

# Link

The magazine for people with  
Spina Bifida and/or Hydrocephalus



June/July 1994

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# Comment

A **VERY** full *LINK* this issue - a proper magazine with plenty to read and a fairly good mix of articles. We hope you like it.

Maddie Blackburn, ASBAH's research fellow, starts a four-part series about her fellowship work over the past three years. The first part is a thought-provoking account of the state of sex education for people with disabilities. For those with the time to read in greater depth, she has placed copies of her theses in various libraries but has popularised her results specially for *LINK*. Thanks for remembering the more general interest of us lesser mortals, Maddie; we know you intend to keep researching in the field of disability, initially with the help of a Calouste Gulbenkian Foundation grant, and we all applaud your devotion and perseverance.

Once again, we were delighted

with the quality of all our contributions - particularly one which came, unsolicited, from consultant neurosurgeon Bernard Williams. It's a key text, both for those working in the field and for those who have never before heard of syringomyelia and how this spinal condition can impact on people with spina bifida. Off-prints of the article will be offered to patients attending Mr Williams' syringomyelia clinic in the Midlands, believed to be the busiest of its type in the world.

Then there was the 'Your Voice in ASBAH' spring conference, reported for us so succinctly by Zem Rodaway. As a sounding board for people with the disabilities, YVIA has come a long way in its first two years while remaining integral to the Association. There is an awful

lot of talent there which they are determined will not be wasted.

ASBAH is working on a new leaflet called 'Hydrocephalus Shunts - Guidelines for General Practitioners' to alert doctors unfamiliar with hydrocephalus to the signs of possible shunt failure, and the importance of obtaining appropriate specialist treatment for their patients as a matter of emergency. We are also producing a medical alert card which people with CSF shunts can carry in wallets or handbags to tell ambulance staff and doctors of their particular type of shunt and the symptoms to watch out in case of shunt malfunction. More, much more, of these in the next issue and the relevant media.

**FINALLY**, there's a sign in the local off-licence which reads: "Do not ask for credit, as a smack in the mouth often offends." Reminds me of the crushing blow delivered by the Government to the Civil Rights Bill; somebody should copy it to Nicholas Scott.

*Tony Britton*

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## Help with NHS Hospital travel expenses

DO YOU know that help is available to families on modest incomes to cover NHS hospital travel costs? Families who qualify for help also receive FREE NHS prescriptions and FREE NHS dental treatment.

You will not get help if you have savings of over £8,000. To check whether you qualify on low-income grounds, obtain leaflet H11, NHS Hospital Travel Costs. This should be available from your local Benefits Agency Office, family doctor or NHS hospital.

A family in the following situation will qualify for help:

- A couple with take-home pay from full or part-time employment of £200 a week with two children - one child of whom receives Disability Living Allowance. The couple will be paying either mortgage or rent (less any housing benefit) of £60 a week AND Council Tax of £10 a week.

Leaflet H11 explains who will be entitled to help on low-income grounds. You will also need to obtain form AG1, which should be asked for at the same time as you obtain leaflet H11.

Entitlement lasts for six months, after which you will have to apply again by filling in a new claim form AG1.

Families in receipt of Income Support or Family Credit automatically qualify for assistance and do not need to apply.

If you have difficulty tracking down leaflet H11, write to: BAPS, Health Publications Unit, DSS Distribution Centre, Heywood Stores, Manchester Road, Heywood, Lancs OL10 2PZ.

## Bleak picture painted of future prospects

A NEW publication from a top research institute paints a bleak picture of the prospects facing many of Britain's 200,000 teenagers and young adults who have disabilities.

In *Unequal Opportunities*, published for the Social Policy Research Unit at York University by HMSO at the end of May, the authors state bluntly that many youngsters are unlikely to attain an independent adult and working life.

Choices open to disabled young people are limited and their transition to adult state is likely to be prolonged and difficult. There is no single government department or agency co-ordinating services to ensure they can enjoy full social and economic participation. This is a vacuum which needs to be filled.

Authors Michael Hirst and Sally Baldwin compare the circumstances, lifestyles and aspirations of over 1,000 young people with and without disabilities. They describe the views and experiences of disabled young people in finding employment, having money of their own and living independently of their parents; assess their social integration, personal autonomy and self-esteem; and look at the continuity of provision for their health and social care needs.

The research shows that:

- severely and multiply-disabled young people are most disadvantaged, and are often marginalised and segregated from the mainstream
- the disadvantages facing disabled young people increase as they grow older and many fall increasingly behind their non-disabled peers on the road to adult life
- parents and professionals alike often find it difficult to recognise and encourage the young person's emergent independence
- services for disabled young people after leaving school are patchy, under-funded and poorly co-ordinated.

The authors argue that if we are to value young people with disabilities, respect their contribution to our communities and enable them to achieve their ambitions, these findings demand action.

*"Unequal Opportunities: Growing Up Disabled"* by Michael Hirst and Sally Baldwin, published in the *SPRU Papers* series by HMSO, price £13.

SAFTA, mentioned in LINK No 150, has changed its full name to Support Around Termination For Abnormality instead of After Termination to stress its wider role. Tel 071 439 6124.

## DLS manager moves to hospice

RACHEL Stanworth, who has been ASBAH's disabled living services manager since October 1989, is leaving at the end of June to undertake research at St Christopher's Hospice, South London. She will spend the next three years studying the nature of spiritual pain.

Rachel, who is 34, hopes to be awarded a PhD degree by London University at the end of her study project. Before joining ASBAH, she was a staff nurse at St Bartholomew's Hospital, London, and also qualified as a teacher.

## DOCTOR PAT RETIRES AT TRELOAR COLLEGE

GENERATIONS of past students and staff at Lord Mayor Treloar College, Hampshire, will be interested to know that Dr Patricia Tomlinson retired at the end of May after 14 years as college medical officer.

All students at the college have severe physical disabilities and 'Dr Pat', as she quickly became known, became expert in many of them, but particularly in spina bifida and hydrocephalus.

For over 10 years, about a quarter of the college students had these conditions and, for four years, her case load included 80 such young people between the ages of nine and 20.

At a very early stage, she recognised that shunt complications were far more common than had been previously believed and she also recognised that early signs of malfunction were immensely variable and often reported to her by professionals outside the medical field.

One of her greatest strengths was her ability to listen to all those concerned with the young person before coming to the conclusion that urgent hospital treatment was needed. Often hospital staff were disinclined to listen to anything other than clinical evidence and she had to be very persuasive to overcome their resistance.

Gradually, through publications and lectures, her expertise has been acknowledged and even now, in the first months of her retirement, she has been asked to address the 38th Annual Scientific Meeting for Research into Hydrocephalus and Spina Bifida being held this month in Connecticut, USA.

Her paper, "Shunt complications in spina bifida adults - an evolving problem", is based on follow-up research into a number of former Treloar students in early adult life.

Her message is quite clear - once a shunt is inserted it will remain an issue which must always be considered before anything else,

and that there is an infinite variation of early signs and symptoms of malfunction. It is not uncommon for a problem to develop after 21 years during which it was considered that the shunt was no longer functional.

### Karl Goddard - an apology

In the April edition of LINK, we carried brief comment upon the BBC 'Children's Hospital' film on Karl Goddard's preparation for school. The family have criticised LINK for intrusion into their family affairs and for failing to speak with them before publication. We apologise for causing them distress, and we did not wish to imply criticism of the Goddard family.

The film did, however, raise some professional concerns about the content of the film which ASBAH has taken up separately with the BBC.

## Officers & Staff

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# A royal launch to benefit ASBAH

Our Patron, HRH The Duchess of Gloucester, will next month open the new Royal Copenhagen and Georg Jensen showroom at Mulberry Hall in York - a prestigious china and crystal shop, near the Minster.

Two limited edition pieces - the Royal Copenhagen Botanical Cup and Saucer and the Georg Jensen Silver Spoon - have been crafted exclusively for Mulberry Hall to mark the opening of the new showroom on 7 June. All sales of these items will bring a generous benefit to ASBAH.

The first in each edition will be presented to the Duchess during the ceremony, which will be attended by other senior representatives of both the National Association and North Yorkshire ASBAH.

The proprietors of Mulberry Hall invited the Duchess because of her Danish background.

ASBAH will dedicate the proceeds from this to the national mobile assessment service START, which will be based in Yorkshire. START



## Mulberry Hall

(Service Team for Assessment, Rehabilitation and Training) will start work later this year, after the Five Oaks closure.

The Royal Copenhagen Porcelain Manufactory was founded in 1775 by Queen Julianne Marie and was for many years owned by the Danish Crown.

Inspired by their famous Flora Danica service, the 2.5-inch high Botanical Cup and Saucer is richly decorated and gilded. Its design features a blue wild flower. Below the gilding is a rich pink openwork design which, on the saucer, links small sprays of

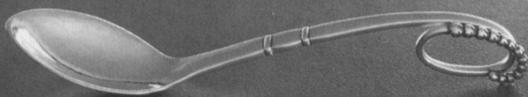


*The commemorative cup and saucer*

flowers. The cup is straight-sided and octagonal, and is in a limited edition of 500. The price is £195.

The Danish silversmith Georg Jensen, who died in 1935, was hailed by the New York Herald Tribune as "the greatest silversmith of the last 300 years". An elegant 5.5-inch long spoon in his style has been made in Danish sterling silver. The handle is curved to form a ring with individually applied silver beading. This is another limited edition of 500, and costs £175.

*A leaflet describing the two pieces can be obtained by telephoning Mulberry Hall on 0904-620736. After 7 June, they can be viewed in the setting of the new showroom at Stonegate, York, close to the Minster.*



*The Georg Jensen silver spoon*

## International honour for Midlands neurosurgeon

BERNARD Williams, who has contributed a 4-page article on syringomyelia in this issue of LINK, has won an international prize for his work in the field of cerebrospinal fluid physiology.

Mr Williams, a consultant neurosurgeon at the Midland Centre for Neurosurgery and Neurology in Smethwick, is this year's Pudenz CSF Physiology

Award nominee. For 20 years, he has been researching pressure changes in CSF - particularly acute pressure changes and their relationship with disorders of the central nervous system especially aqueduct stenosis, spina bifida, hydrocephalus, hindbrain herniation and syringomyelia.

