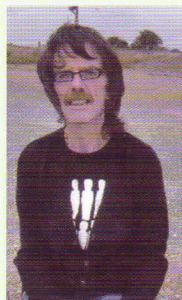


# Your Voice, Your Choice

AUGUST 2008

## Hello everyone



Welcome to the latest edition of Your Voice Your Choice.

In this issue we have a 'View from the Top' by ASBAH Chief Executive, Andrew Russell, a week in the

life of an ASBAH adviser, reports of international conferences in Cork and Lisbon and an Eastern Region study day.

There is also a report about the recent Looking Good Feeling Great event in Manchester and information about the up and coming conference entitled 'Have Wheels Will Travel' in the Leicester Marriott from Friday 31st October to Sunday 2nd November 2008.

Our focus on a YV committee member this time is on Geraint Catherall, the committee's new Vice Chair. The YV Committee wish our Chair, Paul Manning, and Geraint the best of luck in their posts. We also thank our outgoing Chair Lisa Cain for all her hard work.

Last but not least we have our new Pen Pal corner. Want to know more? Just contact Barbara Robinson, Policy Officer (User Forum). Until we see you again, enjoy the rest of the summer and remember EACH DAY IS A NEW DAY – do enjoy.

Regards

Mike Bergin

YV Committee



Hello YV...

My name is Julie Turnbull

**I am regional adviser for South and East Yorkshire, North and North East Lincolnshire, and the Wakefield area of West Yorkshire. I have been asked to give you a brief outline of a week in the life of an ASBAH adviser. I will endeavour to give you examples of a typical week but there are many other things that advisers do in the course of our work but it would read like War and Peace.**

**Monday 9am:** In the office to plan for the coming week. I check and respond to outstanding e-mails and telephone messages.

**1-30pm:** Home visit in Rotherham to meet with the adaptations officer from the local authority at the home of a 4-year-old child whose home requires major adaptations. She is a full-time wheelchair user and the plan is to build on a downstairs bedroom and bathroom and provide ramped access. As the costs involved are huge it is important that the facilities are right for the child and will continue to be suitable as she grows.

**4pm:** Back in the office to write up this visit and document the information. Three telephone messages to deal with, one of which is urgent as it is regarding the birth of a new baby with spina bifida and hydrocephalus. I have a long conversation with the nurse who is referring the baby

*continued overleaf*

**Tuesday 8.15am:** Home visits today in Grimsby and Cleethorpes so I make an early start as it is quite a distance and the motorway could be busy.

**9.45am:** I attend an annual review for a child of 7 with hydrocephalus, who has a Statement of Special Educational Needs, and the staff require strategies to help him learn.

**11am:** finds me at the home of a 21-year-old with spina bifida and hydrocephalus who wants to live independently but is having conflict with parents regarding this.

**2pm:** I visit one of my older clients who has had a successful independent life but is struggling with continence issues as she ages.

**5.30pm:** Arrive back home.

**Wednesday 9am:** Into the office to catch up with calls and e-mails from yesterday before I set off for the hospital to see the parents of the new baby. They are still a little shocked as the spina bifida had not been picked up via scan. I answer their immediate questions and leave ASBAH information and arrange to visit them at home following baby's discharge. While at the hospital I call on to the ward to see who else may be in and find two children that I know quite well, one who is having surgery the next day and the other is experiencing shunt problems so is having pressure monitoring.

**2.30pm:** sees me at the child development centre where I have been asked to attend the playgroup by the physiotherapists. There are five children attending and all of them have spina bifida. I already know four of them but the other child is new to the area so I give mum our information and arrange to visit them at home. Back to the office again to catch up with telephone calls and e-mails.

**Thursday 7am:** Very early start today as I have a 70 mile journey - I am on the team manning the ASBAH stand at a major exhibition to raise our profile. This is also a brilliant way to network and pick up useful contacts. I don't arrive back home until 6.30pm.

**Friday 10.30am:** I visit the family of a 12-year-old in Doncaster who have received renewal forms for Disability Living Allowance and have requested help to complete them because there have been several changes since the last claim.

