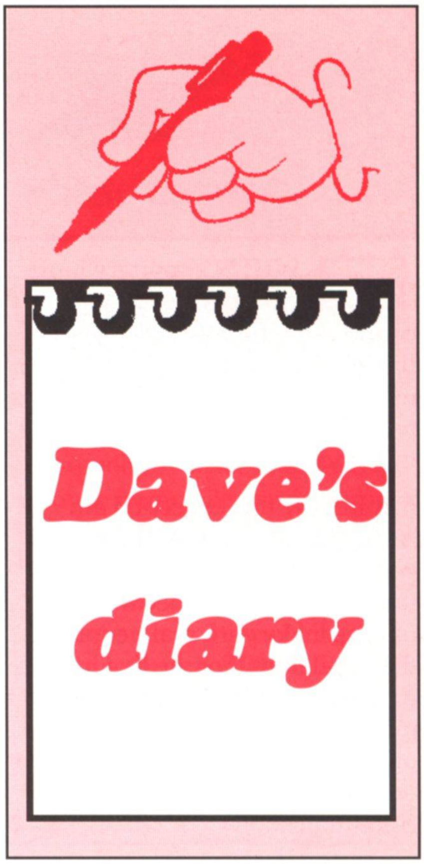
Carolyn, who has spina bifida, was secretary for Bedford ASBAH for two years before resigning when she was due to get married.

However, she is still group contact on the back page of *Link* and sends out copies of the magazine to local subscribers.

Tim, aged 37, is a staff nurse at Bedford Hospital. The pair *(pictured above)* are about to move into a larger home.

They tied the knot at St Andrew's Church, Bedford, followed by a week's honeymoon in Spain.

Carolyn, aged 32, a revenue assistant for Inland Revenue, said: "We had a lovely wedding day. I was so happy I cried all the way down the aisle."



A WHILE ago I got a phone call from a friend (I still have a few). As you do, he asked me how I was. I replied that I was well and asked how he was. Staggering stuff. Then he replied that he was fine but his 'significant other' (girlfriend) was in hospital and everyone was a bit nervous. He followed this up by saying that he supposed I'd be used to all this hospital stuff. I made encouraging agreeable noises then, but later began to think about what he meant.

My friend seemed to think that because I was disabled I should automatically be able to cope with hospital and be immune to it! I've been to hospital a few times (14 or so) but that doesn't mean that I enjoy it (it is several millionth in my list of fun things), that it's just something I do, or that it doesn't scare me just because I've eventually become used to it. Whatever I have learned about the experience of going into hospital has been gained through a lifetime of experiences. People with little experience of hospitals, like my friend, seem to think that, if you are disabled at birth, you must have been issued with a booklet on how to cope with hospitals and the like. All I can say is that if someone did get such a book, then I was obviously in the wrong queue and could I please borrow a copy?

Going to hospital was one of my earliest and most unpleasant memories. But it wasn't all bad (on reflection). Whenever I went in I always got two things: a new toy out of my guilt-ridden parents, and a shiny plaster cast on my legs for school mates to write on.

These days I no longer have ops on my legs. The few ops I've had in recent years have moved on to new and more interesting/ sensitive areas. I buy my own 'treats' too! Yes I realise you don't need presents in order to go into hospital, but if you get the opportunity why not treat yourself? I usually buy myself a good meal before 'going in.' This ensures that (a) I get a decent meal inside me, and (b) I can't say I missed out on some gastronomic delight if something goes wrong.

The fear of something going wrong is always with me. Anyone who says they aren't even the slightest bit afraid, is either lying or doesn't realise what's going on. This is no slur on the skills of doctors and surgeons, merely an awareness which came with old age that, as the number of ops grow, so must the chance of something going pear-shaped. There are three possibilities for my belief: (a) I have a tenuous grasp of statistics, (b) I will believe anything which allows me to stuff my face, (c) I'm just a terrible paranoid drama addict!

