

YOUR VOICE

NEWSLETTER

OCTOBER 2007



Welcome to the first issue of the Your Voice newsletter which will keep you in touch with YV news and events.

We've included a wide range of articles which we hope will interest you. Of course we're keen to hear your views and suggestions for items for future issues... so please get in touch.

The articles this time include a write-up on our recent event in Birmingham "Ageing Disgracefully". There's also news of the next event in November in Reading.

As you can see the newsletter hasn't yet been named, so we're running a competition to find a suitable title.

To enter send your suggestion to - Name our Newsletter, Barbara Robinson, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ.

Closing date for entries is 1 January 2008

I hope you enjoy reading the newsletter and find it informative and enjoyable.

Best wishes

Lisa Cain

Chair of Your Voice



Ageing Disgracefully

By Michael Bergin,
YV Committee member

This year's summer Your Voice event at Jury's Inn Hotel in Birmingham city centre attracted plenty of interest... there was even a waiting list for places.

The conference, Ageing Disgracefully, was held from Friday 10 August – Sunday 12 August, was very successful with lots of positive feedback.

The 20 delegates arrived just after 3pm on Friday, some were accompanied by carers, who were all catered for as well. It was great to see a variety of ages.

Everyone enjoyed a lovely three course dinner that evening, which was followed by a welcome meeting hosted by chairperson of Your Voice, Lisa Cain, committee member Michael Bergin and policy officer of the user forum, Barbara Robinson.

Saturday's proceedings got under way with our first speaker Mike Long of the University of the Third Age (U3A). Mike explained how U3A works and how to get involved.

After a short break for tea and coffee, we listened to a talk by Mary Kirkham, an advanced nurse practitioner in Urology, who was awarded oncology nurse of the year for her work with patients living with urological cancer in 2005.

Everyone enjoyed Mary's in-depth presentation on the aging bladder and she answered many of our questions.

Next up was Sue Frost, a bowel nurse specialist for 17 years, who gave her talk on a new revolution in bowel management - try saying that last thing at night after a few glasses of wine!

After lunch the second session began with ASBAH's Rosemary Bachelor whose talk focused on health issues as you get older.

Before the coffee break Mel Cox, an NHS community dietician spoke about the importance of healthy eating.

Saturday's programme ended with an art demonstration by Mike Thompson entitled 'Easy as 1-2-3'. He showed everyone how to use just three colours and mix all other colours that are needed from them. Mike did a beautiful painting of a landscape scene, assisted by Keith Collins of 'Your Voice', who recently joined one of the classes Mike runs. They donated the painting to 'Your Voice' but more about that later.

After dinner delegates were left to their own devices. Some people went to the cinema, others ventured out on to Broad Street while several retired to their rooms. Undoubtedly everyone enjoyed themselves.

Sunday was our last day and while it may be described as a day of rest, there were no lie-ins for us.

First up was Maggie Pickard; a course director for the Extend fitness organisation. If anyone thought they could escape they were wrong as Barbara was on door patrol! *continues overleaf...*

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Maggie encouraged everyone to try out some simple stretches to get their circulation going. Some people hoped Maggie would get going...only joking Maggie! Everyone appreciated your presentation.

There was no time for breaks as next up we had Yvonne Davies, chief executive of Birmingham's Citizens Advice Service.

Yvonne gave a very good talk and offered some excellent advice about different benefits. Once again there were lots of questions asked – and Yvonne answered them with ease.

The event ended with 'Your Voice' information and a feedback session. This was followed by lunch.

Oh and about that painting of Mike's... we put all the names into Mrs Robinson's bin for a prize draw. The winner was Jeannette Prentice - another happy delegate going home with a wall mounted painting.

As this conference was over-subscribed we hope to repeat this event, however next year's events have already been decided and so it will form part of our planning for the future.

The conference itself took a great deal of organising and was organised by Lisa Cain, Mary King, Paul Manning and myself Michael Bergin. We had great help from the one and only Barbara Robinson and all photographs were taken by Peter Farrall, director of marketing and communications for ASBAH. Sadly Paul was unable to attend due to ill health -get well soon Paul - and Mary had a prior engagement.