**2pm:** and back in the office to complete the week's paperwork and catch up on calls.

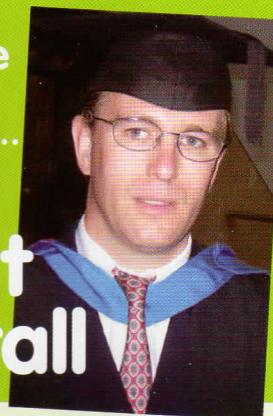
**3.30pm:** I am finishing early today.

**Saturday 2pm:** The local association are holding a fun day for families and like me to attend if I can. These events are always enjoyable and it enables me to see people who are not having any difficulties and living their lives.

**I hope this short article has given you an insight into some of the things ASBAH advisers are involved in.**

## YV Committee Member

# Meet Geraint Catherall



**I am originally from North Wales. After leaving school I studied at a local college, where I decided upon a career as a dental technician. After training for three years at Manchester Metropolitan University I gained employment at Glenfield Hospital in Leicester. I work full time in our dental department. We cover all areas of dentistry - Orthodontics (braces), crown and bridge work, and dentures. I work with five other technicians, four consultants, dentists who come from outside the hospital, and eight dental nurses.**

Outside of work my main hobby is cycling. I cycle with a club and regularly compete in time trials, at all distances from 10 miles to 100 miles and 12 and 24 hour rides. I am also a keen musician and have been learning to play the flute, having sat my grade 1 and 2 theory exams and grade 1 practical exam.

Although my parents have received 'Link' for as long as I can remember, it is only in the last four years or so that I have really been involved with ASBAH. The first YV event I attended was the 'Know Your Shunt' day in November 2005. I have since attended three other events - the sports weekend in Cardiff, employment weekend in Leeds and more recently the independent living weekend in Reading.

In joining the YV committee I hope to be able to share my experiences of employment and living independently, and to be able to contribute to ASBAH and help to improve the service for other users.

# Looking Ahead with Hydrocephalus

Study Day

By Geraint Catherall

**I attended this Conference on 14th May in Nottingham with our Chair, Paul Manning. The event was attended by 80 delegates and chaired by Dr Roger Bayston, who opened the day by describing how cerebro-spinal fluid is produced and profused through the ventricles. He discussed how Normal Pressure Hydrocephalus develops in older people, and the effects that it has on children before describing the treatments and handing out shunts for people to look at.**

**Dr Colin Dunkley, Paediatric Consultant,** then gave a presentation on the assessment and treatment of epilepsy. He emphasized the importance of taking a full case history, as misdiagnosis of epilepsy is common, and went on to discuss how epilepsy can occur after damage to different parts of the brain. He discussed different treatment options, although it is important to get a balance between treatment of epilepsy and the patient's quality of life.

**Mr Andrew McEvoy – Consultant Neurosurgeon from The National Hospital for Neurology (NHNN) and Neurosurgery and Institute of Neurology (ION) London** gave a presentation on the surgical treatment of epilepsy when drugs have been ineffective. This is not a new treatment but was less effective in the past. It now involves a team approach to include a psychologist and the latest scanning procedures. Surgery is performed while the patient is awake and language tests are carried out during surgery.

**Dr Hugh Richards Senior Research Associate, Department of Clinical Neurosciences Neurosurgery Unit** gave a presentation about the Shunt Registry. A small group in Cambridge conducts an anonymous audit of individual centres and compiles statistics to analyse data on why shunts fail. Research shows that under drainage is the commonest cause of shunt failure. Revisions due to infection are most common early on; over/under drainage is most likely to affect shunts mid term and fracture affects shunts long term. He reported that all shunts seem to have the same reliability and there is no significant difference in the success rate of different centres.

**Dr Catherine Loveday, Neuropsychologist at the Chelsea & Westminster hospital** with special interest in memory and executive functioning, talked about the effects hydrocephalus can have on a person's memory. She described how memory, attention and language are assessed, and explained how she works with people with hydrocephalus to help them develop coping strategies. Few people use strategies to overcome problems, which can range from difficulties with language, spacial awareness, learning, attention, memory retrieval and information processing. Dr Loveday explained that it is important for people with hydrocephalus to be allowed sufficient time to do things, to develop strategies to help them cope, to eat healthily and get plenty of sleep.