It would be unfair for people to get alarmed over what is essentially me being a wimp. I still trust the skills of surgeons, doctors etc backed up as they are by the new and improved devices and facilities that have arisen since I was a lad.

David Fulford-Brown

Editor's note: Dave will have more to say on hospitals in the next issue.

DATES FOR YOUR DIARY

Monday 11 November

Spina bifida/hydrocephalus support group meeting, Disability Resource Centre, Poynters Road, Dunstable, 1-3pm. *Sue Davies, ASBAH Adviser, tel: 01234-347494, or Valerie Bottoms, tel: 01582-605749.*

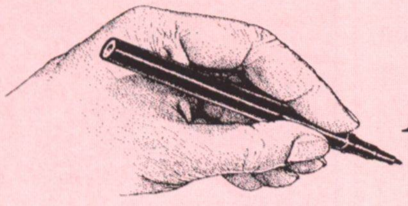
Saturday 16 November

ASBAH study day, '30 Years On – Making the Most of Life,' Park Dean School, Oldham, Greater Manchester. 9am - 4.30pm. Speakers include consultant neuro-surgeon Miss Carys Bannister FRCS, consultant paediatric neurosurgeon Michael Vloeberghs and discussion by participants on living with disability. Also welfare rights advice offered privately by an ASBAH Adviser. £7.25 each, including coffee, lunch and tea (£1.50 per child, limited number of creche places). *Details: Jean Black, ASBAH Adviser, Newbridge Resource Centre, Newbridge Lane, Stockport SK1 2NY. Tel: 0161-476 0059.*

Saturday 16 November

Surrey ASBAH study day on education, Banstead Mobility Centre, Carshalton. Registration 9.15 - 10am. Finish 3pm. Speakers: Anna Wright, head of educational psychology, Surrey County Council; Kate Evans, assistant co-ordinator, Partnership with Parents (Kent & Surrey); Peter Walker, education adviser, ASBAH; Leonie Holgate, former specialist adviser, ASBAH. £5 per family; £15 per professional. *Alan and Margaret Twyford, tel: 0181-390 0853.*

More diary dates on page 26



Letters

We invite letters for publication. Send them please to: *Editor, ASBAH, 42 Park Road, Peterborough PE1 2UQ.* The Editor reserves the right to edit letters for publication, so keep them as short as possible.

WHEN a military junta enforces a coup in a country, the first thing it seizes is the television and radio stations, not the parliament. What does this tell us about the power and the influence of the media?

Inspired by this concept, I am researching images of disabled people in advertising and importantly the connection those images make with real people in their real lives. For we live in a pictorial world, both surrounded by images and creating them in our own minds. Pictures are one of our fundamental forms of communication.

It is well established now that by far the greatest proportion of representations of disabled people are negative. Historically overtly so; more recently as the absent 'other' or 'super crip'. I won't go into detail of how negative images are disabling as this is well documented elsewhere. What I would ask you to consider is how this constant barrage of one dimensionality makes a disabled person feel, and whether these images become a self-fulfilling prophecy.

Adverts are everywhere. They are there when you turn on the television, in every magazine and on every street. Snapshots that draw upon our deep-rooted cultural beliefs. I ask: where are the disabled people? According to Government statistics (1988) 1 in 8 people in the United Kingdom are disabled. Six and a half million invisible people! Taboo people. Six and a half million people with spending power. Six and a half million people who are perceived as in need of intervention and adjustment to 'normalise' them again, while the physical and social environments are assumed to be fixed and unalterable ... But historically human beings have always moulded their environment to suit their needs.

So where do we go from here? One of our problems is our instinctive belief that disability is anathema. We do not consider what it is really like to be disabled, that there are as many positive aspects as negative and that being disabled has the ability to give as much as it takes away. When most people see a positive image of a disabled person they are thrown into chaos. Take the picture of Shannon Murray that appeared on the front cover of the March edition of *Disability Now*. People recognise the good bits: the good looks, the lovely clothes, the fantastic figure, the vibrance, the assertiveness, the sexuality, the bits we aspire to, as non-disabled. But the less palatable bits, say the wheelchair, are regarded as disabled. They do not want to recognise this person as disabled and want to believe otherwise. How can we both want to be and not want to be the same person at the same time?