On behalf of 'Your Voice' I would like to thank everyone for coming and hope you all got something from the weekend. A big thank you to Lisa and Barbara who did so much over the weekend you girls were both so great.

We look forward to seeing you and new people again soon. That's it from me I am off now. Be happy, enjoy life and remember each day is a new one.



Meet... Paul Manning

In each issue we will profile a member of the Your Voice Committee. First under the spotlight is Paul Manning, who joined the committee following the November elections and was elected Vice Chair.

Paul, from Ceredigion in mid Wales, has been involved with ASBAH's work locally for about 12 years and held the post of Chair of the local association for around seven years.

Over the last few years he has also been very active with the ASBAH Cymru (Wales) Advisory committee, of which he is Vice Chair.

Never one to take things easy, Paul has attended many Your Voice events, in Cowbridge, Leeds and York. He has also provided valuable technical help at these events making sure the right cables are connected... "Blue to Blue and wiggle it".

Paul also has the honour of being the first committee member of Your Voice living in Wales. The Welsh cause is close to his heart and he has always been keen to hold a Your Voice event in Cowbridge, south Wales.

Paul hopes to put across the voices and views of the Welsh as some of the government departments are run by the Welsh Assembly Government instead of Central government in London.

Paul said: "I joined the committee because I wanted people in Wales to have more of a say. "I hope to bring hard work and good humour to the group and to play my part in helping Your Voice grow from strength to strength and be more accessible and available to the wider membership"

Paul has a full-time position as Support Worker with people with learning disabilities in a community home where staff help them to live as independently as possible.

He is also a familiar face at his local MENCAP society where he has been their Social Secretary for the last 10 years organising parties on a quarterly basis for the whole of the county and runs the weekly swim group for people with learning disabilities.

Paul has been involved for the last 10 years in the local Gateway Club – a leisure group for people with learning disabilities.

Who will it be next time.....?

Ugand

By Jon Burke

I represent ASBAH on the board of The International Federation for Spina Bifida and Hydrocephalus (IF), which is the world-wide umbrella organisation for Spina Bifida and Hydrocephalus (SB/H) organisations.

The IF works with spina bifida and hydrocephalus organisations in more than 50 countries across five continents.

The federation was set up to improve the quality of life of people with spina bifida and hydrocephalus throughout the world and to reduce the numbers with these conditions through primary prevention.

Part of my role on the board is to attend the IF annual international conference which this year was in Kampala, the capital of Uganda, East Africa.

The conference is held in Europe every two years and then another part of the world in the years in between.

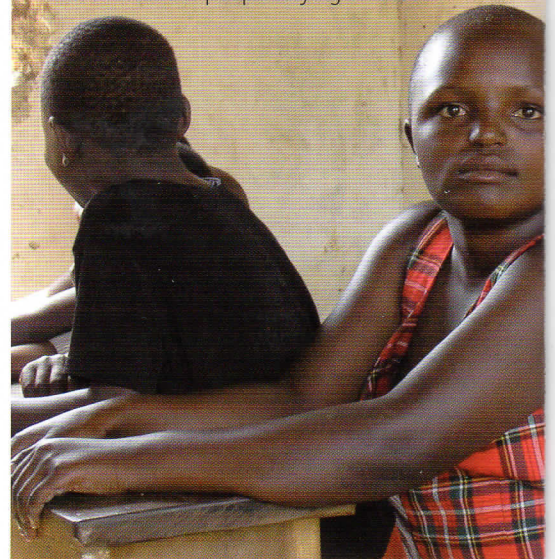
More than 150 people from 21 countries participated in the conference. The main emphasis of the event was prevention of spina bifida and secondary disabilities, but it was also a fantastic opportunity to learn about facilities and opportunities for people with sib/h in that area of the world.

But what were those facilities like? Before I set off for Uganda I was warned not to expect things to be like home and I found that was certainly the case.

Healthcare is very basic, education is extremely limited for most, there is no accessible public transport, there is nothing like the Disability Discrimination Act protecting the rights of disabled people and there is no financial help from the government for people who find it difficult to work.