He runs the country's only syringomyelia clinic at the MCNN,

which deals with patients from all over the world and spina bifida problems in adults, including hydrocephalus. For the first 12 years of his research, he was using equipment donated by ASBAH.

Mr Williams is likely to receive the award at the International Society for Paediatric Neurosurgery meeting at Birmingham in September.

MARY BARTON, the physiotherapist who helped develop ASBAH's independence training programmes at our Five Oaks Centre in West Yorkshire, retired in May.

She kept pace with demographic change throughout her career and had been greatly involved in Five Oaks' most recent work - assessing the needs of women with spina bifida and/or hydrocephalus with babies or wanting to have children. Following a recent trawl for information, ASBAH knows of at least 80 women with these disabilities who have now started their own families - twice our estimate of a year ago.

After training and three years general experience, Mary embarked on a career in paediatrics. She worked in a number of schools and units - including Great Ormond Street Hospital and the regional child assessment unit at Leeds - before Moyna Gilbertson recruited her to ASBAH in April 1979.

Mary began as holiday activities organiser at Five Oaks and therapy supervisor for the small resident group of children, then aged between one and eight years old.

Her extensive professional

## DEPARTURE OF PIONEER PHYSIOTHERAPIST MARY



contacts meant she could quickly find colleagues elsewhere to fill in the finer details and backgrounds of new arrivals.

As Five Oaks grew older, so did the age range of its residents. It became a 'home base' for teenagers and school leavers who could not be cared for at home, or who had little contact with parents. Well-structured independence training courses were set up, and Mary was one of those who started taking this expertise 'on the road'.

In 1980, mini-ITCs started for children as young as nine were started so they could acquire basic personal care and living skills much earlier in life.

Reports then started to come in of the difficulties that hydrocephalus was creating for older children and young adults as they failed to transfer skills easily from one place to another. Five Oaks responded by lengthening its courses to allow for longer maturation periods. Very quickly, the centre established an international reputation for its self-care training and this was recognised by the presentation five years ago of the European HELIOS award.

Mary, who lives in Burley-in-Wharfedale, was also active in the National Toy Library Association/Play Matters, contributing to its yearly 'The Good Toy Guide' and she is a recognised expert in hand function in children with spina bifida. We wish her well: retirement will give Mary more time for her hobby of painting, and for enjoying her cottage in Wales.

## Help & Advice

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

### London, Surrey, Kent, Sussex

123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (081) 449 0475  
Regional Co-ordinator: Gina Broughton.

### Northern Ireland

73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (0265) 51522  
Regional Co-ordinator: Meta Harvey.

### Rest of England and Wales

National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (0733) 555988



# SEX EDUCATION...

**Maddie Blackburn, ASBAH Research Fellow, explores the need for more work in this area**

IN THE first of four articles outlining some of the major work areas undertaken by Dr Martin Bax and myself, I would like to begin by thanking ASBAH for awarding me a research fellowship.

It has been a great privilege to work with so many committed staff, young people and families. We would especially like to thank all the families and young people who gave generously of their time, allowed us into the privacy of their homes and shared some difficult issues about their lives. We sincerely hope that some of the results may lead to the development of services to improve the overall quality of lives and services of people with spina bifida and/or hydrocephalus. Over the next few months, we shall be reporting on the following:

1. *Sexual Knowledge and Experiences of Young Adults with Spina Bifida and/or Hydrocephalus.*
2. *The Health and Social Needs of Young Adults with Spina Bifida and/or Hydrocephalus.*
3. *Parents' Views and Perceptions of the Health and Social Needs of Disability.*
4. *Evaluation of a new Adult Disability Service for people with Spina Bifida and/or Hydrocephalus.*

The first article addresses the sexuality and disability research project.

## **Sexual Knowledge and Experiences of Young Adults with Spina Bifida and/or Hydrocephalus**

THE MAJOR AIMS WERE

1. To elucidate the sexual knowledge of young people with spina bifida and/or hydrocephalus.
2. To identify the content and source of sex education received.
3. To describe the relationship experiences of adults with spina bifida and/or hydrocephalus.
4. To design, produce and evaluate introductory training materials as indicated by the study findings.

### **What has been noted before?**

The extent of sexual knowledge in neurologically disabled adults appears to be limited (*Edser and Ward, 1991*). *The importance of*

*providing appropriate sex education for disabled people, enabling teachers and carers to receive specific training in sexuality, sex and disability and listening to what disabled people tell us about their sexual needs and feelings is of paramount importance.*

The notion that disabled people may have the same or similar sexual feelings as able-bodied people is still relatively new. The subject of sex is one which many carers, "professionals" and even politicians have difficulty in coming to terms with, let alone knowing how best to discuss the subject with others.

Dr Steven Dorner, a member of ASBAH's medical advisory committee, in an earlier study suggested that denying disabled people the opportunity to have sex does not necessarily suppress their sexual feelings. He noted that sex-

ual interest was of a markedly pre-occupying nature in young adults with spina bifida and/or hydrocephalus. Such preoccupations often increase with maturity and the total absence of a sexual partner may sometimes result in displays of "inappropriate sexual behaviour", such as masturbating in public or seeking excessive physical affection from a carer. Disabled people, from an early age, therefore need to be aware of the wide range of adult relationships, both sexual and non-sexual. Sexuality need not be perceived solely as penetrative sex. Sexuality should encompass all that is loving and sensuous (*Edser 1990*). Some disabled people may never be able to have full penetrative sexual intercourse. Other ways of giving and receiving sexual satisfaction may need to be discussed and explored.

It is now recognised that sex education has a place in the state secondary education curriculum for both disabled and able-bodied people (*Education Act 1993*). As society begins to acknowledge the sexual rights of able-bodied people, we owe disabled people the assurance that they too will receive appropriate sexual information and help where necessary, throughout life, which also considers the specific physiological and memory features of the disability as well as personal, cultural and religious beliefs.

### **RESULTS**

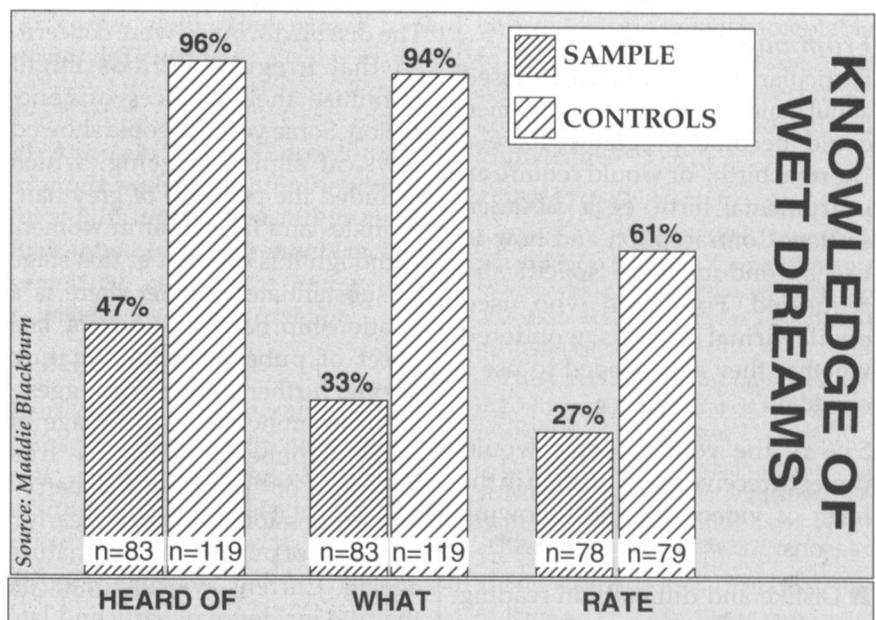
91% of those taking part in this study had hydrocephalus as well as spina bifida. Two men and three women were engaged to be married. Two of the women who were engaged have married since interview. None of the people had children at the time

of the interview, although two are planning a family soon. A wealth of information was gathered. The major findings only are reported in this article. Others findings have and will continue to be reported in publications. A complete text is contained within a thesis/report held by ASBAH in Peterborough and at Charing Cross and Westminster Medical School. This may also be borrowed from the University of East London library and other university databases.

### Sex Education

Although 80% of the people interviewed had received sex education at some stage of their lives, information was not always consistent or appropriate to their individual needs or complex disabilities. Only 18% had received specific information about sexuality and disability. 16% could not recall receiving any sex education.

Many young adults complained that texts/information were often too long, written in an academic style and that diagrams and illustrations frequently depicted stereotypical "able-bodied, white, body beautiful" male and female images. Illustrations seldom showed people wearing a stoma bag, a penile urinal appliance, a catheter in situ or how to deal with bowels in a sexual relationship. ASBAH, the ABCD Pack (Abuse and Children who are Disabled), SPOD, the Brook Advisory Centre and Dr Ann Craft and associates from Nottingham University Mental Handicap Unit design materials specifically for disabled people. Such organisations have sought to reform the image of "white, able-bodied" sex education materials. Many adults complained that their sex education was segregated from able-bodied education programmes. Two men were told that they could leave the sex



education class and attend the hydrotherapy pool, as the material was irrelevant to them!

24% who had received sex education (mainly in their adult years) stressed the importance of continuing sex education throughout life. Although earlier work by Dr Martin Bax and his colleagues suggested that disabled adolescents may be isolated and have infrequent opportunities to have a sexual relationship, this study has indicated that an increasing number of disabled adults are keen to find a sexual partner.

### Where sex education was provided

School provided most sex information for people with spina bifida and/or hydrocephalus. Parents provided sex education for about (37%) 24% had received information or counselling about relationships and sex at colleges of further education. 6% had requested information about sex, relationships and marriage from a sexual counsellor. Little or no sex education had been provided by other relatives, hospital staff, family doctors, care staff or

social workers, although 19% reported that they had received some genetic counselling from doctors.

