

# Link

The magazine for people with  
Spina Bifida and/or Hydrocephalus



April/May 1993

Issue No 145 Price 80p



## LIFESKILLS DEVELOPMENT COURSE

**18 - 23 July , 1993**

at Beaumont College  
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For more details and an application form, contact

**Lynn Thomas**  
**ASBAH House**  
**42 Park Road**  
**Peterborough PE1 2UQ**  
**Tel: 0733 555988**

ASBAH is indebted to the Association for Wheelchair Children for  
supporting this course, but it is necessary to make a minimal  
charge of £95 (including £25 non-refundable deposit)

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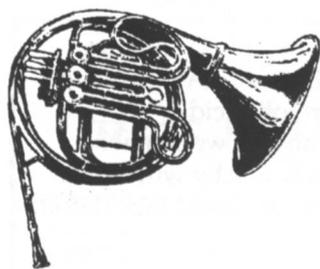
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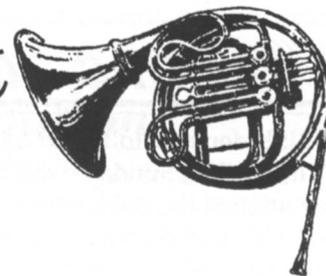
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# Classical Concert for ASBAH



Our President, Jeffrey Tate, will conduct The English Chamber Orchestra in October, in a concert to support our fundraising efforts.

The concert of classical music will be held in the presence of our Patron, HRH The Duchess of Gloucester, on 17 October at Cambridge Corn Exchange. The soloist will be Stephanie Gonley, leader of the ECO.

The programme for the evening will be:

**Mozart - Symphony in D Major, K133**  
**Mendelssohn - Violin Concerto in E minor, Opus 64**  
*Interval*  
**Mahler - Adagietto from Symphony No 5**  
**Mozart - Symphony No 35 in D, K385, "Haffner"**

*The performance will start at 7.30pm.*

The concert hall seats 1,205 people and ticket prices will be : Band A - £18, 690 seats, Band B - £15, 354 seats, Band C/D - £12.50, 161 seats.

The venue welcomes patrons with disabilities and stewarding staff will be pleased to give assistance. Wheelchair users require two Band A seat spaces and 12 wheelchair spaces are provided next to 12 seats for accompanying partners. The charge for wheelchair spaces will be £18 per person. A further 10 seats are equipped with an infra-red hearing enhancement system. Guide dogs can remain if their owners occupy seats situated at the end of rows. There is a level access entrance to the main auditorium and a suitably adapted toilet.

Paul Wootton, assisted by Deirdre Pawsey, has undertaken the negotiations, planning and cost assessment and they will assist with any queries which the booking office cannot satisfy.

Tickets will be on sale on a first come, first served basis. The box office address is Wheeler Street, Cambridge CB2 3QB. Telephone: 0223 357851 (fax 4633378) and is open from 10am to 6pm, Monday-Saturday, and 6pm-8pm on the day of the performance. Unsold tickets will be available on the day at half-price to registered disabled people, students, unwaged people and senior citizens.

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## **Folic acid in the news**

BRISK demand followed a story in 'The Mail on Sunday' which mentioned the publication of a free ASBAH leaflet on the importance of taking folic acid in the diet to combat spina bifida.

The article also lambasted the Department of Health for doing little in the last three months to get the message across to women before they become pregnant.

Within a week of the story appearing, 400 people had requested the ASBAH leaflet by telephoning a Freephone number set up for us for Kellogg's - who fortify some of their breakfast cereals with folic acid.



*Roy Johnston with the folic acid leaflets*

The demand is expected to continue as the Freephone number is publicised more widely. The details have been trailed round a number of Sunday, daily and local newspapers, women's magazines, TV and radio programmes by staff working for ASBAH and Kellogg's.

"Nothing is ever guaranteed but we expect more coverage soon", said Barbara Atkinson, associate director of the Kellogg's public relations agency involved.

ASBAH appeals manager Roy Johnston added: "The Department of Health announced just before Christmas that all women intending to become pregnant should increase their intake of folic acid. But they have done nothing yet to launch a promised major public health information campaign.

"We thought, rather than waiting for the Government get its act together, ASBAH should - despite its own cash shortage - do something now to help reduce levels of spina bifida and hydrocephalus in pregnancy."

Roy recruited both Kellogg's and Marmite to help us plug the information gap. Marmite produced a leaflet being sent on request to health care professionals. Kellogg's - who already covenant £2,000 a year to ASBAH - agreed to cover the cost of a separate leaflet which can be obtained by anybody using a Freephone number.

Both leaflets stress how important it is for all women intending to become pregnant to increase their intake of folic acid by eating folate-rich and fortified foods and taking a tablet of 0.4mg folic acid every day - from before conception until the 12th week of pregnancy. Bar charts in both leaflets show folic acid levels in various foods.

The leaflets can be obtained as follows:

*Kellogg's Freephone 0800 626 066*

*or write: the ASBAH leaflet, Unit 2, Colville Court, Calver Road, Winwick Quay, Warrington, WA2 8QT*

*The Marmite leaflet (bulk supplies for health care professionals) write to: Sylvia Meredith Health Education Advisory Service, 3 Elgin Road, Sutton, Surrey SM1 3SN.*

*Please help ASBAH keep its costs to a minimum by not asking us to supply either leaflet.*

The Government is resisting pressure from ASBAH to waive charges on folic acid prescriptions for women who have already a baby with spina bifida or other neural tube defect.

Women who have already had a neural tube defect pregnancy are recommended to take a daily 5mg tablet obtainable only on prescription - which will be reduced to 4mgs when a suitable product becomes available.

The chief medical officer, Dr Kenneth Calman, has refused to extend exemptions on health grounds. He says government policy continues to target people who need free prescriptions for financial reasons.

In a letter to ASBAH executive director Andrew Russell, Dr Calman says those who qualify for free prescriptions include women in households receiving Income Support, Family Credit or covered by a 'low income remission certificate', those currently exempted on health grounds, young people under 16 and students under 19.

Prescription charges - recently increased to £4.25 an item - represent a significant disincentive for people on low incomes to take medication, said Mr Russell.

He has now written to Health Secretary Virginia Bottomley seeking to persuade her to overturn Government policy.

