

Bonnie Serdecki, 5, from Stamford, Lincs helps to celebrate ASBAH's 40th anniversary at a balloon release of over 3,000 sponsored balloons in Peterborough



Connect

Welcome to the fourth issue of *Connect* – a quarterly news and information bulletin for ASBAH Local Associations

Helpline ready for take off thanks to Big Lottery Fund

ASBAH has made a huge step towards its Helpline and Information Service Appeal target in its 40th year thanks to a massive grant from the Big Lottery Fund.

News of the funding – worth £224,000 over three years – was announced in March to the delight of ASBAH staff.

Now the team is working to get both the technology and staff ready for the proposed project start date of 1 June 2006.

The funding will now allow ASBAH to ensure that details of its Services are present at every point of diagnosis of either spina bifida or hydrocephalus.

This could be at the point of an ante-natal scan; premature birth; or – later in life when normal pressure hydrocephalus is diagnosed or a spina bifida occulta affected spine begins to cause problems.

Over the years ASBAH knows that on many occasions families say that they only learn of ASBAH and its support from a chance remark by medical staff or referral from someone else.

Now ASBAH will have the resources to reach out to everyone affected by spina bifida or hydrocephalus.



LOTTERY FUNDED

Mary Malcolm, Assistant Director (Services) told Link: "Everyone was obviously thrilled to hear that we'd been given funding for the Helpline and Information Service.

"There is a lot of work to be done to meet our proposed launch date, but it is a very exciting time."

The technology and systems are already in place so the first major task will be to recruit staff and decide on a location for the office.

Mary added: "We initially plan to recruit and train two part-time staff to man the helpline. Obviously the amount of training needed will depend on the experience and knowledge of the people we employ, but we do intend to run an ongoing training programme for them."

The operators will be expected to deal with a huge variety of calls, providing help and support on all aspects of spina bifida



Two more Compact signings

Two more local associations have signed up to the Compact, bringing the total number to more than 20.

Both the Greenwich & District and Leicestershire local associations voted to sign up to the agreement, designed to bring all local associations together with ASBAH to offer better information and services for everyone affected by spina bifida or hydrocephalus - wherever they may live.

The agreement, which was launched in 2005, is improving standards both at ASBAH and within the local associations, to benefit everyone involved, particularly those with spina bifida and hydrocephalus, their families and carers.

Alison Twomlow, secretary of Leicestershire, said the committee voted unanimously to sign up to the Compact in December.

She said: "We would have signed up earlier - it was just a matter of getting everyone together at one time to discuss it.

"I think everyone felt that signing the Compact was really the only way forward and it will bring benefits to both our association and ASBAH.

"We're quite a dependent group because we don't have an adviser in the area, so hopefully we'll gain through the sharing of information."

Her views are shared by Margaret Myers, secretary of the Greenwich & District local association, which serves more than 80 families.

She told Connect: "It did take us a while to make the final decision to sign the agreement. We did want a while to think about it in detail and also it was simply a matter of getting the committee together at one time to vote on the matter.

"It was very much a unanimous decision and the committee members all believe it to be of benefit to us and to ASBAH. It should certainly improve the lines of communication between everyone.

"It has also served as a reminder to us that we can get more information and help from ASBAH."

If your Local Association would like to sign up for the Compact, Agreement, forms and details are available from Peter Farrall at ASBAH, Tel 01733 555988 email peterf@asbah.org

Local associations for the benefit

Local Associations that close can consider passing on their funds to ASBAH, safe in the knowledge that their hard earned money will continue to help people with spina bifida and/or hydrocephalus in their area.

Financial help continues in South Wales

Substantial funds from the South Wales local association, which closed in 2005, are now in a restricted fund with ASBAH. The money from fundraising and local legacies can only be spent on people in South Wales, enabling the local association's invaluable work to continue even after its demise.

Brenda Sharp, the retiring Chair of the South Wales Association for Spina Bifida and Hydrocephalus, was a member when this local charity was formed over 40 years ago. She said "Our local association started before ASBAH, when parents felt they needed to support each other. Today families and individuals receive help and support from many areas including ASBAH."

"In the last few years it became very difficult to find new people to take over the running of the association and so at our AGM in 2005 it was agreed that we should fold."

"But people in the South Wales area won't lose out. Our service users still need assistance and so we have placed our remaining funds with ASBAH to ensure that help will still be available."