### What did people know?

There were considerable differences among those adults who had heard, could define and understand different terms. For example, 81% had heard the word "vagina". Only 69% knew the correct definition and 66% understood the meaning. Two people thought vagina was a "non-meat eater". A variety of intriguing spellings were also offered for vagina, such as virginia or virgin! Wet dreams were frequently associated with urinary incontinence. Sadly, there was a lot of ignorance about sex, but memory difficulties also contributed to some of these difficulties.

### What did people want?

Although many had received information about conception, length or pregnancy, birth/labour and birth control, many young adults requested further information about labour (54%), contraception (50%) and conception (46%).

*Continued on next page*

# ...OUR DUTY TO SHARE

### **From page 9**

Particular concerns were expressed about male sexual potency, if women could become pregnant, have a "normal birth" or would require an instrumental birth, eg a caesarian section. Contraception and how to use a condom were specifically requested. Four men who used penile urinal sheaths wondered whether they also needed to use a condom.

55% of the young people would prefer to receive sex education in the form of videos for the following reasons:

- Dislike and difficulty in reading the written word
- Able to look at video material repeatedly to help memory
- Able to select particular sections appropriate to individual needs
- Convenience. Able to view materials in privacy, either with or without a partner and/or carer. (This was particularly important for those adults who were living independently or continued to be supported by parents/carers either at home or in residential care after leaving school).
- Less embarrassing than discussing a topic among a large group of people
- Wider choice of materials, including both sex education and Certificate 18 "blue movies". Eighteen regularly watched Certificate 18 movies in order to obtain information about sex, but also to overcome sexual boredom and frustration in the absence of a sexual partner.

#### **Puberty: early and late onset**

13% reported early onset of puberty between seven and 10 years. 5% reported onset of regular periods from the same age. Two women had their first period at six years. Of the 19% women who reported irregular periods (less than two monthly intervals), the majority reported mood swings and feelings of irritability either just before or at the onset of their menstruation.

The disabled women were concerned that irregular periods might minimise their chances of conception. Some young people showed physical signs of ageing, which included the presence of grey hair, wrinkles and facial hair in women. Although it is difficult at this stage to substantiate whether there is a relationship between early or late onset of puberty and premature ageing, further studies are suggested to examine the average age of onset of puberty, assess the true incidence of "precocious puberty" and any possible link between early/late onset of puberty and premature ageing. Current available data on the true incidence of early and late onset of puberty is still limited (Furman, 1990).

#### **Relationships:**

39% reported that they previously had or were presently "in a relationship" ("steady or long term" relationship being defined for this purpose as one of three months duration or more). There was some initial confusion as to what constituted a "relationship". Four women reported "crushes" on teachers or taxi drivers and inappropriately interpreted such an infatuation as a relationship of long duration. Two men and one woman living in residential care were so obsessed by their carers that either they or their carers were relocated or moved premises. Three men reported homosexual relationships. One man was HIV positive. 48% of the group were ambivalent about having a child.

Although only 21% had engaged in penetrative sex, many more would like to have some form of a sexual relationship. Penetrative sex was not considered the only way of obtaining sexual satisfaction. Other forms of communication were recognised as being equally important such as talking to, smelling and touching your partner, masturbation.

#### **Continence and Sex**

Both urinary and bowel incontinence were significant findings

within this study. 60% expressed particular concern about urinary continence and sexuality and 28% about bowels and sexuality issues. Although urinary odours caused particular relationship difficulties for six adults, three people were unaware that their smells might be "off putting" to their partners. Those who had experienced intimate sex elaborated on some of their personal difficulties, how society views continence, discussing continence with partners, carers and professionals, how to make continence more aesthetically pleasing, availability of information and assistance with continence management.

#### **Abuse**

10% retrospectively disclosed either physical, sexual, emotional abuse and/or grave concern. Two people still risked abuse. The interviews did not specifically seek to obtain abuse information. Such information was volunteered. I believe the number of disclosures might have been higher had the study included more specific questions about abuse. The positive role that sex education plays in heightening sexual awareness and attempting to minimise physical, sexual and emotional exploitation cannot be underestimated.

#### **Recommendations**

This study has provided a wealth of information which has implications for both disabled children and adults with spina bifida and/or hydrocephalus, other disabled people, (adult) partners, carers and health professionals as well as for the future provision of services, sex education and legislation in England and Wales.

*The following recommendations are suggested for people with spina bifida and/or hydrocephalus:*

##### **1. Sex Education and Counselling**

a) *A mandatory, gradual, non-segregated sex education programme throughout school. This should include information about sex specific to the individual*

disabled person's particular needs.

b) Availability of sex education and counselling within colleges of further education and work environment.

c) Sex education for disabled adults living in residential care or at home.

d) Information and counselling for partners who are engaged in a sexual relationship with a disabled person.

e) Sexuality and disability awareness programmes for health care professionals.

f) Development of specialist training materials for people with spina bifida and/or hydrocephalus. Information and materials should be presented clearly, succinctly and consider the retentive memory and sequencing materials which may be associated with hydrocephalus.

g) Information for adults addressing the following: attitudes towards sexuality and disability, terminology, genetic risks, continence, pubertal body differences, child birth, love-making and prevention and awareness of abuse.

h) Availability of audio-visual materials, particularly videos and "easy to read" leaflets.

i) Production and evaluation of a training package addressing some of the subjects identified within the study.

## 2. Counselling

a) Availability of specialist counsellors to discuss relationships, continence and sexuality, love-making, physical, emotional and/or sexual abuse.

b) Reinstatement of ASBAH's specialist counselling service.

c) Expansion of ASBAH's continence advisory service to address the specialist and delicate issues of both urinary and bowel incontinence.

d) Expansion of local continence advisory services.

e) Availability of counselling support for partners, parents and

for carers supporting people with sexual difficulties.

## 3. Services

a) Availability and development of adult multi-disciplinary services for adults with spina bifida and/or hydrocephalus. These should include sexuality, continence and genetic counselling service provision.

## 4. Legislation

Protection of "vulnerable adults" (those who have experienced abuse or risk abuse) after the recommendations of the Children Act 1989 cease to apply to adults.

## CONCLUSION

The Warnock Report (1978) indicated that sex education and counselling provision for disabled people was particularly poor in schools. Since this report, legislation has addressed the importance of providing a sex education curriculum for both able-bodied and disabled people (*Education Acts 1981, 1986, 1993*).

Our study has suggested that sex education should be individually designed. Although the 1993 Act stipulates that sex education must be provided to all pupils in state secondary schools, how and who should provide such information is a source of current debate. Some teachers argue that is the role of parents; health specialists suggest it is theirs but have received occasional criticism for doing so!

Many parents, although recognising the importance of sex education, feel uncomfortable and ill-prepared about discussing sexuality. If we are to avoid perpetuating ignorance, further taboo and a fear of sexuality, someone has to assume responsibility.

The majority of disabled adults in our study felt sex education provision was the collective responsibility of parents, teachers and health specialists. Equally, imposing this educational responsibility on those who find difficulty was pointless. Surely the most important issue is to acknowledge the individual sexual needs of disabled people. These must not be ignored and information should

be provided in a manner acceptable to the individual by those with whom s/he has the greatest trust, confidence and perceived knowledge.

## LITERATURE

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## RESEARCH SUMMARY

98 young adults with spina bifida and hydrocephalus, aged 16-25 years, were interviewed about their sexual knowledge and experience. 123 able-bodied young adults and a small sample of young adults with cerebral palsy were also interviewed. The study aimed to compare knowledge and understanding of sexuality and offer recommendations for sex education if found deficient. Findings suggested the necessity for specialist sex education for both children and adults with spina bifida and/or hydrocephalus and that education should be for life and not cease on leaving school. Particular concerns were expressed about continence and sex (60%) and giving birth (54%). The particular memory and sequencing difficulties often associated with hydrocephalus were also significant. A pilot video, entitled 'Sexuality and Disability in Spina Bifida and/or Hydrocephalus' was produced in response to survey findings. Consumer and professional evaluation was sought. 76% thought the video was suitable for the defined audience. The development of further materials involving greater initiation and participation by disabled people, was suggested. 'You, Your Partner and Continence'. a video, booklet, audio cassette and samples were launched in June 1993 in response. A further training video is being produced with a Gulbenkian Foundation award..



**Sally-Ann Hughes, 28, from Farnborough in Kent, will never forget the day that the bottom fell out of her world but, in a way, it made her world at the same time.**

## THE STORY OF

Trevor and I started going out together in the August of 1988. It was a bit of a whirlwind romance and friends used to joke about us getting married. It was too early for us and we never really thought we would.

We went on holiday to Lanzarote at the end of February 1989 and little did we know how much our lives would change in the months to come. By the beginning of April I discovered that I was pregnant and, although we had only known each other for eight months, I was really happy. When the pregnancy was confirmed, Trevor was over the moon. He immediately phoned his parents and friends to tell them the good news. He had even told them all that we were getting married. I suppose he just assumed that it was alright with me.

All of a sudden I was being carried along with all the excitement. Trevor and my mum thought that we should get married before the baby was due. I was quite happy to wait until afterwards, but mum and Trevor won in the end.

The next thing I knew the day was booked. What with all the fuss and arrangements I never took much notice when I started to suffer with terrible pains in my stomach. I just thought it was a part of being pregnant.

Our wedding day came and went in a flash and we were blissfully happy. One month after we returned from our honeymoon, my scan date arrived. I will never forget the day.

Trevor came home from work so that he could go the 3 o'clock appointment with me. I remember it was a really hot July day and we were so excited. I drank pints and pints of water before we went so

that we would get a good scan picture of our baby. It was in that scan room that our bubble burst.

The radiographer pointed out the baby's arms and legs and then the head. It was very hard to make out what was what. He was measuring the head's circumference when I said it looked as if there were two heads. He then asked another man to come in. We never thought anything of it.

I was then asked if I could go and drink some more water because it was such a hot day. We waited another half an hour for the water to reach my bladder and went back to the scan room. This time another radiographer came into the room. Trevor now suspected that something was wrong.