**Naomi Marston - Education Adviser ASBAH** discussed the transition from education into further education and employment, and the need for support and supervision. She discussed options open to people on leaving school, - further education, work or volunteering (which can help develop life skills). She reminded people about the importance of being honest about our condition, and keeping motivated and also reminded us about the information that is available on the ASBAH web site.

**Mr Richard Ashpole- Consultant Neurosurgeon – Queens Medical Centre Nottingham** discussed the future of shunts and the care of older people with hydrocephalus and normal pressure hydrocephalus (NPH). He discussed diagnosis, and symptoms associated with acute or chronic hydrocephalus. He went on to discuss the incidence, diagnosis and treatment of NPH in older people (about 5 % of elderly patients with gait (walking) disturbance, mild dementia and impaired bladder control were found to have NPH), which is often under diagnosed, but responds well to treatment.

**The study day finished around 4pm. The Your Voice stand attracted a fair amount of interest from young people with hydrocephalus and a number of parents.**



**Andrew Russell**

## A view from the top

**The influence of people with spina bifida and/or hydrocephalus (SB/H) within ASBAH, and more widely, has increased greatly in the last three years. This has been an exciting period of funding from Comic Relief to pay the salary of the part-time Policy Officer, who helps to co-ordinate and administer the group's growing activities. Although this 3-year grant finishes in July 2008, the work of YV and the key role of the Policy Officer is now so well recognised that ASBAH has offered to continue the funding from general funds.**

The main aims of the project have been to increase the number of disabled members involved, and to build up the abilities and confidence of people with SB/H. A lot of progress has been made. The number on our database has shot up from 238 to well over 400, and those who have attended the meetings and conferences have been introduced to a broad range of activities designed to be enjoyable and to stretch horizons.

Much of the focus has been on improving quality of life by encouraging interests, stressing the importance of a healthy lifestyle, a good diet, a bit of exercise, and looking good through fashionable clothes, make-up and a positive outlook. These are key factors for everyone, disabled or not, but they are often a particular challenge for young people with SB/H because of health issues, continence management, mobility problems and lack of confidence.

To combat the widespread negative images of disability and dependency, YV insist that ASBAH should consistently promote positive messages and dynamic images, to push forward towards a more inclusive society. This was the central aim of the Comic Relief "Fighting For Justice" funding programme.

A system of elections to the YV Committee (a formal advisory committee of ASBAH), has



### YV Event:

# Looking Good Feeling Great

**Location: Worsley, Manchester**

**Date: 11-13th July 2007**

### **Lisa Cain, one of the organisers writes:**

Your Voice held an event in July at the Worsley Park Hotel in Manchester. The theme was self-improvement and called "Looking Good, Feeling Great" this event celebrated the group's achievements over the past 3 years under the Comic Relief Funding. Workshops included The Body Shop, Tia Chi, Holidays, Information, Slimming World, and Confidence Building by Simon Wrigley. There was also a session on YV. Seventeen members plus organizers Lisa Cain and Jon Burke and Barbara Robinson attended the weekend. We had six new members and our first assistance dog Wesley!!

ensured that new members have joined this organising committee to participate in leading YV. This involvement has built on people's organisational skills and encouraged the disciplines of working together for a common aim, such as organising a national conference event. A knock-on effect has been that a number of disabled members have been elected as new Trustees of ASBAH and have joined the Board, so that now, for the first time, more than half the Board (ASBAH's governing body) is made up of disabled members.

This means that people with SB/H take a prominent part in ASBAH's high-profile receptions in the Houses of Parliament, meetings with politicians and with other disability organisations. YV members are now regularly travelling to international meetings to help represent ASBAH amongst the other national

**And Jan, a new YV member who was attending her first event writes:**

*"I have just come back from my first YV event in Manchester and can honestly say it's the very best thing I have ever done.*

*I live at home with my Dad who is my sole carer since my Mum passed away in 2004, and he does so much for me I was worried about how I would cope without him, but I knew it was something 'I just had to do'. My worries were completely needless and everyone from the fantastic organisers of the event to the hotel staff and all the other delegates (a lot of whom had attended other events) were brilliant. I have made some great new friends. Well done to all concerned.*

*I had the best weekend of my life!"*



**SB&H associations.**

YV's views have influenced ASBAH's policies, an example being the adoption, as a principle, of the social model of disability into ASBAH's 5-year Strategic Plan. Other policy issues raised by YV have been a concern about ageing with SB/H, and discussions about the thorny subjects of prevention of SB through the vitamin folic acid in pregnancy, and of termination of pregnancy after antenatal diagnosis of SB or H.