So does that mean Ugandan people with sb/h are sad about this situation and feel sorry for themselves? Oh no! The people I met were some of the most pro-active, resourceful and optimistic disabled people I have ever met.

There is no hint of people relying on the

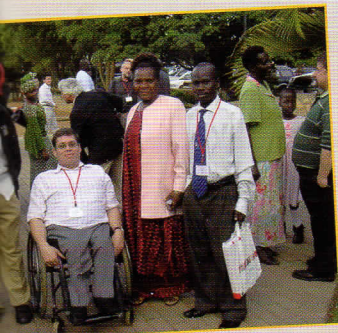


a conference

state to provide them with enough money to live on, because they know the government simply isn't able to do this.

Consequently there is a strong sense of doing what you can for yourself, because no one else is going to provide for you. I think a lot of disabled people from the richer European countries could learn an important lesson from that.

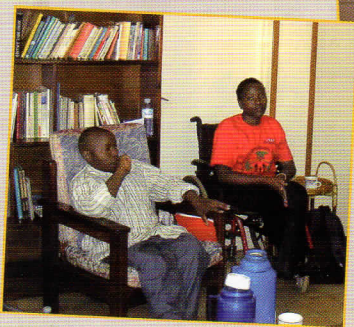
There is no question that the highlights of my trip were related to the people I met and below are pictures of some of them.



Geoffrey brought his mum and dad to the conference and this is us during one of the breaks. During the adult workshop that we held at the end conference, which I helped to organise,

Geoffrey talked about the discrimination he'd faced because he looked different and he found some tasks difficult because of his hydrocephalus. But he also talked about his determination to get a decent education, because he knows that is the only way he will be able to lead a good life.

Billy and a friend came to the conference with a group of people from Kigame Children's Hospital in Kenya. They travelled for 14 hours on a bus that



broke down twice on the way there. However, you will be glad to know they got home, because I've heard from them since! Billy and his friend are members of an integrated basketball team at home and Billy kept challenging me to go one on one with him. But my basketball days are long gone and I knew I wasn't up to the challenge.

Lastly I want to tell you about Katalamwa, a rehab centre for children needing neuro or orthopedic operations which is a project IF helps to fund. It provides different medical, psychological and social support to children with spina bifida and hydrocephalus and other disabilities and it is the only centre of its kind in Uganda.

This is Joanita (left). A couple of years ago she was very sick and could hardly walk and missed a lot of school, because of hydrocephalus, which had gradually grown worse ever since it had appeared

ten years ago. Now, at 14, after an operation in January 2006, she attends the village school and shows great skill at reading, writing and drawing. Joanita is rapidly catching up, her favourite subject is science, she has learnt a little English, and her dream is to be a lawyer.

At Katalamwa, in addition to medical support, they have a workshop where they provide a wide variety of mobility equipment, prosthetics and footwear for people using the centre.

You can imagine my shock when I saw a donated wheelchair, exactly the same as I used to have about 20 years ago. But they don't only accept wheelchairs that people from other countries no longer want - they prefer to build their own out of locally available products and to a design more suitable to the local terrain.



An example of this chair is shown below, being modelled by one of the stars of the conference. We all know how much difference it can make to have a decent wheelchair or footwear, so I came away from Uganda determined to help fundraise for the workshop at

Katalamwa, and if you would like to help me with this please contact Barbara Robinson at ASBAH on 01733 421322 or email barbarar@asbah.org

Overall, my time in Kampala was an unforgettable experience, and it was particularly a special privilege to meet such resourceful, friendly and positive people.

My lasting impression of Uganda was of a place and a people that were very welcoming and did whatever they could to make our stay the great experience it was.

Even when visiting the towns, away from the conference, I was far more conscious of being a European visitor than being a disabled person. In this way I sometimes felt more accepted and welcomed than I would do even in here at home in the UK.



The highs and lows of fundraising

By Keith Collins

After receiving ten years of excellent support and advice from ASBAH, I decided to organise a fundraising event to say thank you to the organisation.