The radiographer didn't say anything to us about our baby. He just spoke to the assistant across the room to ask him to take a couple of pictures. He then turned to me and said: "There seems to be a problem with your pregnancy." With that I burst into tears. He asked me if I had seen my obstetrician. When I shook my head, he said that I should go and see him immediately. He telephoned Mr McQueen to let him know we were on our way.

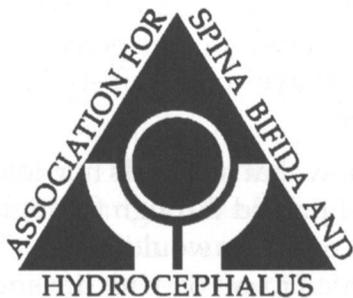
I asked the radiographer what the problem was and I will never forget his words: "I think you should hear it from the horse's mouth..."

*My mind was racing. What could be wrong with our baby? Was it us, were we incompatible? Did we do something wrong?*

We raced to the hospital where my obstetrician was. Trevor didn't seem too worried, he was trying to comfort me. He said: "It's probably just laying the wrong way round or something". It wasn't until we got to Mr McQueen that he

# Hydrocephalus Network NEWS

ASBAH, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.  
Telephone: 0733 555988 • Registered Charity Number 249338



SUMMER '94

## HYDROCEPHALUS AND TWINS: 3-PAGE FEATURE INSIDE



*Stories of love and hope: Alexander and Rhys Walden - one of the mischievous pair of twins featured in this edition of H N News. See pages 2 - 4.*

### ■ STUDY DATES FOR YOUR DIARIES ■

We are organising three Hydrocephalus Study Days later this year - two in Northern Ireland and one in North Wales.

For details of the study days at Musgrave Park Hospital, Belfast, on 14 September, or at the Library HQ, Omagh, the following day, please phone ASBAH's regional centre on 0265-51522. Information about a study day in Llandudno on 8 October can be obtained by phoning Lynn Thomas at our national centre on 0733-555988.

Topics to be discussed include medical management and developmental aspects.

### ■ A cry for advice from worried mother ■

A mother worried about her young daughter's unshunted hydrocephalus would like to receive letters from people with the condition:

"I would like to contact someone who has hydrocephalus that has arrested and who has not had any treatment or a shunt fitted. My daughter was diagnosed at 14 months after various tests and has had problems since birth with development. She starts infants' school in September with a teacher's aide."

Rosemary Batchelor, Hydrocephalus Network co-ordinator at Peterborough, will be happy to pass your letters on.

MY STORY starts long before I actually gave birth to my twin sons. I wasn't sure of the date of my last menstruation so I had an early scan at 8 weeks. Twins they said - my husband and I were shocked! Two, I couldn't believe it - how would I be able to love two at the same time I wondered. I told everyone, of course, I couldn't keep such exciting news to myself.

Then tragedy struck. My full fetal scan at 18 weeks revealed that one of the twins had hydrocephalus, a build-up of fluid in the brain. We were told it could be treated at birth but that it often caused brain damage. Not much was apparently known about the affects of congenital hydrocephalus as such pregnancies were often terminated. My husband and I were devastated. The thought of terminating two lives was absolutely out of the question. I thought that having twins would be difficult enough but having one with a handicap. How could I cope?

The news got worse however. Three weeks later, I was scanned by the 'best' scanner

# TWINS: To Know or not To Know

## A personal story by Shari Sapp

in the country. He diagnosed my child with a fatal brain abnormality. We were told that no child had ever lived with such a condition. I couldn't believe it - now I was going to lose one of my precious babies. I remember I used to lay in the bath talking to both of them, wishing and praying with all my might that the doctors were wrong or that some miracle would take place. But I still had to come to grips with the fact that I was carrying a child that might live hours, days or at most weeks after birth.

The weeks went by and all my friends kept asking what I thought it would be like to have twins. In retrospect we made a bad decision not to share our bad news and grief with those around us. Instead, I smiled sweetly and tried not

to say too much at all. I went home to the States and faced a "baby shower" - opening gift after gift of two of everything. I look back and don't know how I managed to laugh and smile.

It was important to me to go through a grieving process for my son so that I could enjoy the birth and life of my healthy twin. I saw a psychologist once and began to adjust my dreams of the future to having one baby.

Then, eight weeks before my due date, I went into premature labour. After several days in hospital my waters finally broke and I went in for an emergency C-section. The paediatrician was on hand along with nurses from SCBU. The healthy baby was delivered first. They said he seemed fine and whisked him away. The baby they delivered next had a very large head due to the collection of fluid in it as well as a bilateral cleft lip and palate. The doctor said that he probably wouldn't live through the night so I gave him a kiss and whispered "good-bye" on the operating table.

I know that it sounds horrible but I prayed through the night that my baby would die. I wanted to get on with life and not have to deal with the eventual death of a child I could very well get attached

**These stories first appeared in the Newsletter of the Twins & Multiple Births Association (TAMBA).**

**Membership of TAMBA Special Needs Group is effectively membership of TAMBA without receiving their magazine 'Twins, Triplets and More'. Members receive a membership card and number which entitles them to all the general benefits of the Association, including discounts.**

**The cost of joining the group is £5, and this includes three TAMBA Special Needs Group Newsletters a year (October, February and June) and an up-to-date contacts list.**

**To apply to become a member of the group, please send a cheque for £5, payable to TAMBA Special Needs Group, to Jane Parker, 24 Belvoir Avenue, Trentham, Stoke-on-Trent, Staffs ST4 8SY, tel 0782 644179.**

**TAMBA is a registered charity.**

to. When morning came my husband reported that both babies were doing well. Neither had needed to be ventilated nor needed further oxygen support. The nurses encouraged me to go down to the special care nursery as soon as I was able. But I was scared to death to face what was there. How would I react? Eventually they wheeled me in and I held my babies for the first time. Richard was small and fragile but beautiful. It took me a long time to look at Michael closely. Most of you probably don't know what a cleft lip and palate look like before they are repaired by plastic surgery but, believe me, it is not a pretty sight. But I gathered my nerve and I studied this little person. He had a firm grip and a survival instinct that I would eventually come to recognise.

The boys stayed in hospital for three weeks and every morning I would wake up wondering if Michael was dead or alive. The doctors confirmed Michael's fatal diagnosis but he continued to hang on to life. We had decided, along with the doctors, not to try to prolong Michael's life and to let nature take its course. That might sound a very brutal thing to decide but it seemed to make sense at the time. I knew that it would be harder the longer he lived and the more attached I became to him. I couldn't even try to breast feed Michael because of his mouth, but I learned to feed him through the NG tube and to do all the care and cleaning required. One of the nurses let me take him into my hospital room where I was finally able to cry and sob to

my heart's content. It was such a relief to be able to hold him and cry until no more tears came. The day came when Richard was ready to go home. We decided we wanted to take Michael home and take care of him until the day he left us.

Our friends and family didn't know what to say to us. It was a time of celebration mixed with one of grief and fear. I could only deal with life by taking it one day at a time. Eventually, I stopped wondering each morning whether Michael would die that day. I kept pushing that day away in my mind. He was getting difficult to manage as his head kept growing in size so I put my foot down and demanded to see a neurosurgeon and have him shunted. (A shunt is a tiny tube that is inserted into the brain to drain the fluid that collects - it the drains into the abdominal area where it is absorbed by tissue.)

Before operating Michael had a CT scan. In front of nine or 10 student doctors, I was told by the neurosurgeon that Michael did not have a fatal

brain abnormality but had a severe case of hydrocephalus (which is not fatal at all). I was stunned. The only thing I could think of was "what have I done to my baby"? I went home and held his twin brother and cried and cried. I was going to have my twins after all but what did it all mean? How handicapped would he be? What would this do to the future of my family? So many questions, so many emotions, so many unknowns.

Michael had his shunt operation, and later his lip and palate repaired. We spent several months in and out of hospital but, for almost two years now (knock on wood), Michael has not been under an anaesthetic and has been given the best chance to develop.

Two years later, and numerous sessions with speech therapists, physiotherapists, occupational therapists, psychologists and other community support groups, Michael is a beautiful little boy with a mind and character of his own. He is significantly developmentally delayed but making progress on all fronts.



*Richard and Michael Sapp*

Overall, I cannot imagine life without him. He is part of my heart and soul. When I look back, I can't understand why I didn't fight harder for his life - where were my maternal instincts? And that is where the question comes in. To know or not to know? If I hadn't known, hadn't gone through a grieving process beforehand would I have fought harder? I hope so.

*I know for many of you it was a surprise to have one of your twins become a child with "special needs". I can't imagine how I would have taken such news months or even years after the baby's birth. But I do know that I thank God again and again for the life of my disabled son after months of thinking he would not be part of my life.*

I will always carry a certain amount of guilt with me and certain amount of residual anger toward the doctors who misdiagnosed my son and put me through a hell that needn't have happened. But time and the love of two children are wonderful healers and both emotions seem to be dissipating.

I know that each of us who receives this newsletter has a different story to tell. But we all have things in common too. The biggest of which is probably anxiety about what the future will bring for our family and our special children. I am sure that we all know that no one has the answers (especially doctors) so it is up to us to take life one day at a time - and to keep hope in our hearts. Children are incredible creatures. Their very fight for survival should be respected and then developed into a self-

respect that will help them find a place in the world.

## TWIN Delight

**A personal story by  
Michele and Richard  
Walden**

**AFTER two miscarriages, one at eight weeks, the other - a baby girl - at 20 weeks gestation, and fertility treatment, we were both delighted and worried to find out that we were expecting twins.**

An anxious few months followed, with me threatening to miscarry on several occasions and going into premature labour twice. We were told at 15 weeks that I had lost the majority of my amniotic fluid from around Rhys and that he was unlikely to survive the pregnancy.

Eventually, my waters broke from around Alexander and the boys were born at 28 weeks gestation on 10 October 1992, Rhys weighing 2lb 1.5 oz and Alexander 2lb 4oz.

We were told that Alex was doing well but Rhys was very poorly and it was touch and go for quite a few days.

Rhys had a cerebral bleed at birth and, at 10 weeks, hydrocephalus was diagnosed. Alexander had pneumonia at six weeks but otherwise sailed through, coming off his oxygen and being ready to come home in the middle of December. But, on doctor's advice, he stayed in hospital with Rhys.