Brenda added "All the financial help that we have provided in the past years including grants for a wide range of needs and money towards the costs of the ASBAH Regional Adviser and the Wales Regional Office will continue whilst the funds remain."

"Of course it is very sad to see your association close after so many years, but it became inevitable because there were so few of us running it."

Brenda first became involved with the local association in 1965 when the social worker she worked for began a social research project into babies with spina bifida.

"It started when the project put parents with children with spina bifida, in touch with each other and the association grew from there."

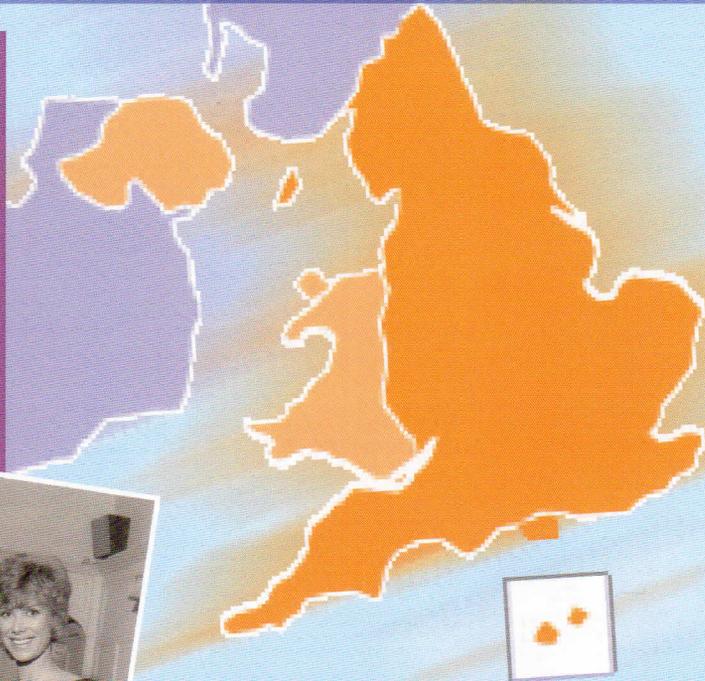
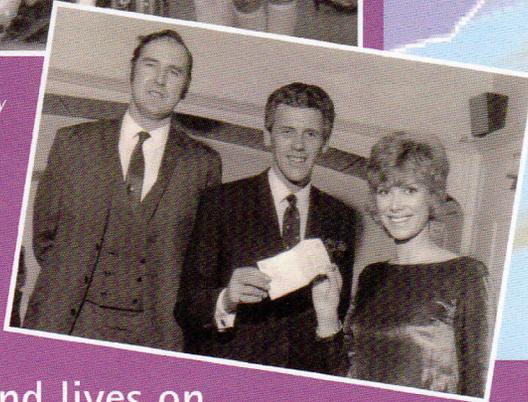
Brenda was one of many who became involved with the South Wales association. She moved away to train as a social worker but on her return to South Wales resumed her membership, becoming Secretary for 20 years and then Chair for the past 4 years. She continues to be a member of the ASBAH Trustees Board, a position she has held for over 18 years.

ions funds: of local people



Joint founders Tony Bassett (left) and Erik West with actress Wendy Craig

Erik West pushing Wendy Bassett in her wheelchair at one a Staines and Hounslow Christmas fair in the late '60's.



The Wendy Fund lives on

Service users in the Staines and Hounslow area will continue to benefit from local association funds even after the group's recent closure.

The Wendy Fund, named after Wendy Bassett, daughter of one of the founder members, has now been passed to ASBAH's South East region office, ring fenced for local use only.

Tony Bassett, who helped to launch the local association in 1968 with co-founder Erik West, explained that the funds will be spent in the way they always have... directly helping families and individuals in the area through grants and by helping to fund the local adviser.

Tony told Link: "It was always very important to us that any money raised should be given directly to the family, mainly as a contribution towards special equipment or towards a holiday in a hotel, to give the parents a real break.

"I'm obviously very sorry to see our local association close after all these years, but due to ill health, treasurer Pam Page and I wanted to step down, and there simply wasn't anyone interested in taking over these roles.

"But it is some consolation to know that our money will still be used to support people in the area, and we're happy to continue fundraising to keep the money topped up."

Tony helped to set up the Central and North London association in 1964 when his eldest daughter Wendy was born with severe spina bifida and hydrocephalus.

