

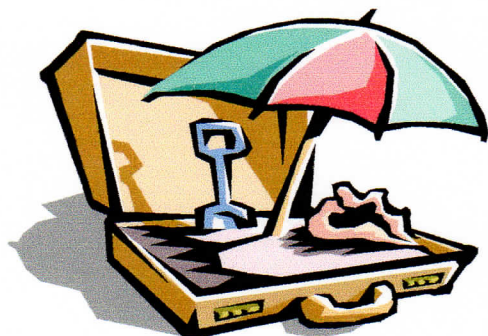
LINK-UP

SPRING 2004

TAKING OFF

ENABLE Holidays, a travel company for disabled people, their family and friends, has been launched with the endorsement of Scope.

Enable features holidays in mainstream destinations including Greece, Spain, Portugal and Florida, where a range of accommodation has been audited to ensure that the needs of people with mobility impairments are met. Hotels, apartments and resorts are graded according to their suitability for access in terms of door widths, gradients of ramps, numbers of steps and so on.



Holidays can only be booked by phone (0871 222 4939 or www.enableholidays.com for information) so that advice can be tailored to individual needs. Scope, which reviewed the auditing process, receives a donation for each holiday booked.

WARNING

BLUE badges are currently being stolen and sold for anything between £200-£700. PLEASE ensure that you keep yours safe.

WHEELCHAIRS ON PUBLIC TRANSPORT

THE CHARITY Ricability has produced a guide to using a wheelchair on public transport. *Wheels within Wheels* tells you what you can expect from newer trains, coaches, buses and taxis. It has information on how you can find out where accessible services are running and gives tips on travelling in a wheelchair. It also lists the key dimensions of wheelchairs currently available in the UK and which of them will fit onto public transport. For a free copy send an A4-sized s.a.e. (56p) to: *Wheels within Wheels*, Ricability, 30 Angel Gate, 326 City Road, London EC1V 2PT or telephone 020 7427 2460. www.ricability.org.uk

(Reprinted from ASBAH's journal 'Link' Winter 2004)

HOLIDAY CARAVAN - PRESTATYN

TWO Pemberton 12' wide caravans, purpose-built for disabled people, are on site in Prestatyn. The caravans are owned by Leeds and Bradford ASBAH and available for non-members of their Association, subject to availability.

Both caravans are fully accessible for wheelchairs, have an open-plan lounge/dining area with TV/Video, two bedrooms sleeping 4 people (with a pull hoist over one of the beds) and a bathroom with a wheel-in shower. Costs £95-£275 per week, including calor gas and passes to leisure centre. Quilts and pillows are provided, but guests need to take their own sheets, towels etc.

Information and booking: Jo Baxter 01274 591850

STUDENT GUIDE

Skill (National Bureau for Students with Disabilities) has published 'Into Higher Education 2004' which it describes as 'an informative and practical guide for disabled students considering applying to university or college.'

It features lots of advice about applications, getting support, grants and benefits as well as profiles written by disabled students about their own experiences in higher education. Copies are £2.50 for disabled students or £12.50 for professionals and can be ordered on 020 7450 0648 www.skill.org.uk Another useful number is NHS Wales Student Awards Unit 029 2026 1495

From the Editor ...

OK, so I've been very quiet for a number of issues, not because I've had nothing to say, but because there has been so much material to bring you that I've been *squeezed* out!

So now it's my turn and I have to tell you that this is the last issue of 'Link-Up' that I will edit, as I shall be leaving North Wales ASBAH at the end of April.

Many things have happened since I started working for the Association in January 1992, not least of which has been taking-over the editorship of 'Link-Up'. This has been a very enjoyable task and I hope that the newsletter will continue for many years to come.

Although I have met most of you in name only, you have become an extended family and I know I am going to miss you in the future.

Many thanks to all the contributors and *please* keep sending in ideas, features and photographs.

JOHN W. HOLTER

The Society for Research in Spina Bifida and Hydrocephalus in the USA has reported the death Dr John Holter, one of their honorary members, in December last year.