The boys were due home at the end of December but Rhys became seriously ill with bronchiolitis on 23 December, and just avoided having to be reventilated. After a subdued Christmas, Rhys and Alexander eventually came home from the SCBU on 18 January when they were 101 days old, with Rhys still on oxygen.

Two and a half weeks later, with less than 24 hours notice, we were called to the Oxford Infirmary for Rhys to have a shunt fitted to drain the excess fluid from his brain.

We were warned that the risks to Rhys having an anaesthetic with his damaged lungs were quite high but, without the operation, brain damage would occur. The four hours that he was in theatre seemed the longest of our lives. Thankfully, he coped well and came home after only four days, several days earlier than expected.

His shunt is now under review and we are currently waiting for a decision to be made as to whether Rhys needs it replacing or not.

Alexander now weighs about 25lb and is thriving, enjoying flirting with everyone. Rhys is still on oxygen at night and has a few problems. He has reflux broncho-pulmonary dysplasia and gross motor problems, but he weighs just over 20lb and is already capturing hearts.

Rhys and Alexander are a constant source of joy to us and are well worth every minute of the pain and heartache we suffered to finally have our family. We'd do it all again tomorrow to have them!

# SALLY-ANN'S BABY

realised it was something much more serious. By the time we reached the hospital, I had resigned myself to the fact that I wasn't going to be a mother.

We waited for only five minutes for him to look at the scan pictures and report. He then came back to us. He told me that my baby had a severe defect of the head, anencephaly. Basically, there was a lesion at the back of the head and everything was growing out of the skull. He told us the baby would not survive outside the womb and that, as I was five months pregnant, I would have to undergo a 'mini labour' and have the baby.

*I will never forget the numbness I felt at that moment. Everything seemed to go in slow motion. Trevor became inconsolable. He was crying and sobbing and very angry. I had never seen anyone*

*react like this before and I just didn't know what to do. He had wanted our baby so much.*

Mr McQueen asked me if I would like to be induced that evening or the next morning. I opted for the morning.

Back home, I was trying to come to terms with what was happening. Trevor called his friend Mark to make some important business arrangements. I felt so numb and helpless. When Mark arrived, Trevor clung to him. Mark cried for Trevor and all I could do was to make them cups of coffee.

The following morning my mum arrived and we drove to the hospital. On the way, all I remember seeing was other mothers pushing prams. Trevor and mum stayed with me at the hospital and they even gave Trevor a camp bed in my room so

he could stay with me that night.

The obstetrician started to induce labour from 10am. At 1.30am the following day, I had excruciating pains and an urge to push. Trevor called the midwife. It took just one good push. The midwife asked if we would like to see our baby or would we like to know anything.

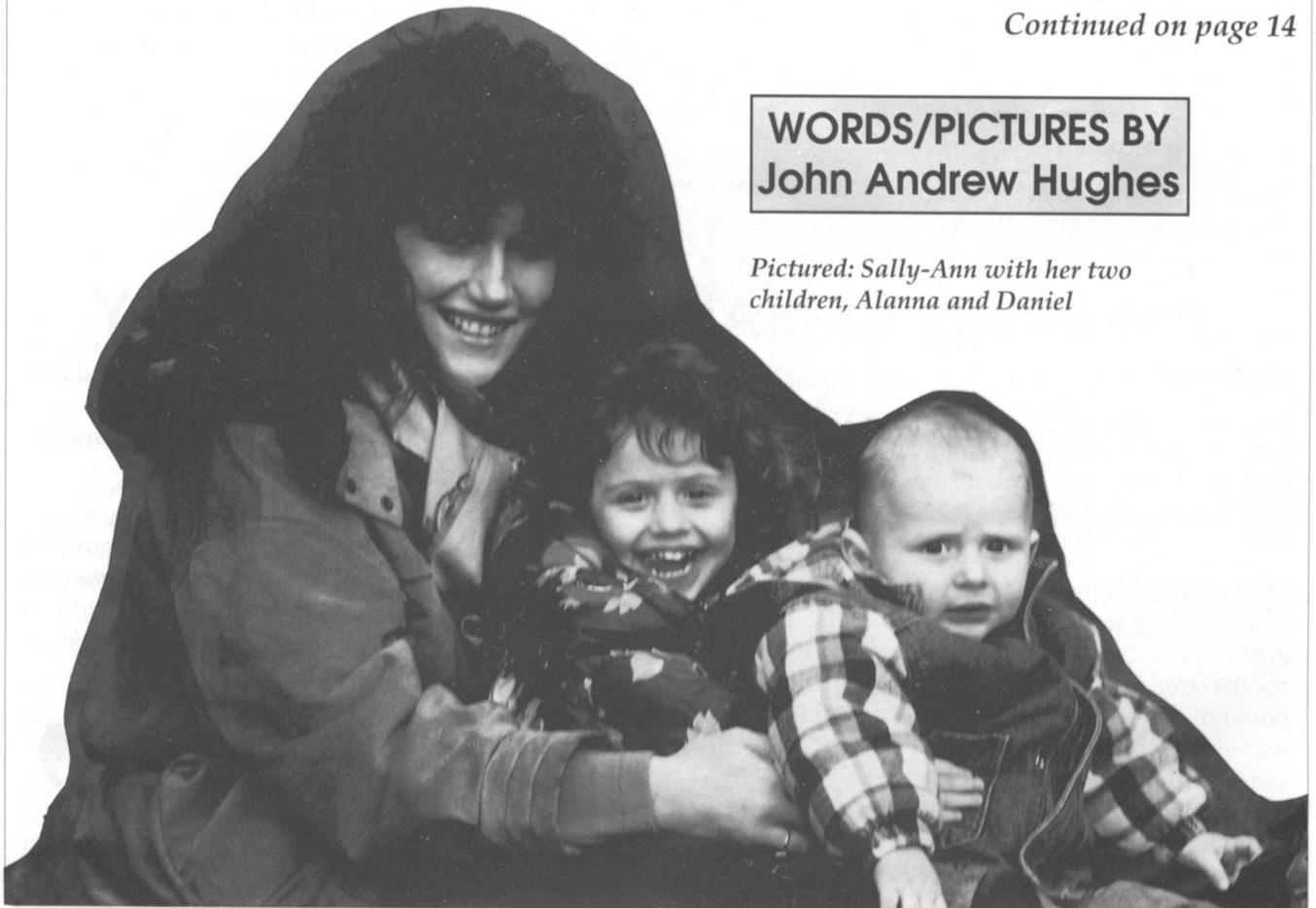
We felt that the less we knew about the baby, the easier it would be for us to put it to the back of our minds. We decided that we would rather not know what sex the baby was.

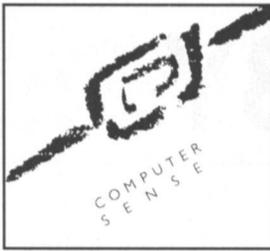
In the weeks to follow, I received excellent aftercare from my obstetrician, Mr McQueen. He advised me that, if I wanted another baby, not to try for at least three months. He also told me I was to take a vitamin supplement which included folic acid before and during the first 12 weeks of

*Continued on page 14*

**WORDS/PICTURES BY  
John Andrew Hughes**

*Pictured: Sally-Ann with her two children, Alanna and Daniel*





# We take a big Mac byte.... for charity!

IT IS one of the distressing facts of modern life that money is needed for virtually anything and everything. ASBAH needs a steady, continuous flow of money in order to pay for all the costs of employing the services staff and the backroom staff who support them.

If income fluctuates at the whim of donors, government, interest rates, etc it is very difficult for any charity to do its work properly. Indeed, many charities have found that their income has reduced dramatically during the recession of the past three years and they have had to close down.

Many readers of LINK know that ASBAH has had its problems and has been unable to fill vacancies when service staff have left employment. Maintaining the numbers of fieldworkers and disabled living staff can only be guaranteed when we have guaranteed income.

Our new trading subsidiary, Computer Sense Ltd (CSL), has

been formed in order to help provide that continuing, guaranteed income. All the annual taxable profit made by CSL is passed over to ASBAH, who own all the shares.

Every large and medium-sized company uses computers of one sort or another, and so do many small companies. Apple computers - often called 'Macs' or 'Macintosh' - are to be found in thousands of businesses throughout the country.

CSL specialise in selling and repairing 'Macs', together with printers, monitors, hard discs etc that are used with 'Macs'. CSL must make businesses aware of its existence but advertising costs money - ASBAH's money - money that could be used on providing services to those with spina bifida and/or hydrocephalus. But no advertising means no business which means no profit which means ????

That is where YOU, the readers of this magazine, come into the act.

You can make a positive contribution to our income, AT NO COST OR EFFORT to yourself, simply by suggesting to your employer, friends, relatives and neighbours that they use CSL for their Apple computer needs. Explain to them that CSL is run by people with lots of experience with 'Macs' and that all profits go to ASBAH - not into somebody's personal bank account.

It does not matter where you live or work because, by using an overnight courier, equipment can be turned round for repair within 48-72 hours and new equipment delivered next day. Businesses within about 100 miles of CSL can receive personal services.

We need YOUR help to spread the word about CSL and to get new business for them. Please talk to your employer, friends, relatives and neighbours and get them to contact Computer Sense Ltd, Grovelands Business Centre, Hemel Hempstead, Herts, tel 0442-252555, fax 0442-219222.

## THE STORY OF SALLY-ANN'S FIRST BABY

*From Page 13*

pregnancy. Research has found that taking folic acid reduced the chances of mothers having further babies with neural tube defects by 72%.

The hospital put me in touch with ASBAH. They were very helpful, gentle and encouraging and gave me the strength to try again. It is not until you speak to other people that you realise others are in the same or similar situations to yourself and that help is always at hand.

Six months later, I fell pregnant

again. Mr McQueen monitored me very closely and I felt every confidence with him. My first scan came at only eight weeks. At 16 weeks I had an AFP (Alpha Feto Protein) test, then more scans at 20 weeks and 32 weeks. They all showed no neural tube defects.