"There are relatively few clear and cost-effective measures for the prevention of severe disability, but this is one. It seems to be a perverse policy to insist that affected women pay prescription charges over what could be many months of pre-conception, as this will be a strong disincentive to those on modest incomes," he told LINK.

"Exemption does not apply to most women of child-bearing age."

## Cornish athlete aims high

Our cover picture this issue shows budding athlete Mark Barbery, who after early difficulties with his mobility has been selected for the English team by the British Wheelchair Athletics Association.



Mark, who lives at Tregony, near Truro in Cornwall, got his sporting break through ASBAH.

The 28-year-old found out about us only two years ago. Since then, local people have rallied to his support - raising almost £1,500 to buy him a lightweight sports wheelchair, which has put him on the road to fame, if not fortune.

After winning medals on his sporting debut last year, Mark was spotted by a scout from the BWAA and was invited to a national training weekend. After testing his aptitude, he has been entered for the shot putt, javelin and discus competitions at the National Senior Wheelchair Games held at Stoke Mandeville during the second week in June.

After losing his job because of an earlier deterioration in his mobility, Mark is now appealing for sponsorship to help cover his additional expenses.

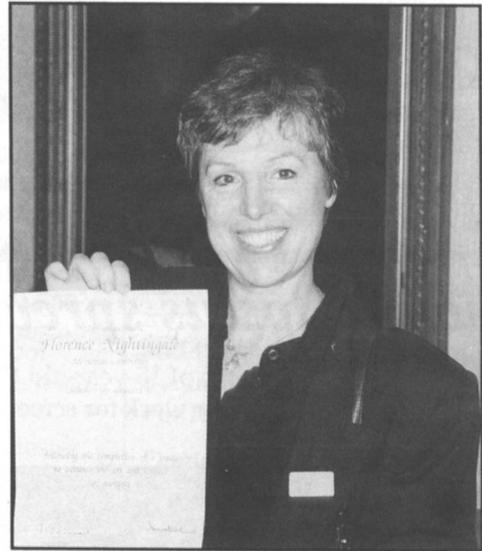
Lynne Young, our fieldworker in Cornwall, commented: "Mark really does feel that his life has turned round for the better since getting to know us."

## Mary gets 'Top Nurse' recognition

The lady with the lamp couldn't have done it better! Mary White grins broadly after receiving a certificate marking her successful international travel scholarship awarded by the National Florence Nightingale Memorial Committee.

Mary, one of ASBAH's continence advisers, asked the committee to let her broaden her knowledge in her field. The resulting scholarship enabled her to travel to 11 specialist centres in the USA and Canada last summer, and prepare a report for circulation among fellow professionals.

She and two dozen other successful candidates were presented with their 'signing-off' certificates at the Royal Society of Medicine in London last month.



# Officers & Staff

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Mrs Gill Winfield

## Gill steps up

Gill Winfield has been promoted to Information Officer after nearly three years as Editor of 'Link', and our other magazines and newsletters. Gill, who started her new job on 1 March, succeeded Pat Corns, who retired at Christmas.

There were over 180 enquiries about the post of Information Officer, after it was advertised in the Peterborough local press and these produced some excellent outside candidates for interview. Gill was the only inside candidate.

Succeeding Gill as ASBAH's Editor is Jeanette Dixon, who was expected to have joined us on 1 April. Jeanette has experience of editing similar magazines and, most recently, has been working in the publications unit at PHAB.



Above: ASBAH House information assistant Margaret Black shows new information officer Gill Winfield the ropes.

## Ruth helps us spread the word

A camera crew gets a close-up of 15-year-old Ruth McClure, who helped us make a brief film about our work for screening throughout Northern Ireland.



Ulster TV did their filming at New Row, Coleraine, where we have our regional centre and, besides Ruth, the brief footage is also expected to show her father, Arnold, office secretary Karen King and regional coordinator Meta Harvey, who provides the voice-over.

The film, a one-minute, free community service announcement, is being shown 10 times within a fortnight on Ulster TV, to mark the second anniversary of the setting up of our fully-staffed regional team in April. Two of the transmissions will be at prime viewing times.

## Raring to go

Thanks to ASBAH, the Upside Down Sports Club and his friends, 16-year-old Matthew Coleman has the wheelchair he needs to achieve his potential in racing.

ASBAH was able to help towards the cost of a specially designed racing wheelchair with funds given to us by Children in Need.



Above: Matthew, from Cambridgeshire, in his mean machine.

## Lists being compiled

Enquiries have started to arrive for details of our Lifeskills Development Course being held at Beaumont College, Lancaster, in July. The course aims to improve a variety of skills in young people aged 11-15 years - including their mobility, personal independence and sense of self-awareness. There are 30 places available. Details: Lynn Thomas, DLS, ASBAH House.

Twenty places are also on offer at an ASBAH weekend mobility course being held in Liverpool in May. This will concentrate on developing wheelchair skills. "Unlike the full-scale Lifeskills course, which covers a number of topics, the Liverpool weekend will home in on mobility only", said mobility adviser John Naudé. Initially, the details are with fieldworkers in Liverpool and Cheshire but John has details at ASBAH House.

# NEWS IN BRIEF

## Change of venue

Unresolvable problems in organisation have resulted in a late change of host country for this year's annual conference of the International Federation of Hydrocephalus and Spina Bifida (IFHSB).

Although the event is taking place at the same time - August 19 to 22 (inc) - the IFHSB has had to switch the conference from Paris to Deinze in Belgium, between Ghent and Bruges.

A three-night package, including accommodation, meals, excursions, entertainment and conference fee, will cost approximately 1,290 Belgian francs per person for a single room and 1,090 based on a double room. Travel to and from Belgium is not included.

The language of the conference will be English.

Up to 250 people, including families, usually attend these annual meetings. *Details from Teresa Cole, Fieldwork Manager, ASBAH. Tel: 0733-555988.*

## Penfriends

**Alan** is 27-years-old and has hydrocephalus. He likes any music that you can sit and listen to.

**Kelly** is almost 16 and lives in Belfast with her parents and older brother.

She likes swimming and discos and would like a slightly older penfriend, either boy or girl, in the UK or abroad. She has spina bifida.