Perhaps the most exciting opportunity to reach more members is through the website, which is easily accessible and more interactive than ever. We hope to see more and more members joining, participating, travelling to our events, and gaining new friends and opportunities.

**Andrew Russell**  
**ASBAH Chief Executive**



## IF in Portugal...

Mike Bergin reports:

**This year's International Federation conference was held in Lisbon from 5-9 June. I was fortunate enough to attend to represent Your Voice, along with my colleague, Lisa Cain.**

The conference was opened by Pierre Mertens, President of the International Federation for Spina Bifida and Hydrocephalus.

There were several speakers over the weekend all of whom were excellent. It was interesting to find out from other people how their countries dealt with SB/H, and after listening to people from different parts of the world I realized that we can sometimes take things for granted.

It was an excellent conference and the title of it was Drawing Smiles. The whole experience certainly made me smile! We were made to feel very welcome by Luis Quaresma (President of the Portuguese Association) and his lovely wife Wanda who did so much over the weekend. Wanda is a tour guide of Lisbon and she gave us a great tour of the city. The conference was an excellent example of people working together.

Thanks also to our Policy Officer, Barbara Robinson. Without her hard work we would not have been able to attend.

**Mike Bergin, YV Committee member**

*A full report from Lisa on the conference can be found on the YV website:*

[www.yourvoicegroup.co.uk](http://www.yourvoicegroup.co.uk)

Mike Bergin (left) meets Pierre Mertens (right) and Luis Quaresma (middle).



Your Voice presents

## Have Wheels Will Travel

Date and venue:

Friday 31st October to  
Sunday 2nd November 2008

Leicester  
Marriott

**Book NOW**

Weekend delegate rate £95  
includes accommodation,  
workshops and meals.

Day delegate rate £30  
(Saturday 1st only)  
includes workshops  
and lunch.

Email: [barbarar@asbah.org](mailto:barbarar@asbah.org)  
Telephone: 01733 421322

**Up and coming  
YV event in 2009**

**Lifestyle & leisure**

A focused day event in South  
Wales March 2009

# Pen-Pal Requests

Since our last Newsletter we have received three requests for a pen-pal:

My name is Sian Phillips. I am 39 years old. I would like to have a pen-pal/pals. I would like to write to a male or female aged 30 onwards. I like reading true stories, watching TV (especially soaps) and writing letters. I work full time but still have lots of time to write back to anyone who would be interested in writing to me.

I have been married for four years. My husband's name is Richard. He is 43-years-old. He is able bodied. We have a Yorkshire terrier called Paddy, who is ten-years-old and very spoiled.

I am interested in the pen-pal service. What sort of person? Male or female, any age. Hobbies/interests: *music, meeting people, films, the normal things.* **C. Drury**

Joy Jones would like a pen-pal, male or female with spina bifida/hydrocephalus, age range 35-45. Interests: reading, creative writing, pop music and competitions.

***If you'd like to be a pen-pal to any of these people, send your letter to them c/o Barbara Robinson, who will forward it on to them.***

## Your Voice goes International

Report from Paul Manning on IASBAH's 40th Anniversary Conference in Cork.



**I left Aberystwyth to go to the Port of Fishguard to catch the 14.30 ferry to Rosslaire. I arrived early and joined the queue in the heat wave.**

We docked at 17.30 and I started on my way to Cork. It had been a while since I had been in Ireland and had forgotten about the 3rd lane they have there. I soon learnt that I was meant to pull into it whilst still driving if someone wanted to pass or someone was passing going the other way. It was very confusing!

By the time I got to Waterford it had started raining as well! I arrived in Cork at 21.00 but it took time to find the airport and the hotel. To top it off I was given a message to join the CEO and his colleagues for dinner (at 8pm!). They were just walking out as I went in!