On the 19th October 1990, I have birth to 'Alanna Jayne', a beautiful, healthy 8lb girl. Alan now has a baby brother, Daniel, who is 16 months old.

When I sit in our local park, it is so easy to take it all for granted now. I am experiencing happy

memories. The sun shines and our two children scream with excitement as I push them on the swings.

*I now know that our first baby was a girl and I have a picture of her which I always keep with me. I am so grateful that, although at the time I didn't want to know, the hospital took the photograph just in case I every changed my mind. It was with my medical file. I will never forget our first baby, who brought our family together.*

© John Andrew Hughes, 1994

# YVIA PAVES THE WAY

OUR first conference was held on Saturday, 30 April. For those of you who may still be wondering what YVIA is, the initials stand for 'Your Voice in ASBAH'.

We are a group of about 12 people who have been meeting for the last two years, and have been working towards increasing the representation of people with spina bifida and hydrocephalus within ASBAH's committees, and commenting on relevant policies and press coverage.

We felt that it was time that we held a conference to enable disabled members of ASBAH to find out what we have been doing, what we plan to do, and to get feedback.

About 26 people came on the day, from all over the country, and from as far afield as Devon.

After opening remarks from Jonathon Burke, YVIA chair, we were welcomed by Patrick Daunt, ASBAH's chairman. We then split into small groups for the morning.

The first sessions was 'The Story So Far'. For those unable to attend the conference, here is a brief rundown - we have secured two places on the executive (currently held by Terry Denyer and myself) and we are trying to achieve representation on various other committees.

We have commented on a number of documents - including ASBAH's equal opportunities policy and its education policy - as well as monitoring general press coverage and relevant articles.

For the second workshop, 'Back to the Future', we asked for suggestions of possible future work for the group, and obtained support for four resolutions which, if accepted, would guide the group's future direction.

## *Zem Rodaway reviews their successful spring conference*

These resolutions are:

- 1) That YVIA works with ASBAH to set up an awareness and training initiative to be targeted at local Associations;
- 2) That YVIA encourages ASBAH to declare public support for the

call for comprehensive Anti-Discrimination Legislation;

3) That YVIA investigates further the question of editorial input to the major publications of the organisation.

4) That YVIA explores the issues



*Mik Scarlet makes a point. Listening are Lydia Carr, Kevin Towner and Jon Burke.*



Another view from the YVIA conference

involved and identifies the major factors for and against the setting up of a separate members section of the organisation. The results of this investigation should be presented to a further open meeting of disabled members of ASBAH, organised by YVIA, before any further decisions are made.

After a delicious buffet lunch, participants had the choice of four different afternoon workshops.

We were pleased to welcome Anne Pridmore to lead a workshop called 'Discovering Sexuality'. The other three workshops - on self-autonomy, access and practical issues, and positive images - were led by YVIA members.

After another opportunity to feedback our discussions to the main group, we welcomed Mik Scarlet as guest speaker. He talked

about how he got into TV, and about his experiences in and impressions of TV.

It was good to hear someone with such a positive, and in some cases unusual, outlook on life. For example, a lot of people don't get the chance to take time out of work so, if you are unable to work or cannot find a job, you can use the time to pursue an interest or hobby, and may have the opportunity to get paid work later on.

At the end of the day, the new YVIA committee was announced. Twelve people (including four new members), the exact number we needed, had put themselves forward.

The new committee is as follows:

■ **Carole Armour (Birstall, Leicester)**

■ **Jon Burke (Newsome, Huddersfield - chair)**

■ **Terry Denyer (Rochester, Kent - YVIA rep on executive)**

■ **Christine Helliwell (Brighouse, West Yorkshire)**

■ **Matthew Jenkins (Taunton, Devon)**

■ **Mani Morice (Worthing, West Sussex)**

■ **Tracey Proudlock (Muswell Hill, North London)**

■ **Zem Rodaway (Hull - secretary, YVIA rep on executive)**

■ **Beverley Rowe (Peacehaven, East Sussex)**

■ **Margaret Twyford (Surbiton, Surrey)**

■ **Alan Twyford (Surbiton, Surrey)**

■ **Kevin Towner (St Leonard's, East Sussex).**

For those unable to come on 30 April, this was a taste of what you missed! If you have any comments on the resolutions, or anything else you would like us to look into on behalf of ASBAH's disabled members, please let us know through the pages of LIFT magazine.

Lastly, we would like to say a big thank you to - Andrew Russell and Patrick Daunt for giving up their Saturday to attend - Mike Scarlet and Anne Pridmore - the students who helped with the creche - and especially Tony Britton for all his hard work beforehand, without whom the conference would probably never have happened.

A QUESTIONNAIRE in the last LIFT magazine about its readers, LIFT and ASBAH services attracted a lively response. Ninety five readers returned completed forms - about 4%.

LIFT is ASBAH's free quarterly publication for young people with spina bifida and/or hydrocephalus. Replies showed a 35-year range in readership. Some complained of too little material to satisfy any age-group.

One said LIFT had lost its way and was boring. Others that it needed more stories and more pages. There were calls for an advice column, a penfriends page, stories on pop music and about disabled people getting on in the world.

Plenty of readers, but few offered to write for it. No one committed themselves - perhaps they felt incorrectly that they were not important enough or perhaps they had been let down in the past.

One crying need: readers with poor sight relied on other people to read LIFT to them. They want taped material from ASBAH; this is an area which YVIA and staff will explore shortly.

More about this in the July LIFT. The magazine will only be sent to those who have already let us know they want to continue receiving it. But LIFT can be ordered, even now. Phone your order to Lynn Thomas, 0733-555988.

# GOVERNMENT SCUPPERS THE

THE THIRTEENTH attempt to provide a framework of law for civil rights for disabled people was sunk on Friday, 20 May, when Minister for Disabled People Nicholas Scott 'talked out' the Civil Rights (Disabled Persons) Bill in the House of Commons.

The Minister spoke for so long during the third reading of the Private Member's Bill that no other MP could get a speech in edgeways. The debate ran out of time before a vote could be taken, and - under the rules of the House - the Bill was lost.

Disability rights campaigners refused to take Mr Scott's speech as the last word - leaving their wheelchairs in the street and attempting to crawl through the front door of Parliament before being stopped by police. Alan Holdsworth, co-ordinator of the Direct Action Network, promised more publicity stunts until the Government brought in anti-discrimination laws.

Mr Scott's daughter, Victoria, who is parliamentary officer for RADAR, also continued to demand her father's resignation.

In the Sunday press, Downing Street sources were quoted as saying that Mr Scott had the full support of the Prime Minister.

Mr Scott repeated his objections to the Bill. It would cost industry £17bn immediately and then £1bn a year.

"However sympathetic one is, you cannot impose that sort of cost on British business and industry without having widespread consultation with them on the impact that it is likely to have on their operation", he told *The Independent on Sunday*.

The Government has promised to bring forward its own proposals following six months of public consultation. There would be measures to tackle job discrimination, access to buildings and services, and the formation of a national advisory body.

The promises have done nothing to pacify civil rights campaigners.

## DISABILITY BILL

### ASBAH condemns 'sabotage debacle'

*This ASBAH news release was issued on 12 May:*

MINISTERIAL tactics to sabotage the Civil Rights (Disabled Persons) Bill have brought great discredit on the Government, the Association for Spina Bifida and Hydrocephalus said today.

In a letter sent to 10 Downing Street, executive director Andrew Russell has told the Prime Minister:

"On behalf of many thousands of people disabled by spina bifida and hydrocephalus, I am writing to express our disappointment at the manner in which your Ministers have conducted tactics to sabotage the Civil Rights (Disabled Persons) Bill, which had the unanimously expressed support of Parliament.

"Events reflect great discredit not only on Mr Nicholas Scott but of course far more widely, including on the Secretary of State for Social Security, and on yourself. Explanations that a temporary oversight led to untruths being stated to the House simply do not stand scrutiny. The fact that no amendments were tabled by the Government until two days before the third reading, when 80 government-prepared amendments were fed to backbenchers to talk the Bill out speaks of government planning. Please do not ask disabled people to believe otherwise.

"ASBAH has tried to build a working relationship with a succession of Governments based on good faith. We deplore the bad faith exhibited by your administration in this recent debacle. Apologies should be directed not only to the House of Commons, but to several million people with disabilities.

"We hope we can take at its face value your Secretary of State's claim that the subject of civil rights of disabled people will be brought back into immediate, serious discussion which will lead to action".

*Note to Editors: ASBAH provides close support to 15,000 individuals and families throughout England, Wales and Northern Ireland at times of special need, and helps through its network of fieldworkers and specialist advisers to give power and choice to people with spina bifida and hydrocephalus.*

**THERE is a complex relationship between spina bifida and the little known disorder of syringomyelia. Readers may be helped by a previous article in *LINK* (April 1992) on the Chiari deformities.**

**DEVELOPMENT AND NOMENCLATURE**

In normal development, the outer layers of the embryo form a groove. As this groove deepens the edges fuse together to make a closed tube (Fig 1, below). This is the neural tube which forms the brain and spinal cord. The bone, muscle and skin of the spine then form around the tube. The process of the tube forming is called raphism, anything that goes wrong with it is called dysraphism. Spaces develop between the neural tube and the surrounding bone and muscles which become filled with a clear fluid called cerebrospinal fluid (CSF) which is close to water in composition. CSF contains just a little salt, sugar and protein. The linings of the CSF-containing space are called meninges: there are three of these membranes - named from the outside inwards - dura, arachnoid and pia.

Normally closure of the cord is almost complete. A tiny central canal is detectable under a

# SPINA BIFIDA AND SYRINGOMYELIA

by Bernard Williams, ChM, MD, FRCS  
Syringomyelia Clinic, Midland Centre for Neurosurgery and Neurology, Holly Lane, Warley, West Midlands

microscope. Embryologically this is continuous with the fourth ventricle occupying the cerebellum. A communication between and abnormally large central canal and the fourth is sometimes found. This gives rise to one form of syringomyelia.