Reading, music and TV soaps are among the interests of 21-year-old **Gillian**, who lives in Dungannon, Northern Ireland. She would like letters from anyone aged 20 to 30.

**Alison**, aged 22, is a Liverpool Football Club supporter. She likes folk music, basketball and watching TV and lives in Chester. She wants to hear from someone about the same age.

If you would like to contact any of these people as penfriends, send your letters to LINK and we will pass them on.

## For parents who live apart

From 5 April arrangements for child maintenance have changed. A new organization - the Child Support Agency - is now responsible for settling these matters. If you are parents who live apart the changes could affect you. For the free booklet "for parents who live apart" tel: 0345 830 830 or pick up a copy from your post office

## Wheeling around the Algarve

An agency in Portugal, run by an ex-Stoke Mandeville nurse and a wheelchair user, offers a service for disabled travellers to the Algarve. Aimed mainly at wheelchair users, their leaflet describes options for a package holiday - with accommodation from luxury villas to mini-hotels and transport, nursing care, medical aids and leisure facilities. For further details contact:

David Player or Angela Wicks, Rua 5 Outubro 84 - Apartado 421, 8136 Almancil - Algarve - Portugal.

## Change of bankers

ASBAH has changed its bankers from the National Westminster Bank to:

Co-operative Bank, 33 Westgate, Peterborough. Sort Code 08-90-40. Account Number 70784071.

## LINK index

An index to all major articles which have appeared in LINK over the past five years is being prepared. If you would like a copy, please write to Gill Winfield at ASBAH House, enclosing a large SAE. Copies of articles listed can also be obtained from the Information Department (send SAE also).



## PRODUCT NEWS

A non-slip tray!

Attention to small detail can often result in a winning product, and Dycem hope for the same with their smart, lightweight tray made from a compound called ABS. The firm says the tray is strong, hygienic and will not chip, scratch, dent or rust. Above all, it really is non-slip.

Look for it in the new Homecraft and Nottingham Rehab catalogues, or ask Dycem themselves about it. *Dycem Ltd, Ashley Hill Trading Estate, Bristol BS2 9XS (tel 0272 559921).*



# Hydrocephalus - Current management and future prospects

*Dr Eric Guazzo, senior research associate in the neurosurgery unit at Addenbrooke's Hospital, Cambridge, gives an overview of hydrocephalus - bringing us up to date with treatment prospects.*

Hydrocephalus is the end result of a diverse group of predisposing conditions, which all result in an imbalance between the production of cerebrospinal fluid and its reabsorption. The imbalance is typically due to obstruction of CSF flow at some point in the pathway from the ventricular system to its reabsorption. Very rarely hydrocephalus is due to CSF over-production.

Production of CSF is a constant phenomenon, hence any degree of obstruction to flow results in CSF accumulation (3). This leads to ventricular dilatation, elevation of intracranial pressure and brain compression. The cause of hydrocephalus can be categorised into three broad groups.

The first - congenital hydrocephalus - usually presents in neonates or infants with a clinical syndrome of enlarging head circumference, tense fontanelle, split sutures and the late sign of sun-setting eyes. The common congenital deformities in the CSF pathway include aqueduct stenosis or occlusion, fourth ventricular outlet obstruction or more complex deformities which may be associated with conditions such as spina bifida or the Dandy Walker Syndrome.

Tumours can also lead to obstruction in CSF flow.

Inflammatory conditions, be they of infective origin such as in a post-meningitic state or a result of irritation from substances such as blood in post-traumatic or post-subarachnoid haemorrhage cases, lead to impairment in CSF absorption.

## Current Management

The current management of hydrocephalus has evolved over the last 30 years (8). Since the development of the first valve-regulated shunt mechanism in the late 1950s (5,6), there have been significant advances in the management of hydrocephalus leading to a much improved outcome for these patients (4). With improved operative technique, many more of the obstructing lesions such as tumours are able to be removed and the need for a shunt in these

conditions has been avoided. However, the majority of the patients still require diversion of CSF from the ventricular system. The standard form of shunting procedure today is a ventriculo-peritoneal shunt.

In the majority of patients, the decision that a shunt is required is clear. The patient has a progressive, symptomatic hydrocephalic state and there is no alternative to a shunt. However, in others the decision is not so clear.

There are many varieties of

shunting mechanism available on the market but all consist of three components as illustrated in the diagram: a ventricular catheter which is connected to a valve reservoir chamber and this in turn connected to a catheter tunnelled subcutaneously to the peritoneal cavity. A ventriculo-atrial shunt is rarely used and predominantly in those patients in which the peritoneal cavity is not appropriate. Examples would include peritoneal sepsis, chronic inflammatory bowel disease or multiple previous abdominal procedures.

## Problems

As with any form of drainage procedure and implantation of foreign material, there are potential complications. The complications of CSF shunting procedure fall into three broad categories: under-drainage, infection or over-drainage (4). Under-drainage or malfunction in the past was primarily due to defects in the shunt assembly, however, with improved technology this is much less common. Fracture and kinking rarely occur. The main reason for shunt malfunction seen today is ventricular catheter obstruction due to choroid plexus obstructing the proximal tip of the ventricular catheter.

The implantation of any foreign material into the human body results in the risk of infection. The majority of shunts that become infected do so in the first six months after implantation and this usually occurs as a result of contamination at the time of insertion. Many changes in surgical technique have been introduced to continually lower the risk of shunt infection and presently the rate is below 5% (1).



With improved shunt technology, we are now seeing the problem of over-drainage. This results in the ventricles becoming slit-like and subdural collections may occur. This problem can be very difficult to manage, but usually responds to changing of the valve type to alter the opening pressure. Improvement in valve technology to avoid over-draining may soon be available (7).

#### Shunt Malfunction

The detection of shunt malfunction is often straightforward. However, in some cases, it may be insidious and difficult to detect. As can be seen from the associated table, most symptoms are due to the elevation of intracranial pressure. But, in some patients the shunt malfunction may not be total, or it may indeed be intermittent and symptoms may be perplexing. A high level of awareness is required. Careful clinical evaluation with radiological investigation in the form of CT scan or ultrasound usually allows the diagnosis to be made. A more advanced test, such as CSF-flow studies or intercranial pressure monitoring, may be required in difficult cases.