Suffice to say that I believe images of disabled people should be mainstream and positive. That is, until we have learnt to recognise disabled people as 'people', with an identity and a pride in their own culture, then will be time for a broader representation. As this happens, the dividing line will move, because in truth we all have problems – they simply depend on classification. I hope that the findings from my study will influence policy and good practice, enabling this to happen.

Philippa Armstrong
One Step Beyond
Disability Equality Consultancy
Watsons, Belsford Harberton
Totnes, Devon

DIARY DATES EXTRA

Wednesday 20 November

Hydrocephalus Study Day organised by Sussex ASBAH. The Hawth, Crawley, West Sussex, 9.30am - 4pm. Speakers: Dr Roger Bayston; Leonie Holgate; representative from West Sussex Education Department; Jeanette Robertson (SASBAH education adviser). £15 professionals, £6 parents/ adults with spina bifida and hydrocephalus. *Mrs Anne Bush, tel/fax: 01798 813663.*

Thursday 21 November

British Epilepsy Association one-day conference Growing Up with Epilepsy, The Park Hotel, Cardiff. *Tickets/info: Catherine Moul, British Epilepsy Association, Anstey House, 40 Hanover Square, Leeds LS3 1BE. E-mail: epilepsy@bea.org.uk.*

Saturday 22 February

Study day on sexuality, for people living in Leeds and Bradford, organised by ASBAH's START service in conjunction with Leeds Young Adult Team and Bradford 16 - 30 Group Project, St Mary's Hospital, Greenhill Rd, Leeds. *Rose Hinchliffe, 01943-609468.*

HOLIDAY ACCOMMODATION

When booking, check to make sure the accommodation suits your particular needs

WEYMOUTH BAY

Fully-equipped, wheelchair accessible caravan – sleeps five; on Haven Holiday Park, full use of all facilities – heated indoor & outdoor pools, bars, children's club & full entertainment programme. Three miles from Weymouth.

Details from Margaret Humphreys, tel: 01494-714270 (Bucks & E Berks ASBAH).

ISLE OF WIGHT ASBAH

Fully-equipped two-bedroom holiday bungalow, sleeps six plus cot. Clubhouse, indoor heated pool, shop etc. Site overlooks sea. Own transport advisable.

Details: Mrs P Burden, 36 Sherbourne Avenue, Binstead, Ryde, IOW, PO33 3PX, tel: 01983-564604.

mar y sol

Mar Y Sol – Tenerife

Wheelchair accessible apartments. Heated pool with hoist. Restaurant, poolside bar. Equipment hire. Ring today for cheapest summer and winter prices.

Algarve – Portugal

Wheelchair-friendly luxury villas with swimming pools or friendly hotels with adapted rooms.

Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx TW19 5NX.
Tel: 01753-685718.

SELSEY, WEST SUSSEX (SASBAH)

Fully equipped purpose-designed for wheelchair access mobile home. Sleeps six, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainmernt, heated swimming pool, free site bus service. Nature reserves and places of interest nearby.

Details from Mrs B Nunn, tel: 01903-763473.

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Long Eaves
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Blackpool
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Calderdale
Mr A L Crowther
12 Elm View
Huddersfield Road
Halifax
HX3 OAE
Tel: 01422 341497

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Southfork
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Tel: 01948 663627

OTHER ASSOCIATIONS

SCOTTISH SBA
Executive Officer:
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190 Queensferry Road
Edinburgh
EH4 2BW
Tel: 0131 332 0743

IRISH ASBAH
Ms Claire Gill
Hon Secretary
Irish ASBAH
Old Nangor Road
Clondalkin, Dublin 22
Tel: Dublin 003531 4572326

Association secretaries requiring changes to this list should contact: ***LINK EDITOR, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733 555988 Fax: 01733 555985.***