There are many forms of dysraphism. They include abnormal inclusions of skin trapped within the spinal canal (dermoids and epidermoids), duplication of the spinal cord (diplomyelia), sometimes with a bony spur between the two limbs (diastematomyelia) and abnormal collections of fat (lipomas) inside the spinal canal. The fundamental defect in spina bifida occurs when the neural tube does not close properly. The bone may not form around the tube if it has not closed and tends to be present as two spurs (Fig 1). Hence the term spina bifida. The region where the cord

and the surrounding tissues have failed to close may be called the primary lesion or the plaque. When the spinal cord is dysraphic, it may adhere to the plaque, usually near to the bottom end of the spine by fat or other abnormal tissue. This is called a tethered cord (Fig 2, next page top).

Syringomyelia is a longitudinal cavity within the spinal cord. Most syrinx cavities are partly lined with scarring inside the cord, which is called gliosis. The cavities are usually big in the neck, where the nerves arise which control the diaphragm and the arms (Fig 3 & 4, foot of next page and overleaf).

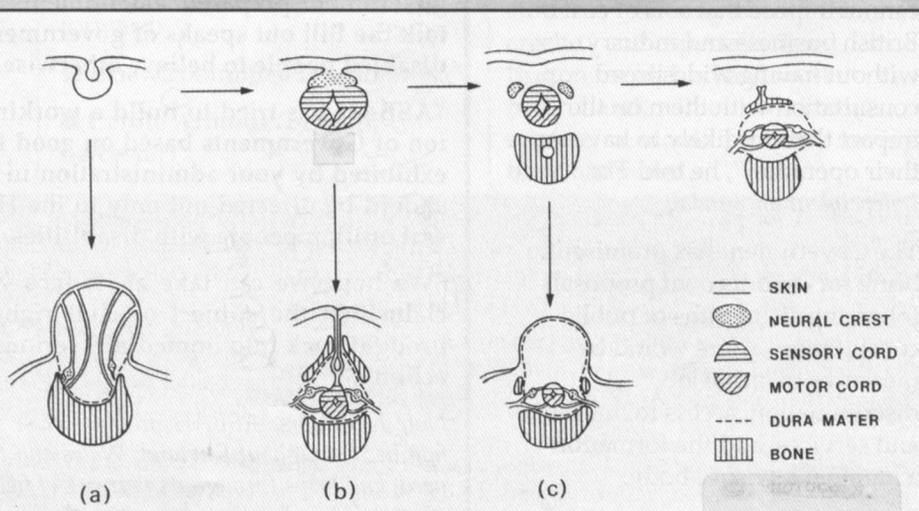
The commonest cause of syringomyelia is an abnormality at the foramen magnum, the big hole at the base of the skull. Normally the medulla goes through the foramen magnum and blends in with the spinal cord below. The commonest cause of syringomyelia

*The forms of spina bifida illustrated as cross sections of the spine. The top row of diagrams represents normal development. If there is arrest of the process of raphism at different stages the final anatomical picture is as shown in the bottom row.*

*(a) In the full-blown myelomeningocele, the cord is flattened and everted and takes the place of skin. Note the bone present as bifid spines.*

*(b) A small track may remain where the tissues fail to heal perfectly in the middle.*

*(c) If the cord forms normally but the skin is blown out by CSF the result is a meningocele.*



**Fig 1.**

is hindbrain herniation, sometimes called the Chiari deformity. The terms Arnold-Chiari or Chiari Malformation are sometimes used. This describes displacement of the hindbrain downwards through the foramen magnum so that part of the brain protrudes outside the skull (Fig 3).

Syringobulbia means symptoms from the hindbrain, usually directly from the hindbrain herniation. These symptoms in adults may be of headache, fainting attacks, dizziness, deafness, tinnitus, swallowing or voice problems with sometimes tongue or palate weakness. In babies, problems with breathing or swallowing predominate because of compression of the tissues at the foramen.

### PROGRESSION OF PATHOLOGY

The cord is destroyed at the level of the plaque in the severest form of spina bifida, known as myelomeningocele. The legs and the bladder are paralysed, sensation below the lesion is likewise affected and the bones of the spine and legs are deformed.

The next factor is hydrocephalus. CSF is made in the ventricles, about 20 cc an hour is made day and night. It is absorbed over the outside of the brain. If the pathway is blocked or partly blocked then hydrocephalus results. In spina bifida babies, the low pressure in the spine causes the hindbrain hernia and hindbrain hernia causes hydrocephalus. Such a hydrocephalus often communicates with the centre of the spinal cord.

Hydrocephalus often progresses within the first few days after birth so that a valved shunt is put into the ventricles and the CSF is diverted into the peritoneum (abdomen) or via the veins of the neck into the heart. Such an operation is usually successful in controlling the advance of the hydrocephalus and limiting the increase in head size.

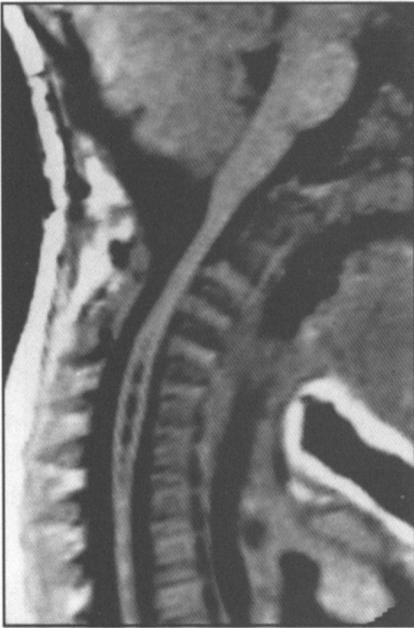
*Continued on next page*



*The plaque here takes the form of a fatty lump on the back of the sacrum (F). The syringomyelia shows as blacker area within the spinal cord. The cavity looks like a string of irregular black beads. The cord is severely compromised by dilatation and stretching of the walls.* **Fig 2.**



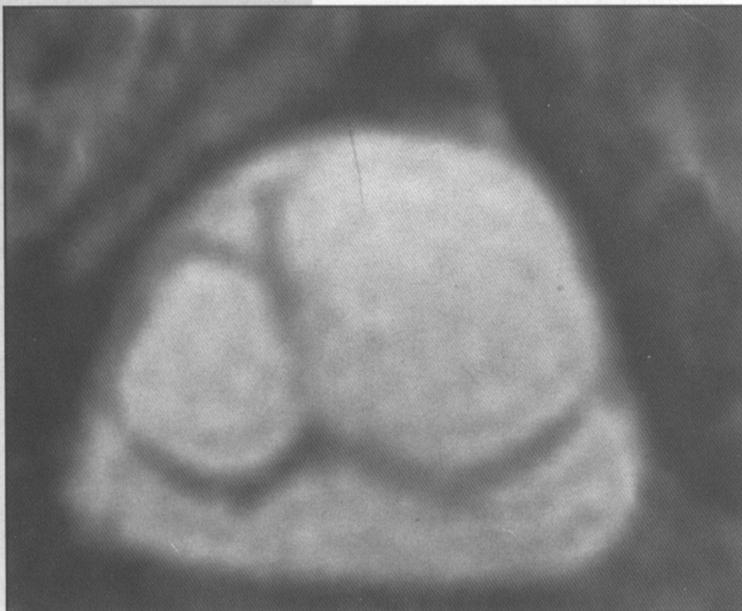
*The top of the cord in the same case as Fig 2. There is a hindbrain hernia, the cerebellum (C) is herniated downwards through the foramen magnum (Arrow). Because the hindbrain hernia might be aggravated by direct operation upon the plaque, the first procedure chosen was hindbrain hernia decompression. The syrinx cavity (S), which looks as though it has spread up from below, is still present like a string of black beads within the spinal cord.* **Fig 3.**



**Fig 4.** Same case as Figs 3 and 4 after hindbrain hernia decompression. Note the production of a big space at the back of the cerebellum with rounding off of the bottom end of the cerebellum and the striking diminution of the syrinx cavity. The cord below the first thoracic vertebra, (T1), has almost returned to normal and the progression of the syrinx has clearly been arrested. The plaque was operated upon later with further improvement.

Below: This is an MRI image of the bottom of the spina in a lady who did not know that she had spina bifida. It is thus spina bifida occulta. This sequence shows the CSF as white. The two white circles show the fluid of the syringomyelia. The spinal cord is present as two separate limbs, diplomyelia, surviving tissues show as incomplete black rings. The other white areas represent the CSF space outside the cord.

**Fig 5.**



### From previous page

If the valved shunt system blocks in the first few weeks or months after it is put in, the relatives usually quickly become aware of it. The child is acutely ill, the fontanelle becomes tense, vomiting starts, unconsciousness develops and so on.

Shunt blockage may sometimes be difficult to diagnose. In older patients, the valve may block and this may be hard to assess because the absorptive pathways may have opened up partially after treatment. The patient remains conscious and may just seem to be generally ill. Obstruction may be intermittent. Diagnoses such as "flu" or "viral meningitis" are sometimes made.

### SYMPTOMS OF SYRINGOMYELIA

Hindbrain hernia and syringobulbia features may occur in severe spina bifida or in more subtle cases where dysraphism may not be apparent. The problems usually start in adolescence or adult life. The symptoms of syringomyelia are often slow in their onset and may not be recognised for some while. There may be pain in almost any part of the body but particularly headache and pain radiating down the neck or into the arms. Headache may be made worse by straining. There may be loss of use

of the hands. The most striking feature is numbness, tingly feelings of loss of the ability to feel temperature or normal pain. Loss of use of the upper limb with wasting and weakness comes on late, more often the arms suffer a vague clumsiness.

### INVESTIGATIONS

The majority of spina bifida sufferers have been well investigated by the time that they are suspected of having syringomyelia. There is often a big gap in time, however, before syringomyelia starts, commonly the family has moved, hospital records have been destroyed and films are lost. Re-investigation depends on repeating the radiology, including Magnetic Resonance Imaging (MRI).

The surgeon wants to know the state of the implanted shunt. Could it be still working? Shunts commonly stop working, or they may not work so well. The plastics of which they are made denature with time and the resistance to flow may rise.