#### Future Prospects

Avoiding the need for a ventriculo-peritoneal shunt,

## Symptoms of Shunt Malfunction

### Infants

Enlargement of baby's head.  
Full, tense fontanelle.  
Split sutures.  
Swelling or redness along shunt tract.  
Fever.  
Irritability.  
Seizures.

### Toddlers

Head enlargement.  
Fever.  
Vomitting.  
Headache.  
Irritability/sleepiness.  
Swelling or redness along shunt tract.  
Seizures.

### Children and Adults

Headache.  
Vomitting.  
Fever.  
Irritability/Sleepiness.  
Personality change.  
Decline in academic performance.  
Incontinence.  
Ataxia.  
Seizures.

wherever possible, is the goal. With the increasing availability of endoscopic techniques used within the ventricular system, congenital obstructions may be overcome. Endoscopy may also be used for more accurate placement of ventricular catheter to lower the risk of choroid plexus obstruction of the ventricular catheter. These techniques are currently being evaluated (2).

Improved valve technology to reduce the incidence of over-drainage may soon be available. This may allow patients with a ventriculo-peritoneal shunt to achieve a more normal physiological environment intracranially.

The rate of infection of ventriculo-peritoneal shunts has fallen considerably. However, continuing improvement in techniques will allow the rate to be lowered further.

#### Conclusion

Improvement in the management of hydrocephalus has allowed many of these patients to achieve a more normal life style. The goal of achieving an adequately functioning shunt with a low complication rate is achievable. The condition leading to hydrocephalus is now the main determinant of outcome as the

hydrocephalus should be well controlled.

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**-We have the technology-  
-Using high tech equipment to-  
-assess walking patterns-**

*Gait Analysis (which assesses walking patterns) can be used to plan correct treatment and appropriate surgery for children with disabilities. Used in conjunction with an oxygen-consumption analysis meter, it can help to determine whether a child would benefit more from using a wheelchair, or whether they should be encouraged to walk. The Gait Analysis Laboratory at Musgrave Park Hospital in Belfast tells us about its work in this area.*

The Musgrave Park Gait Analysis Laboratory was opened by Snow White (alias Dana, the singer) and retired children's orthopaedic surgeon, Mr Jimmy Piggott, on 2 September 1992. Since then we have performed about 50 analyses on children with walking disorders.

The laboratory was established by one of the present children's consultants, Mr Kerr Graham, to measure the effects of treatment on children and to assist in planning treatment.

Initially, the lab has been operated by research fellow Ian Corry, assisted by technician Joe Murphy. Now that some experience has been built up, there are hopes that we will find funds to staff the lab permanently and be able to provide a regular clinical service.

The analysis is based on the images of small reflective markers attached to the child's skin which are tracked by infra-red cameras. (photo 1) The cameras send out an infra-red flash 50 times per second and receive the reflection before sending the information to the computer for analysis. Before a patient is assessed, the cameras are calibrated by focusing on a

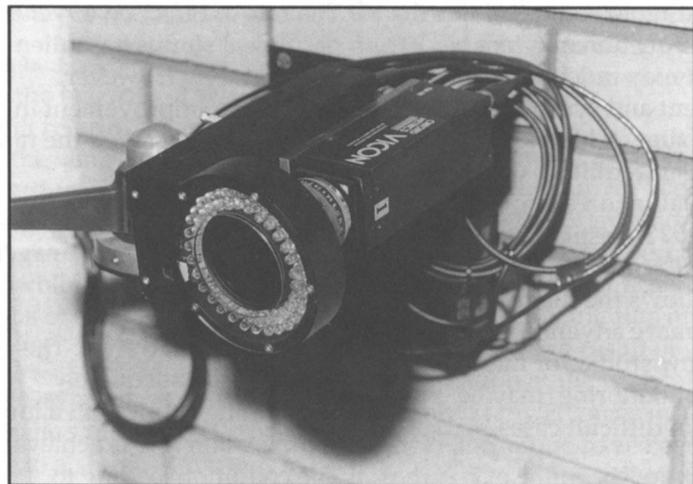


Photo 1



Photo 2



Photo 3



Photo 4

set of markers on rods suspended from the ceiling. (photo 2) When applied to a patient, the markers can be seen even when a walking aid is used as shown in the photograph of an eight-year-old boy. This photo also shows the force plates in the floor which detect the forces going through the feet, although this is only useful without the walking aid. (photo 3)

Extra information is gained by measuring how much oxygen is used during a walk. For this, the lab staff have pioneered the use of a portable oxygen uptake analyser which transmits its signal by radio waves to a receiver in the room. (photo 4) The children enjoy this part of the testing which is like playing "Ghostbusters" or acting as a fighter pilot! A project is just beginning under Katherine Duffy, another orthopaedic surgeon, to look at the energy-cost of walking, in children with spina bifida using this equipment.

The work of the laboratory to date, has been generously funded by charities such as the Royal Victoria Hospital research grants, the Medical Research Council, the Musgrave Park Hospital charity (MITRE), the Variety Club of Great Britain, the North British Trust, the Birnie Trust and a generous donation from the Allergan company.

The future work will be a combination of research and a regular clinical service. Gait analysis should thus become another tool like an X-ray or a scan to assist orthopaedic surgeons in their decision-making, when planning treatment for particularly difficult cases. As always with exciting new developments in technology, there is often hope raised that this will suddenly answer many questions. It must be emphasised that gait analysis is not a treatment but simply another investigation. At present we are learning that, while some questions are indeed answered, often many more are raised.



*Last year, Tracey Proudlock, from Muswell Hill, North London, won an International Air Tattoo flying scholarship for disabled people. In this article, she describes the experience and tells us about her time at Epps Flight School in Atlanta, Georgia.*

"Have you always wanted to fly? Are you a technical wizard? Do you know a lot about engines?" These are all common questions people ask when they find out that I recently came back from the States, having passed the Federal Aviation Authority's private pilot certificate.

But the answer is No - I'm just an enthusiastic novice! My interest in flying started at university when friends joined a local flying club outside

Tracey Proudlock learned how to fly after she was awarded one of the flying scholarships for disabled people - named after Douglas Bader, the World War II fighter ace, who flew planes after losing both his legs in a flying accident.

She said she felt "so proud" when she completed a solo 320-mile flight in America last year, and went on to gain an American flying certificate.