After running a very successful fundraising evening for a local hospice six years ago I settled on using the same ideas which had worked so well first time round. My plan was to organise an evening of entertainment which would encourage the audience to participate in giving more monies to a very worthy cause. I was aware, however, that most people are familiar with hospices, and know of the valuable work they do. Although ASBAH services the whole of England, Wales, and Northern Ireland, it is a lesser known organisation.

I chose to hold the event on August Bank Holiday Monday. With the benefit of hindsight I realise that this was a mistake. Too many people were away or had other commitments. That said, the feedback from those who did attend was extremely positive and I have been asked if I'm planning a similar evening again - not for some time I think. As anyone involved in event planning knows, it can be very stressful work at times.

Nevertheless the evening went well and to date we have made over £1200 for ASBAH. Thank you to all who helped to raise this sum for such a worthwhile cause.

ASBAH's Chief Executive,
Andrew Russell, writes:

Keith's event raised well over £1,200 for ASBAH, which was a huge success and well ahead of our expectation. We're grateful to Keith for using his many contacts, and for single-handedly working to create this wonderful evening of entertainment.

News from the committee

Your Voice committee members brushed up their skills at training day earlier this year.

The intensive session, held in Birmingham on Saturday 19 May, was run by Pauline Nugent, and was aimed at finding democratic and inclusive ways of using the combined talents to progress work of 'Your Voice' committee and ASBAH.

Many subjects were discussed ranging from committee roles and responsibilities, ASBAH committee development plans, scenarios and feedback.

The 11 committee members who attended voted the day very successful and worthwhile.



YV Questionnaire

Thank you to everyone who responded to the YV questionnaire which was sent out in March this year. We really appreciate you taking the time to fill it in.

We received more than 110 responses, with 54% of the responses coming from people aged 31-50 living in urban areas.

30 people who returned their questionnaire told us that they had never heard of Your Voice. We hope that this newsletter will address this and make people more aware of the group and its activities.

When we asked what would improve your life long term and what is your most important social need the top five responses were:

Transport	(13.3%)
Help socialising	(12%)
Personal care and/or support when out	(10.5%)
Better medical care	(8.8%)
Need for adaptations or equipment	(7.6%)

The questionnaire also asked what sort of events people would be interested in attending. There were 38 suggestions for leisure and social events, 26 for lifestyle and confidence and 16 for medical.

The Your Voice committee is really grateful for this information and we plan to use it when developing future campaign issues and events.

Don't miss the next Your Voice conference

Planning for Your Voice's next conference – Moving on Up - is already well under way. The event will take place at Wokefield Park, Mortimer, Reading, Berkshire from 2nd to 4th November 2007.

The conference will focus on independent living, housing and finance. Speakers will include:

- Paul Gamble, Assistant Director of the Housing Association Habinteg -Housing options.
- Liz Dunscombe from Credit Action - Budgeting.
- Caroline McAleese from Action for Advocacy (the central point of information on independent advocacy in England and Wales) - Independent Advocacy to support you to make decisions and access what you are entitled to

Your Voice presents

Moving On Up!

Come along and pick up lots of advice on independent living

Open to all adults (aged 18 and over)

Date and venue:

Friday 2nd November to Sunday 4th November 2007

Wokefield Park Hotel
Mortimer
Nr Reading

Reserve your place NOW

£95 delegate rate including two nights accommodation, breakfast and buffet lunch. Evening meals on the Friday and Saturday only.

The delegate rate is subsidised by Your Voice

Discussion points and speakers on:

- Housing options
- Individual budgets employing and working with personal assistants
- Benefits and living independently
- Advocacy support
- Budgeting
- Personal perspectives from disabled people

Details of the precise content to be confirmed

For further information and to reserve your place contact:

Barbara Robinson
ASBAH House
42 Park Road
Peterborough PE1 2UQ
Email: barbara@asbah.org
Telephone: 01733 421322

association for spina bifida hydrocephalus
ability beyond disability

Registered charity no. 249338

Other professionals and disabled people will also be on hand to share their expertise and experience.

The Your Voice committee organisers have arranged minibus transport from the local station to the hotel on a first come, first served basis.

The last Your Voice conference was over-subscribed, and members are advised to book their place early.



For further information please contact:

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