CT scans show the ventricular size but not syringomyelia. MRI will also show the cord and the ventricles and is thus the preferred investigation for syringomyelia (Fig 2-6).

In severe spina bifida patients, the problems may be difficult to recognise because the damage which has occurred to the brain before or shortly after birth has been so severe that the new features are not recognised. The problems of arm weakness and of clumsiness, with thin hands, are common in spina bifida sufferers. Likewise double vision may be a feature of spina bifida without the intervention of syringomyelia. Symptoms at the level of the dysraphism are not due to syringomyelia. Ascent of pain or the sensory loss above the plaque may occur. When there is a low spina bifida and the patient could at first walk, then the patients may complain of increased gait

difficulty. Bowel and bladder problems are usual with obvious spina bifida and change in these is not often noted.

In spina bifida occulta the presentation may include many of the syringomyelia features mentioned above and the problems may be easier to spot.

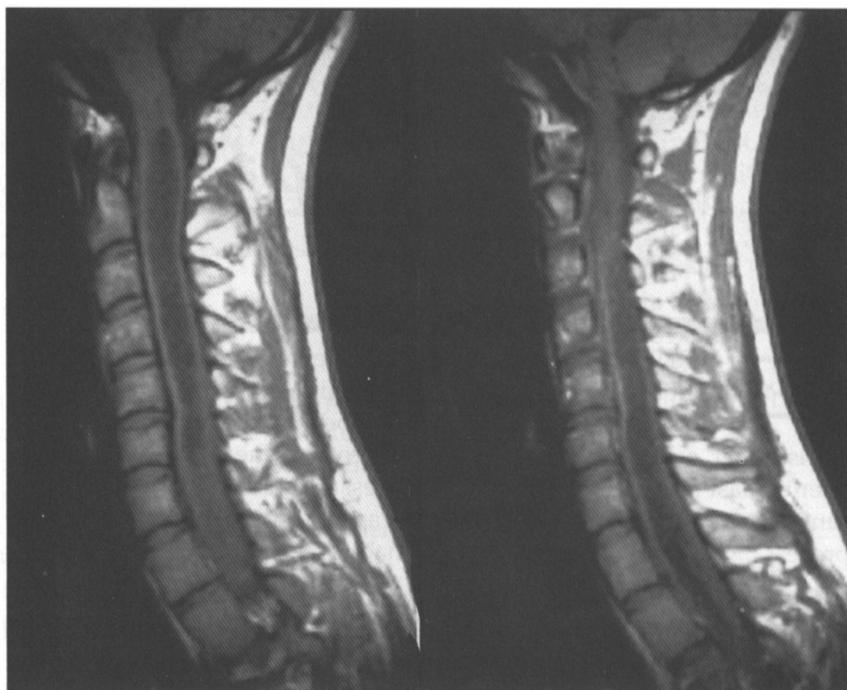
## TREATMENT

The first treatment for cases where there is a persisting element of hydrocephalus is to revise the shunt system to ensure that the CSF pressure overall is low. This method lessens the problems from the hydrocephalus and will lessen syrinx filling. Lowering of CSF pressure helps all kinds of syringomyelia.

The risks of shunting the hydrocephalus in adults when the patients are partly compensated and the structures are bigger than in babies is less than in childhood and good control is expected for the majority of sufferers. Shunting is, however, not free from risk at any age.

In cases where the problems continue after shunting, then it may be necessary to decompress the hindbrain, as described in the article on the Chiari deformity. In some cases there is no hydrocephalus but there is a hindbrain hernia. When there is a syrinx which appears to be filling from the plaque then the mechanisms involved are unclear. Such a case is shown in Figs 2-4. The treatment chosen for this little girl, aged three, was to decompress the hindbrain first. This produced an excellent result in terms of helping her leg and arm function and also a striking improvement in the appearance of the cervical syringomyelia, (Fig 3).

In a small proportion of cases, mostly spina bifida occulta patients, then the initial surgery may be on the lower part of the spinal cord. The spinal lesion itself may keep syringomyelia going and sometimes operation on the



**Fig 6.** The top of the cord in the same case as Fig 5. The fluid is shown as black on this sequence. It can be seen that the cavity extends up almost as far as the hindbrain on the left figure. The right figure shows better the width of the cavity at the bottom of the neck; it is formidable opposite the lowest vertebra shown, which is thoracic vertebra 3. The hindbrain is almost normal in this lady, certainly there is insufficient herniation to justify operation of the hindbrain.

region of the plaque is necessary. Drains may be inserted either into the syrinx cavity or else into the thecal spaces. A striking example is given in Fig 6. In this case a drainage tube was put into the peritoneal cavity. The improvement in the radiology in the neck was striking (Fig 7). and the clinical improvement was similarly impressive with the patient regaining bladder control and having marked improvement in all limb function, especially walking.

## CONCLUSION

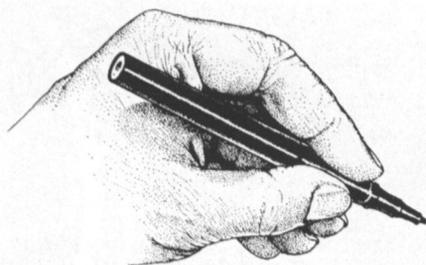
Syringomyelia is a condition of tubular cavities within the spinal cord which is likely to affect patients with any form of spina bifida. It is difficult to recognise clinically and the symptoms may be very variable. MRI scanning is the definitive method of diagnosis and surgical treatment may often be successful in regaining some of the lost function.

*A self-help group for syringomyelia of all types is Ann's Neurological Trust Society (ANTS). The secretary is Anne Lane, The Midland Centre for Neurosurgery, Holly Lane, Warley, West Midlands B67 7JX.*

*Support for the Syringomyelia Clinic comes from ANTS.*



**Fig 7.** The post-operative result in the same case as Figs 5 and 6. The cord cavity has healed and the cord is almost normal. There was a corresponding clinical improvement and this lady is probably free from any prospect of further deterioration. Her hindbrain requires surveillance in the future.



# Letters



I WRITE to tell you about a very brave young man, my son

Christopher, and his experiences over the last few months. Maybe I can help someone else in the process.

Chris has spina bifida and was 31 years old in May. He has suffered from pressure areas for many years. I think they go back to when he had a spinal fusion, which seemed to alter his posture.

Chris tried walking in calipers which came up round his chest and under his armpits. He gave these up while at school (Chailey Heritage) and decided to stay in his wheelchair due to several falls, broken legs and abrasions round his ribs.

He left home in 1990 to become more independent and moved into a residential home for physically disabled adults. Three years ago,

we received a phone call from Worthing Hospital to say Chris had been rushed in to have necrotic tissue cut away from a pressure sore on his bottom. He was in hospital for 13 weeks, and had three operations altogether.

In October last year, Chris came home for the weekend and looked particularly poorly. My wife Ellie said there was something terribly wrong (mother's intuition and mother's feel for these things).

On Sunday morning, Ellie called me into Chris's bedroom while she was helping Chris getting ready to get up, ie dressing and cleaning the pressure sore. She asked me my opinion of the wound, which was going black and getting smelly.

After calling the GP, Chris was once again taken to Worthing Hospital. After 10 days, the doctors operated to cut more bad

tissue away. After he had been in the hospital for about a month, the doctors suggested that Chris have a colostomy to divert faeces from the infected area.

Chris discussed this with us and we all agreed that, as Chris already had a urostomy, a colostomy was a bit severe. The crunch came about three weeks later when we were finally persuaded; otherwise, said the doctors, the infection would spread to the bones.

Chris was finally released into our care on 22 January after 15 weeks in hospital. At the time of writing (10 May), he is still not allowed out of bed and uses a special mattress.

The bone is now infected and Chris has got osteo-myelitis. Talking to us, he says: "Why didn't I have this colostomy done years ago?" Nobody had previously suggested a colostomy, which would have kept him clean and might have prevented his present condition.

If you print this letter, please convey our thanks and appreciation to all the staff at Worthing Hospital Ward 4, Sister Browning and Mr Matholko at Chailey Heritage, and our District Nurses at home, who all are working so hard.

Lastly, may I say how proud we are of Chris. He has never once complained about having to stay in bed all these months, and he has learned to cope with his colostomy.

*Arthur Smith  
Horsham, West Sussex*

*Editor's note: The sad story of Chris highlights the need for early bowel management. When continence management is not established, the effects include formation of mega colon and chronic constipation. Mr Smith's letter also highlights the need for independence and self-care skills to be developed before young adults move into their own homes. Colostomy is a radical option and one which ideally should and can be avoided.*

## FORTHCOMING EVENTS

**9 July** Rights for Disabled People Now! Rally, Trafalgar Square, London, 11.30am - 4.30pm. *Richard Wood, tel 0773-828182; Victoria Scott, tel 071-250 3222.*

**19 July** Claire Rayner officially opens Computer Sense Ltd, ASBAH's new computer sales and service company, Grovelands Business Centre, Boundary Way, Hemel Hempstead, Herts, 11am.

**14 September** Hydrocephalus Study Day, McKinney House, Musgrave Park Hospital, Belfast, speakers include Dr Nan Hill (consultant paediatrician, Royal Belfast Hospital) and Mr Thomas Fannin (consultant neurosurgeon, Royal Victoria Hospital, Belfast), Rosemary Batchelor (Hydrocephalus Network co-ordinator, ASBAH). *Information from ASBAH Regional Centre, 73 New Row, Coleraine, Northern Ireland BT52 1EJ, tel 0265-51522.*

**15 September** Hydrocephalus Study Day, details as for 14 September, except the venue changes to Library HQ, Omagh, Northern Ireland.

**8 October** Hydrocephalus Study Day, Gogarth Special School, Nant-y-Gamar Road, Llandudno, Gwynedd, 9.30am-3.30pm. Speakers include: Paul May, consultant neurosurgeon, Alder Hey Children's Hospital, Liverpool; Leonie Holgate, hydrocephalus adviser, ASBAH. Cost £5 each. *Mrs Lynn Thomas, ASBAH, 42 Park Road, Peterborough PE1 2UQ, tel 0733-555988.*

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