Unfortunately, this does not mean that she can fly solo in the UK. Although any student returning with the same certificate would have to take their British Air Law exam before applying for a private pilot's licence here, Tracey will also need to take a flight medical check; if she passed this, she would be able to fly without a safety officer accompanying her.

Another hurdle in Tracey's bid to fly solo in the UK is that a simple piece of equipment used in the USA, to convert the rudder to hand control, has *not* been passed for use in this country by the CAA. Tracey told us that the UK version of this equipment is much too big and awkward for her to use.

Wing Commander John Patterson, of the International Air Tattoo who organise the scholarship awards, told us: "The rules are different over here. But we have been negotiating with the CAA for some time to find a solution to this problem. One possible solution might be to change the rules."

*We hope the CAA does change the rules soon, and approve the use of the USA hand rudder.*

Leeds. Needless to say, they all thought it unlikely, if not impossible, for me to join too. After all, how can you fly an aeroplane without feet?

Almost eight years later, sitting in Stanmore Limb Centre, I read a magazine article about a woman who had recently won a scholarship to learn to fly in America. The woman, Tina Saddler, was sitting on an aeroplane wing and I noticed she had an artificial arm.

The flying school in Atlanta had developed equipment to assist her and many other disabled people to fly light aircraft. My brain began ticking over.

I made enquiries, filled in an application form and very quickly found myself at RAF Biggin Hill for two and a half days of selection interviews and tests. The RAF made genuine efforts to put us all at our ease (there were 20 final candidates for nine scholarships). The tests were designed not to test our knowledge of flying but our ability to learn and be safe in the air.

Within two weeks of leaving Biggin Hill, I heard that I had been a successful candidate and I needed to indicate when I would be available for flight training in America. Indeed, when would I be available? I was in the middle of planning my wedding and honeymoon. After negotiations, it

was agreed that I would fly out with the last group of scholarship winners in September '92. Prior to leaving, I was given a set of study books and a video - to familiarise myself with aeroplane instruments and basic air laws (great honeymoon material!).

On arriving in Atlanta, I got more than I bargained for. I quickly found myself with heaps of studying and exam work; there was little time for sightseeing or relaxing by the hotel pool in temperatures in the 80s. Typically, the day began with a few hours in ground school, where we'd study such things as engine parts, navigation and weather, and the afternoons would be spent in the air.

The major milestone was my first solo flight. I remember the day my instructor hopped out of the plane and told me to go it alone. I watched out of the window as she walked away from me and my Cherokee (8445 Bravo).

I felt so desperately alone and I looked with fear at the seat she had just vacated.

Adrenalin raced through my body and I nervously announced my intentions to the control tower: "Student pilot ready for take off." My instructions came back from a crisp sounding, young man: "Clear for take off."

Breaking with protocol, I picked up the mike and added: "Tower, you do know I'm a student?" The voice came back: "Yes! Now 8445 Bravo, you are clear for take off." He was bored with my nervous hesitation.

My first solo was a 30-minute flight around Fulton County traffic pattern but it's something no one can deny or take away.

The pace of the scholarship demands that students quickly move on to their next objectives. There is little room for deliberation and day-dreaming. Within two days of my first solo flight, I began my cross country training -



*Tracey, hard at work in ground school learning about navigation*

culminating in a solo 320-mile journey from my school, visiting two other airfields, stopping to refuel on my way home. This long solo flight was exhausting and, as I approached Peachtree Airport (home base), I was so thankful to have made it back that I struggled to maintain concentration on my final approach to landing. I felt so proud: after six weeks at flight school, I began to feel like a pilot.

The aim of the scholarship is not to turn you into a pilot. It is to enable you to experience flying and have the opportunity to study. If you want to turn that opportunity into a certificate, then you can: share your hopes with the instructors and they will supply the pressure and tighten the screws to make you achieve.

Before attending Epps Flight School, I had considered myself tough and independent. The scholarship is anything but a holiday and, finding myself alone 3,000 miles from home, I didn't think I could continue with the heavy pace and standards set at Epps.

The scholarship has certainly changed my outlook on life.

Having gained all my new skills, I am determined to carry on with flying in England. That may be

harder than the scholarship itself because in this country we have something called bureaucracy and red tape. A non-disabled pilot would be able to fly on an American certificate in the UK - if they joined a flying club and passed the club's flight check. But the Civil Aviation Authority will not let me do this.

In Britain, they don't seem to think you can fly safely without any feet!

*(Deja vue!)*

## *Independent living*

CRYPT is a registered charity which provides small group homes in the community for young people with physical disabilities. They have limited vacancies for those aged 18-30 who wish to experience independence while living in a group home (for three or four people).

*Contact: The Crypt Foundation, Forum, Stirling Road, Chichester, West Sussex PO19 2EN. Tel: 0243 786064.*

I first became interested in Acupuncture many years ago, and have been using it as a part of my practice as a Physiotherapist for 12 years. In this brief article, an outline of some aspects of Acupuncture will be addressed and examples of how it works will be described.

#### *What is Acupuncture?*

Acupuncture is a therapeutic technique which forms part of the practice of Traditional Chinese Medicine (TCM). The history of this practice can be traced back more than 3,500 years.

The Chinese evolved a system of medicine which was based on the world about them which, in Taoist philosophy, was made up of the great negative force or YIN and the great positive force or YANG.

When Yin and Yang were balanced, the body was healthy. When out of balance, there was a state of disease.

In ancient times, there were no X-rays, MRI scans or blood tests. The Chinese physicians had to rely on careful observation of their patients. Questions on general health were also very important because a picture of the 'WHOLE PERSON' was essential before a proper diagnosis could be achieved.

#### *Traditional Chinese diagnosis* THE FIVE ELEMENTS

All the organs of the body, together with the various tissues and orifices, are grouped under specific Elements:

FIRE, EARTH, METAL, WATER, WOOD

For example:

- ★ FIRE influences the heart and circulation;
- ★ EARTH influences the spleen

# Pinpointing the problem

*Nadia Ellis, physiotherapist and acupuncturist, continues our occasional series on alternative therapies with an introduction to acupuncture. The use of acupuncture in pain relief, constipation and bowel problems may be of particular interest to LINK readers.*

and stomach and is involved with digestion;

★ METAL influences the lungs and large intestine, the skin and respiration;

★ WATER influences the kidney and bladder and bones;

★ WOOD influences the liver and gall bladder and muscles.