After breakfast in a lounge resembling an aircraft, we got on a bus to go the 20 minute drive to the Radisson which was hosting the conference.

The Friday session of the conference was billed as the Professionals Day. The conference was opened by IASBAH's Honorary Chair Fiach McDonagh. Then George Kennedy the CEO explained the day and spoke in English and Gaelic.

The 1st speaker was Dr Timothy Brei who is a recognised expert in diagnosing and treating children with disabilities. He has written and presented on the subject. Dr Brei himself has spina bifida.

His subject was outlining medical issues for people with SB & H. He explored how professionals interact with individuals and how the professional's own attitudes / values may affect this working relationship.

Next up was Dr Sylvia Dockeray, a Registrar from Cork, speaking about progression from paediatrics to adult services – what is happening in Ireland today. She discussed the medical system that is available to individuals with SB & H in Ireland.

*continued on the back page*

The transition from paediatric to adult services in the Irish healthcare system is still a sensitive issue that causes concerns for many young adults, resulting in a large number of individuals "slipping through the net".

Next was Trish Bartley who spoke on "Reducing Stress through Mindfulness". Trish has over 20 years' experience of working with individuals, groups and organisations facilitating learning and development. Trish is an experienced mindfulness instructor.

Trish showed how mindfulness-based approaches use ancient awareness practices, to form the basis of well researched psychological interventions to help people face stress and difficulty, by learning how to tackle problems differently.

The morning session finished with a panel discussion, with the audience asking questions to the speakers.

After lunch, Pierre Mertens, President of the International Federation of Spina Bifida, spoke about how the quality of life for people with spina bifida and/or hydrocephalus had improved considerably over the decades.

Pierre's explained that IFSBAH is campaigning for all of Europe to fortify flour with folic acid. He gave an update on what is happening around the world and how it has impacted on the amount of babies born with neural tube defects.

Kathy Sawin, a professor and Research Chair in the Nursing of Children, from Winsconsin, USA did a session on "Striving towards Independence". She looked at the point that parents, families and young adults are experts in self management and independence for their situation.

Next was a session on Relationships and Sexuality by Olga de Wit a young psychologist and newly qualified doctor with SB & H. There followed a Panel discussion where the audience could ask questions.

The official welcome by the deputy Lord Mayor of Cork followed at 19.00.

At 20.00 was the optional entertainment but most people stayed and enjoyed themselves till late.

The Saturday was themed as the Family day. First up were Scott and Patrick Price from the USA who did a session called "Looking for Goodwill". Has there ever been good news? Intrigued by that question, father and son undertook an inspiring nationwide search of the USA for goodwill. Next was Timothy on the subject of seeing yourself through able eyes, followed by a question and answer session on the morning's sessions.

After lunch the conference broke into 3 groups:

1. Relationships and Sexuality for 16+ yrs – without parents, by Olga
2. Reducing Stress through Mindfulness by Trish Bartley.
3. Parenting / Promoting Independence and Caring for Carers by Timothy Brei and John Keane.

Then the Youth Forum met and I joined them as they discussed what is happening in their part of Ireland on certain topics like employment, social issues, transport etc. At the end of the session I was asked to introduce them to Your Voice and what we do. I left some copies of our newsletter and contact details and even the thought of doing a joint IASBAH / Your Voice event.

To finish the Conference there was a Catholic Mass celebrating 40 years of IASBAH's work. I was asked to present a candle at the altar on behalf of ASBAH.

After this was the Gala Dinner and a jolly good meal it was – even though I wasn't sure at all times what I was eating. After dinner there was a lengthy period of presentations during which everyone was thanked.

Next it was time for the band to play some songs and the evening finished with a disco. We got back to our hotel about 02.30!

Sunday saw everyone getting up, and having breakfast. The AGM of ISABAH was being held, but I had to give my apologies, as I had to catch my ferry from Rosslaire.

I arrived in Aberystwyth just before 1900, tired but a weekend well worth doing!

**A copy of the full report of the Conference can be obtained from Barbara Robinson.**



association for  
**spina bifida  
hydrocephalus**  
ability beyond disability

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