In the 1950s John Holter's son, Casey, had hydrocephalus, for which there was then no effective treatment. An engineer by profession, Holter collaborated with E.B. Spitz to design a valve/shunt that is implanted into the fluid compartment of the brain to drain excess fluid into the heart or abdomen, thus reducing pressure and maintaining life. Although he was unable to save Casey, the Spitz-Holter valve has helped millions of people with hydrocephalus around the world since.

FREE BT PRIORITY FAULT REPAIR SCHEME

BT's aim is to provide a free Priority Fault Repair Scheme to customers whose telephone is vital in emergencies and an essential link to relatives, friends and carers.

For those who qualify, the Scheme safeguards your line free of charge and will deal with any faults as soon as possible, day or night, every day of the year, including Christmas Day. If you would like more information on this Scheme or other BT services for people with special needs, call them on Freephone 0800 800 150.

NWASBAH NEWS

FINANCE

INCOME from November to January totalled £3,817.46:

Donations:

In Memory of Gwenno Rees Hughes	2,880.80
Doris Morris	20.00
Thanksgiving Service	290.44
Royal British Legion	250.00
Mr Worrell	53.70
Other	52.00

Fundraising:

Raffle (donated doll: Barbara Leech)	30.00
Raffle 2003	24.00

Grants:

Abergele Town Council	100.00
Chirk Community Council	50.00

Bank interest 66.52

EXPENDITURE during the period was £2,470.07 including £546.20 in direct services to members.

100 CLUB WINNERS

Dec - Feb

M. Mason, A. Todd,

I. Fearnley, P. Wood,

J. Hayes, Mrs Manuel

Mrs A. Williams, E.B. Evans

J. Mogridge



JOIN US! Contact the Office

FUNDRAISING

TWO Store Collections have already been lined up for this year. They will take place at **Sainsbury's** in Wrexham on Saturday May 15th and at **Tesco's**, Llandudno Junction on Saturday 7th August.

Volunteers will be needed at both stores. Please contact the organisers if you can help:
Sainsbury's: Trefor Edwards 01978 364576
Tesco's: David Hallows 01492 543543

££££££££££££££££

SPINA BIFIDA &

HYDROCEPHALUS: A History

Spina Bifida Cystica has probably been noticed since time immemorial. Skeletons found in Morocco dating from c. B.C.10,000 and Peru c.5000 B.C. show that SB is of great antiquity.

The first clear description in the West is attributed to Casper Bauchin (1550-1624). SB is also closely connected with Nicholas Tulp (1593-1674), familiar to art lovers as the central figure in Rembrandt's painting 'The Lesson in Anatomy of Dr Tulp' (1632). He was in charge of anatomy and dissections for the Surgeons' Guild in Amsterdam and was a friend of Rembrandt. His book *Observationes Medicae* (1641) described a number of patients with SB and included a sketch of the condition, possibly by Rembrandt.

Later in the same century, Frederick Ruysch came

Skulls showing **hydrocephalus** date back to the late Stone Age. In a grave near Seeburg, Germany, part of a skull of a 5-to-6 year-old child with hydrocephalus was discovered. It is dated c. 6000 B.C. and is probably the oldest known example of H. A number of similar skulls are known from Egyptian burial grounds from archaic to Roman times. Hippocrates, Galen, and early and medieval Arabian physicians, who believed that it was caused by an extracerebral accumulation of water, regularly described cases. Rhazes (850-923), an Islamic physician, devoted an entire chapter to it in his book about children's diseases.

There were numerous studies of the brain in the late Middle Ages in Europe, but more important were the works of the 16th century and extensive works on paediatrics in the 17th, with Richard Lower exploring the formation and circulation of the cerebrospinal fluid and the mechanism of H.

Treatment proved to be difficult. It is thought that the ancient Greeks used incision and drainage and that Islamic physicians used cauterization with a hot iron on the suture lines and temporal veins. These measures were often accompanied by dehydration, using purges and diuretics and the use of compression bandages to the head, and these methods continued well into the 19th century.

The pressure of the CSF had long been recognised, but the circulation had been imperfectly understood. On 15th October 1744, the French surgeon Claude-Nicolas Le Cat (1700-1768) introduced a specially invented canula into the lateral ventricle of a newborn boy with hydrocephalus. The canula was used as a tap and was left in place for 5 days, until the death of the child. This procedure should be seen as the first documented description of a device for repeated ventricular taps in the treatment of hydrocephalus.