Energy (Qi) circulates through each Element in turn.

Thus, in a 24-hour period, energy (or Qi) enters the METAL element through the lungs at 3am and circulates through the organs of the body over a 24-hour period - finishing at the WOOD element in the liver between 1 and 3am.

It is an established fact that many people die in the early hours of the morning. The Chinese would explain this by saying that, when the energy (Qi) in the body is too weak to transform the energy from the air, then no respiration can take place and the life cycle which begins at 3am cannot be initiated.

When taking a case history, the time of day when symptoms are worse or better is significant as this would indicate which organs are affected.

The Five Element cycle is also important when looking at symptom variation at different times of the year. Each Element is assigned a Season.

For instance, Fire/Summer; Earth/Late Summer; Metal/

Autumn; Water/Winter; Wood/Spring.

#### THE MERIDIANS

There are 12 Meridians or Channels identified in TCM, each controlled by an Organ.

When energy is circulating freely along the 'Channels', the body is healthy. If there is a block to this flow of energy, there is disharmony or disease.

The energy level of these can be felt at the wrist on the arterial pulses. There are six pulses that an experienced practitioner can feel on each wrist, each corresponding to one of the 12 organs.

The tongue is also used in the diagnostic process. The colour, shape and nature of its coating all give clues to the TCM practitioner as to the cause of the problem which the patient presents.

There are many other correspondences which relate to the 'Five Elements' which help the practitioner to identify where there is imbalance.

In the West, Acupuncture has been used primarily for the relief of pain.

How is the experience of pain explained by TCM and Western Medicine?

#### TCM

Pain is explained as being the result of an obstruction to the circulation of Qi. Identifying the local acupoints in the area of the

pain and also introducing a needle in a distant point on the same meridian can help to unblock the Qi, re-establish the smooth flow and so relieve the pain.

#### *Western Medicine*

In Western terms, the relief can be explained by the stimulation of nerve fibres which carry messages to the spinal cord and brain. These cause an increase of morphia-like substances in the circulation and thus the pain is relieved.

Are there other condition that can be treated with Acupuncture?

In China, all citizens have a free choice of taking their complaints to the TCM hospitals or to the Western establishments. Many choose the former.

I recently visited China and worked for a few days in a TCM clinic. The conditions presented includes asthma, facial paralysis, sciatica, rheumatoid arthritis, and stomach problems.

While in practice in the UK, I have found considerable success in treating the condition of nocturia (having to get up at night to pass urine) and successfully completed a pilot study, which showed significant benefits from acupuncture.

Acupuncture can also be helpful in constipation and bowel problems and in obstetrics and gynaecology.

#### **AVAILABILITY**

There are many practitioners in the UK. These include medical doctors, alternative practitioners and physiotherapists.

Acupuncture is now available in many NHS establishments, such as GP practices, consultant clinics and physiotherapy departments.

#### **CONCLUSION**

Acupuncture is not an answer for all complaints. It must be considered in the context of its undoubted durability through the ages which, in itself, indicates that

it must work.

Modern Western medicine has also advanced, although its history is somewhat shorter! There are many conditions today that are more efficiently treated by Western methods but there are some conditions, such as those described above, than can be alleviated by Acupuncture and when the sometimes damaging intake of drugs can be reduced or avoided altogether.

The basic concept of treating the whole person is very rewarding. Many patients not only get relief or symptoms but say they "feel better" in themselves.

*For details of acupuncture practitioners in your area and those who may have experience of treating pain or bowel problems in people with spina bifida, contact: The British Acupuncture Association and Register, 34 Alderney Street, London SW1, Tel: 071-834 1012 or 6229*

## **Obituary**

### **Mrs Iris McDowell, a Northern Ireland pioneer**

IRIS McDowell, a founder and one of the guiding lights of Belfast ASBAH throughout its 25 years, died suddenly while on a theatre visit to London on 20 February. She was aged 49.

The tragedy happened while she and her second son, Nial, were at a performance of the hit musical 'Blood Brothers' at the Phoenix Theatre. They had split up earlier in the evening with her youngest son, Michael, and two of her sisters who had gone to watch 'Starlight Express' at the Apollo Victoria - a show which Mrs McDowell had already seen.

Mrs McDowell loved musicals and performing in them. She was a member of Lisnagarvey Operatic Society in her home town of Lisburn, and had been due to appear in their performance of 'Carousel' last month.

"She was so full of life and her death came as an awful shock to us all. We miss her dreadfully," said

Mrs Ann Gilliland, secretary of Belfast ASBAH. "One of the ways we used to relax was to book parties into her shows; we had been expecting to see her on stage in 'Carousel'."

Mrs McDowell helped form Belfast ASBAH after the birth of her eldest son, Brian, who has spina bifida and hydrocephalus. She and her husband, Sid - deputy general secretary of the Northern Ireland Public Services Alliance Union (NIPSA) - had recently celebrated their silver wedding.

Mrs McDowell had done every job in Belfast ASBAH, and was chairperson again at the time of her death. Her determination as a parent to do her best for people with spina bifida and hydrocephalus had led to many developments in the life of the branch.

She had been responsible for recruiting a social worker, Judy Malone, on secondment - a happy

arrangement which lasted for well over 10 years. Branch membership under Mrs McDowell's stewardship grew to its present total of 260 families and, in 1989, the branch acquired offices at Bryson House in the centre of Belfast.

She was greatly involved with the then Lord Mayor, Nigel Dodds, and other committee members in organising Northern Ireland Association's charity ball at Belfast City Hall last year. It was held the night after the General Election; immense efforts were required to make sure the hall was cleared and got ready after the count, but everything came out 'right on the night'.

Lisburn Methodist Church was packed to overflowing for the funeral on 26 February, which was followed by cremation.

We offer our deepest condolences to her husband, their sons and to all the family.

## PIGEON POWER

Pigeon power has transformed the travel prospects for members at our Five Oaks residential training centre set on the edge of Ilkley Moor, West Yorkshire.