"There was no real support in those days and very little was known about the condition," he explained. "We covered a massive area which stretched from Staines to Southend. Parents were thrilled to meet others in the same situation and dozens would attend the meetings.

"As membership grew we formed the Staines and Hounslow group in 1968. In those days it wasn't unusual for 50 or 60 parents to turn up for meetings."

Wendy sadly died in 1985, just before her 21st birthday, and The Wendy Fund was set up in her memory.

Tony, who continued his work with the association, said: "The work we were doing was still so important and we had benefited so much from the association ourselves, that we felt it was important to continue."

Many stalwarts of the association have received awards for their efforts over the years. Erik West has been made a Member of the Royal Victorian Order while Tony, Pam Page, Josephine Beaumont and Kathy Hance have received the Spelthorne Civic Trust Award for services to the Community. Francis Overman and Kathy Hance have been awarded Nationwide Building Society's Certificates for their voluntary work.

Tony added: "The help and support parents and ASBAH have given each other has been invaluable and my wife Deana and I are pleased to think that our work will continue through The Wendy Fund."

and hydrocephalus - from antenatal enquiries, health and social care, education, transition to independence, through to bereavement support. Specialist medical queries will, however, be

passed straight on to the medical advisers.

Some of their work is expected to be sign posting - using the extensive database to give callers contact details of ASBAH area advisers and local agencies or organisations that can directly help.

Mary said: "The helpline will be a fantastic addition to the

broad range of services ASBAH already offers. Whenever people pick up the phone we want to make it as easy as possible for them.

"A one-to-one conversation can do so much to allay people's fears and put their minds at rest. Knowing that there's someone at the end of the phone can be reassuring."

Mary added: "We imagine that the majority of calls that come through to the Helpline will be quick queries or questions where our operators will be able to point them in the right direction for the help they need.

"But until it is up and running, we can't make too many assumptions - it's really a case of wait and see."

From the Chairman...



I am delighted and honoured to continue as Chairman in ASBAH's 40th Anniversary year.

I know you are all familiar with ASBAH's distinguished history during which many tens of thousands of individuals and families have received a huge range of support and help from ASBAH advisors.

But I am also conscious of the difficulties that so many families have experienced over the years and it is gratifying to know that the ASBAH team has always been there for them.

The 40th anniversary year is not just a time for looking back, but also the perfect opportunity for us to take stock of ASBAH's position. We can look forward to the many challenges facing our service users and their families and examine how ASBAH can respond to those challenges.

ASBAH has just completed its new 5 year Strategic Plan to 2011 which reaffirms its commitment to service users. The Plan will ensure that ASBAH continues to give the advice, help and direction they and their families need to ensure they can get the most out of life.

After much discussion we also recently put together our response to the National Service Framework for Long-Term Neurological Conditions. For the first time in government policy, these conditions are identified as worthy of attention and quality services. It may only be words on paper at the moment, but it gives us a definite goal to work towards both, nationally and locally.

Almost three quarters of our affiliated local associations have now signed up to ASBAH's 'Compact' to ensure that both locally and nationally, ASBAH is able to have a bigger voice on behalf of all of our service users.

One particularly exciting piece of news in our 40th year is the

£224,000 award from the Big Lottery Fund to create and run, for three years, our national Helpline and Information Service. This helpline will mean that everyone affected by spina bifida or hydrocephalus will benefit from an additional source of information and support. Local associations can play their part to ensure that details of Helpline are there, at the point of diagnosis in their area. The Helpline will make ASBAH accessible to more people than ever before.

With our adviser network, our website and soon, our Helpline, ASBAH's service provision to individuals, families and carers; and to medical, education and other professionals has never been greater.

But a charity is only as effective as the people within it and I know that without the ongoing commitment and professionalism of the local associations, ASBAH staff and trustees, we could not achieve our aims. So I give my grateful thanks to you all.

My thanks also go to the trusts, companies and individual donors who give the huge financial support which enables ASBAH to carry out its vital work.

So ASBAH can not only enjoy celebrating this milestone anniversary year, but just as importantly, with all your help, we can all look forward to an even more successful future.



Richard Astle, ASBAH Chairman

 **ASBAH**
1966-2006 Challenging the future
Association for Spina Bifida and Hydrocephalus

What would you like to see?

Please get in touch with your stories and pictures for *Connect* and send them to Peter Farrall, ASBAH, 42 Park Road, Peterborough PE1 2UQ or email peterf@asbah.org