The failure of external drainage turned surgeons to internal drainage in the 1890s. It was more logical to transfer the fluid to the bloodstream - the basis of modern operations - and this commenced with Payr in 1908 and McClure the following year. These early attempts failed because of inadequate shunt materials and valves. Modern shunt tubes date from the work of Nulsen and Spitz of Philadelphia and John Holter, an engineer (1952). Since then, a number of valve designs have been used and the material itself has been improved. In the 1990s, there was a renaissance of endoscopic ventriculostomy. Both treatments have transformed the lives of people with hydrocephalus.



The Anatomy Lesson of Dr Tulp

close to recognising a connection between SB and hydrocephalus. Morgagni, professor at Padua, clearly recognised that SB can occur with or without H and gave extensive descriptions of both in his *The seats and causes of diseases investigated by anatomy in 5 Books* (1760).

Cruveilhier first advanced the theory of a fault in development as the cause of SB and in 1875 Virchow described SB occulta. The work of the 19th century was consolidated in 1886 in the classic account of the pathological anatomy of the disease by Von Recklinghausen, a description of all forms of the condition running to 169 pages.

Early surgical treatment was disastrous due to infection, although surgery was made much safer by the antiseptic and aseptic techniques introduced by Lister (1827-1912). Bayer introduced the operation of using flaps for closure of the sac in 1892 and it is substantially the operation still used today.

INSURANCE

IT can be more costly for a disabled person to get insurance because insurance companies see this person as a greater risk. Insurance is based on risk - the insurance company is insuring you against the chance of something happening (eg you being burgled). This risk is assessed by an underwriter and they decide if a premium is set, or not to insure you. If you live in an area that is notorious for burglaries, you can expect to pay high premiums on your house insurance. Similarly, if you have been hospitalised with bladder problems over the past few years and it happens again whilst you are on holiday, your holiday insurance is unlikely to cover it.

Always tell an insurance company if you are aware of any circumstances likely to affect your cover, either when you are taking out your policy or when you renew, as they could refuse to pay any money on grounds of non-disclosure.

The Disability Discrimination Act 1995 came into force for insurance in December 1996. It has made it illegal for insurance companies to deal with disabled customers on less favourable terms than non-disabled customers without justification. To be considered as justified, decisions must have been made by using statistical data (eg statistics on risks associated with various disabilities) or other reliable information. If you feel that your insurer is unfairly discriminating you against, it is up to them to prove that there is an additional risk. The disabled person only needs to show that less favourable treatment has taken place, not that there is not an additional risk.

The office holds a Factsheet, compiled by the Spinal Injuries Association, giving details of some insurance underwriters and some specialist insurance brokers/intermediaries. It does not recommend one firm over another and cannot be held responsible for any actions taken/advice given by these firms.

'LINK' ARTICLES

The following article appeared in the Winter 2004 issue of 'Link' published by ASBAH Behaviour Problems Associated with Hydrocephalus pp27-8

'Link' is published 4 times a year and costs £4.80, including postage. Enquiries may be made to: Link, ASBAH, 42 Park Road, Peterborough PE1 2UQ Tel: 01733 555988

If you do not wish to have a subscription, your Adviser will be able to show you a copy

MOTORBILITY SCHEME IMPROVEMENTS

Motorbility has **reduced prices** and now offers a large range of nil payment cars. In response to customer's requests, this includes a range of automatics.

Adapted vehicles

If your contract hire car is heavily adapted, or is a wheelchair accessible vehicle, you will now be able to extend your contract for up to five years.

Insurance excess - 'not at fault' refund

If you have an accident that is the responsibility of the third party, you will still need to pay the initial £75 to the repairer. But if the claim was not your fault in any way and Motorbility can clearly identify an insured third party responsible R&SAM will return your excess payment within 21 days from the date they receive the information

Tyres

Motorbility announced in August that it will no longer charge contract hire customers for replacing damaged tyres, except in cases where tyres are lost, stolen or vandalised. Motorbility customers can also benefit from a dedicated Motorbility Tyreline via a local-rate number 0845 722 1200.

Customer Helpline 0845 456 4566. You can also contact them via www.motorbility.co.uk