A minibus, bought with some of the proceeds of the 1991 'British Homing World' Show of the Year, was handed over at last year's show in Blackpool - the annual showcase for the country's pigeon racing fraternity.

Since then, the magnificently equipped Renault Master has travelled an effortless 11,500 miles up hills and down dales on expeditions and outings. It has also gone into towns and cities, collecting and setting down passengers.

"We use it practically every day to take residents or visitors out for the day, to collect people from the station and go into town shopping", said centre manager Joan Pheasant.

The minibus replaced a rickety old ambulance, which had seen better days and always lacked the Renault's more luxurious finishing touches.

"With a carpeted interior, heating and air-conditioning and exceptionally comfortable seating, our members now travel in style", added Miss Pheasant.

"With its large windows, good all-round visibility and very audible reverse signalling, it is also a very reassuring vehicle to drive."



Above: A bus with a view - residents and staff at Five Oaks alight to enjoy the mid-winter scenery on Ilkley Moor. From the left: volunteer Christine Cockerill, Helen Clay, Tom Winters and driver Bill Platts.

A tail-lift gives easy access for wheelchair-users. Floor-rails mean passengers can stay sitting comfortably in their own wheelchairs, which are then clamped into place.

Over the years, the 'British Homing World' Show of the Year has developed into ASBAH's most generous supporter.

"We calculate we have received £180,000 from the show - a huge sum by anybody's standards, and most certainly by ours", said executive director Andrew Russell.

"Their regular contributions, including another £20,000 presented at Blackpool this January, have helped us meet the constant challenges of delivering vital services to people wherever they need us."

## Fundraisers take the plunge

Staff from United Overseas Group, a Peterborough-based firm of traders in branded clearance goods, leapt 2,000ft out an aeroplane for ASBAH - to raise several thousand pounds in a sponsored parachute jump.

Right: They were led (foreground) by Debbie Lee, from accounts, who is sister-in-law of ASBAH regional business executive Donna Drew.



Students from Peterborough Regional College are also planning a parachute jump for us - part of a package of fundraising stunts, which include a bedpush and temporarily taking over one of our charity shops.

## Telethon results

The best brains in ASBAH got their heads together for the first time to milk the ITV Telethon for all it was worth last summer. Grants received so far total £11,735 - making the operation very worthwhile from our point of view.

The biggest grants came from the Ulster TV Telethon Trust, which gave us £5,000 towards the cost of a disabled living adviser in Northern Ireland, and from Anglia TV Trust, which provided £3,735 towards fieldwork services and chipped in with a further £500 for helping them make a film, which featured Peterborough's Gilly Thorn and her family's fieldworker, Mary Castle.

Other sums came from HTV West, who gave us £1,000 towards an education study day in Somerset and £500 for our services in assisting with a film about three-year-old Robert Norris, of Yeovil. For our work in helping to set up a film about Patrick Stokes, the ITV Trust made a grant of £1,000.

## DISABLED PEOPLE DENIED RIGHTS

**RADAR is backing the efforts of 350 disabled people in their attempts to obtain social services - part of their campaign to get local authorities to take Section 2 of the Chronically Sick and Disabled Persons Act seriously.**

In the first six months of a two-year project, which aims to clarify the duties of local authorities under the Act, various problems have been identified.

For example:

### Mrs D

*Mrs D has severe back problems and, a few years ago, she was assessed as requiring two hours home help for cleaning and one hour for shopping.*

*Over the years, the service has been reduced to one hour for cleaning, without any reassessment of her needs. In August 1992, the cleaning service was withdrawn - again, without a reassessment.*

RADAR wrote to her social services department on her behalf. The reply was apologetic and confirmed that the home help service had been reinstated to Mrs D's satisfaction.

### Mr F

*Mr F has muscular dystrophy and is unable to get upstairs without the use of a vertical through-floor-lift. The need for this equipment was identified during an assessment in November 1991.*

RADAR felt that he had waited an unreasonable amount of time and

requested a date for its installation. One month later, a reply was received from the social services dept - confirming a date for installation.

### Mr A

*Mr A has multiple sclerosis and is a wheelchair user. He received home help for one hour a week. The charge for the service*

*was increased from £2.90 to £7 each week and Mr A felt that £7 a week was too expensive.*

*He and his wife could not manage without any support, so they requested that the service be reduced to one hour a fortnight. Social Services rejected this request and the service became erratic.*

RADAR made a formal complaint

to the home care manager, which successfully secured a reliable home help service.

Although most of RADAR'S clients experience problems in obtaining house adaptations, special equipment and home help assistance, local authorities are also failing to provide under Section 2 such things as holidays, telephones and day centre placements.

Additional difficulties include long delays in obtaining assessments of needs, and threats to withdraw services if clients do not pay charges levied by local authorities. This, says RADAR, is unlawful.

RADAR will keep plugging away at getting full implementation of Section 2 which requires local authorities to arrange for the provision of various domiciliary services to disabled people where they have accepted that need exists.

These services are

- (1) practical help in the home [home help]
- (2) radio, TV, library
- (3) lectures, games, outings (eg day centres)
- (4) transport to such activities
- (5) aids and adaptations
- (6) holidays
- (7) meals [eg meals on wheels]
- (8) telephone.

RADAR'S Section 2 Project will continue until July 1994. Details of the first year's findings will be published in July/August this year, with a full report at the end of the project.

*Details: John Keep, project officer, 071-637 5400, ext 340.*

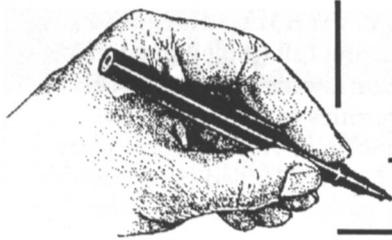


### Dates for your diary



**11-13 June.** The date for this year's Mobility Roadshow held at TRRL, Crowthorne, Berkshire.

**12-14 July:** Introduction to multi-therapy: Holistic Approaches to giving support to people with special needs. A course to introduce Natural Therapies to carers. Including face, head and foot massage and cranial therapy. At Castle Priory College, Thames Street, Wallingford, Oxon. Tel: 0491 37551.



# Letters

I MUST put pen to paper and let you know what a difference intermittent catheterisation has made to my daughter's quality of life. Lucy is three and a half and was born with spina bifida and hydrocephalus.

She has reflux like many children with spina bifida and, at the age of nine months, was sliding into renal failure. She escaped with no permanent damage and was fitted with an indwelling catheter. This remained the method of emptying her bladder up to December 1992.

The time for Lucy to begin nursery was drawing near and, having had her statemented and accepted into mainstream school, I was beginning to worry about how she would cope with an indwelling catheter.

Despite having a rigorous cleansing routine, Lucy would smell of urine. Wearing of shorts and trendy Lycra garments was a definite 'no no' because of the bulkiness of the drainage bag and the constant worry of the bag becoming detached. Leaks were a problem and, even worse, blockages.

As Lucy grew, the Velcro fasteners became tight, causing her to sweat in summer and be uncomfortable in winter.

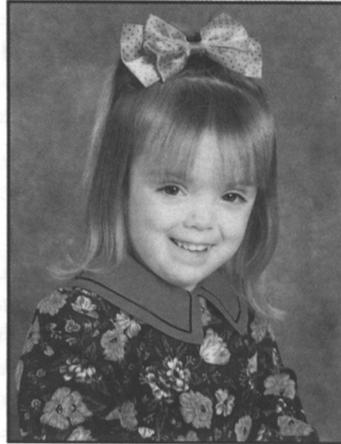
Setting the practical problems aside, I worried about the emotional side of things. It became clearer to me that this method of emptying the bladder was not suitable for a child at school, so I took it upon myself to investigate the alternatives knowing that, if you want anything done for a disabled child, a lot of perseverance is required.

I know little of the alternatives but had read an article in LINK by Mary White, so I decided to contact her. This was the day things changed for the better. Mary came on a home visit, and filled me in on everything there was to know about intermittent catheterisation. She said Lucy would be suitable.

I had to wait a couple of weeks to get the go-ahead from the consultant urologist. Having changed the indwelling catheter for three years, I know what to do - in fact more than the nursing staff who were to advise me.

We started the week before Christmas, emptying her bladder every two hours. It was an instant success, to the surprise of the consultant. By mid-January, we had progressed to three and a half hourly intervals and on the toilet - a simple, clean procedure taking only a few minutes that could be carried out in any toilet. I couldn't believe the simplicity of it: the nearest thing to normal toileting imaginable. I am puzzled as to why this method had not been introduced on day two of Lucy coming into the world as it would have saved so much heartache for me and stress for Lucy.

Lucy has now settled into nursery and we are looking forward to a



summer when Lucy will be able to play out in the garden in her bikini, go swimming and wear pretty summer dresses with white knickers - in the knowledge that nothing will fall out, leak etc.

A huge 'thank you' is due to Mary White for her support and kindness. I hope my story will encourage other parents to be in touch and improve the quality of life for their children.

**Carol Moorhouse, Dewsbury.**

*Editor's Note: Mary White is one of ASBAH's three continence advisers. Contact can be made through the DLS Dept at our National Centre.*



## Telephone shocker

I have recently been asked for help from a family on my patch who have received a telephone bill in excess of £1,500, due to the use of a Premium Rate chat-line. This is the second time this has happened on my patch within two years.

Please urge all families who have not already done so to arrange with British Telecom for call-barring facilities to be put on their telephone to ensure calls are not made to chat lines. BT will arrange this free of charge to anyone who is on a digital exchange.

Families should not be complacent and think that this will not happen to them. Some young people with hydrocephalus have no real concept of time and do not realise exactly how long they have been on the telephone, and the operators are very skilled in keeping the caller on the telephone. The result is a massive telephone bill which families are unable to pay.

BT do not warn customers when accounts are accumulating and the first knowledge a family has of the bill is when the account drops on the door mat.

**Lynne Young**

**Fieldworker, Cornwall**

**HOLIDAY ACCOMODATION**

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

**SELSEY, SUSSEX**

Fully-equipped, six berth mobile home, with colour TV, ramp access, all rooms designed for wheelchair access. Site near sea, heated pool, also clubhouse and small shops. Details: Mrs C. Bugden, 27 The Grove, Sholing, Southampton, SO2 9LT.

**BLUE ANCHOR, NEAR MINEHEAD**

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**NEW FOREST**

Fully equipped caravan designed for wheelchair access throughout, sleeps 5-6, club with indoor pool, shop etc, sited at Bashley Park New Milton. Contact Joan Searle tel: (0705) 376816

**ROMNEY SANDS, KENT**

Two bedroom holiday chalet, sleeps 6, fully equipped, wheelchair accessible, full club facilities, heated pool etc. Across road from beach. For details contact Jan Walton tel: (0892) 832590

**ISLE OF WIGHT ASBAH**

Completely refurbished, fully equipped, wheelchair accessible 2 bedroom holiday chalet, sleeps 6 + cot. Clubhouse, indoor heated pool, shop, etc. Site overlooks sea. Own transport advisable. Details: Mrs P. Burden, 34 Sherbourne Avenue, Binstead, Ryde, Isle of Wight PO33 3PX

**FOR SALE**

**SPORTS Poirier Fizz Wheelchair**, red, with accessories. 14.25ins-wide seat. Cost £1,272, almost new, open to offers. Tel: 0203-341554.

**Mk6 Turbo**, wheelchair vgc, new heavy duty batteries fitted. Offers around £1,500. Tel: 0246 550334

**SERVICES**

**EPC - Equipment for the Physically Challenged** (a company run by the disabled for the disabled). New and second hand lightweight wheelchairs. Authorised dealers for Action Technology, Quickie and Swede. Home demonstrations, wheelchair insurance, advice. For further information, please ring 0252-547939, or our new office in Coventry, 0203-422327.

**LINK Rates**

Editor: Gill Winfield  
Published by **ASBAH**,  
ASBAH House,  
42 Park Road,  
Peterborough PE1 2UQ  
Telephone: 0733 555988.

**LINK SUBSCRIPTION  
6 EDITIONS - 12 MONTHS**

UK ..... £4.80  
Europe and Overseas Surface Mail ..... £7.50  
Air Mail ..... £15.00

All payments should be made in Sterling

Classified Rates: £3 for 30 words max;  
£4.25 for 30-45 words;  
£5.50 for 45-60 words.

Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of Link (April) should be submitted by Friday, 14 May. Please send them to the Editor.

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