

Su Scurr, with her daughter Bryony who has spina bifida, believes that all women would benefit from flour fortification



Connect

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Welcome to *Connect* – a quarterly news and information bulletin for ASBAH Local Associations

Add your voice to folic acid debate

ASBAH has welcomed scientists' recommendations for the compulsory fortification of white flour with folic acid within the UK and hopes local associations and their members will lobby their MP and local media to add their support to the campaign.

The report by the Scientific Advisory Committee on Nutrition (SACN) said that adding folic acid to bread or flour is the most effective way of protecting pregnant women against neural tube defects.

Each year up to 1200 pregnancies in the UK are affected by Neural Tube Defects – 85% of which result in termination. Around 150 severely disabled are born with spina bifida. Taking folic acid supplements, at the correct dose, could prevent over 75% of these pregnancies from being affected.

The Food Standards Agency launched a 13-week public consultation – which ends on 13 March – setting out options for improving the intake of the vitamin folate for young women.

The mandatory addition of folic acid to bread or flour is one of four options being considered by the agency.

Others options being considered are: to continue the current policy of advising women to take folic acid supplements before conception and during early pregnancy; stepping up efforts to encourage young women to eat more folate; and encouraging manufacturers to voluntarily fortify more foods with folic acid.

The FSA will take account of SACN's report plus responses received during the public consultation before advising health ministers on the issue next year.

Chief Executive of The Association for Spina Bifida and Hydrocephalus, Andrew Russell, commented:

"A recommendation of the Scientific Advisory Committee on Nutrition to implement mandatory flour fortification means that at least 300 lives a year could be saved. About 1,000 abortions are carried out each year in the UK and 150 children are born severely disabled, due to neural tube defects.

"Adding a small measure of the vitamin to flour is not "mass medication" but responsible nutrition policy and accepted public health practice in the USA and 38 other countries that have already

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Have your say

ASBAH is calling for all service users to add their support to the campaign for the mandatory fortification of flour in the UK.

In early January all local associations will be contacted for help in preparing their case locally.

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introduced flour fortification. Significant health benefits have been seen including reductions in heart disease and stroke and a dramatic fall in the number of spina bifida - affected pregnancies.

"Unfortunately relying on women to plan their pregnancies and take a folic acid supplement in advance is unrealistic in many cases.

"Former fears that folic acid could "mask" vitamin B12 deficiency in the elderly have now been disproved. The Food Standards Agency's scientific committee, SACN has studied the evidence and concluded that flour fortification would be both safe and effective."

Andrew added, "Moreover since thousands of Americans have taken folic acid in supplements for decades, there is over a billion person-years of experience of folic acid supplementation, with no evidence of any harm from the vitamin, only benefits."

For more information about the mandatory fortification of flour log on to:

Association for Spina Bifida and Hydrocephalus	www.asbah.org
Food Standards Agency	www.food.gov.uk
Scientific Advisory Committee on Nutrition	www.sacn.gov.uk

CASE STUDY

Mother Su Scurr, whose daughter Bryony, 6, has spina bifida, believes that the fortifying flour with folic acid would help reduce the numbers of babies being born with spina bifida in the UK each year.



Su, from Tiverton in Devon, said: "Many women do take folic acid if they are planning a pregnancy, but many pregnancies are unplanned.

"Providing flour fortification is safe - and reports indicate that it is - then it can only be a good thing.

"I took folic acid when I was pregnant with Bryony and doctors have said that her condition might have been more severe if I hadn't. I was put on a higher dose when we planned to have our third child, and thankfully he was fine."

Su, who's two other children are Lucy, 8, and Alexander, 3, added: "I know the fortification of flour has been mandatory in America since 1998, with no ill effects. The numbers of babies born with spina bifida has fallen since then which is good news."

The Big Lottery helps awa



The Big Lottery has stepped in again with a generous three-year grant to help young people with spina bifida and hydrocephalus.

The latest recipient is Sussex ASBAH (SASBAH) whose Young People's Committee, has benefited to the tune of £69,000.

The committee was set up in December 2005 to enable more than 110 younger service users in the area to become more involved both in the organisation and in planning relevant services and events for their age group.

The group's achievements in its first year have far surpassed SASBAH expectations and it has ended the year by scooping a prestigious award at a national event.

It was nominated for the National Council for Voluntary Youth Service's Young Partners Awards and to everyone's delight was shortlisted from more than 200 youth groups in the South East.

Publicity campaign raises awareness of Helpline

ASBAH is reaching a wide new audience thanks to an extensive publicity campaign to advertise the new Helpline and Information Service.

To raise awareness of the new service, 23,000 information leaflets were sent to a wide range of healthcare professionals including GPs, midwives, obstetricians, paediatricians, neurosurgical and neurological clinics, and ante-natal clinics, asking them to publicise the new ASBAH service.

The press campaign also proved a success with details of the Helpline featuring in dozens of local papers across England and Wales.

The response to the publicity campaign has been high with many people, new to ASBAH, getting in touch for the first time.

Helpline manager Linda Lewis explained: "We have seen a high proportion of callers with children or family members aged 40 plus, who are making contact for the very first time, after just discovering that ASBAH is there to support them.

"This just proves what ASBAH has always suspected - that there are many more people we can reach out to if they only became aware that we are there."

The Helpline team, which includes Linda and operators, Dawn and Annie, has helped more than 1,255 people who have called in with queries and concerns since its 1 July launch.

Around 74 per cent of contacts for help and advice have come in by telephone, 24 per cent by email and just under one per cent by letter.

The Helpline team has been able to answer 75 per cent of all queries, with the remaining 25 per cent referred to the medical or education advisers or outside organisations.

Linda said: "The first few months were very hectic because we



award-winning youth group

The committee travelled in style to the awards ceremony at the trendy venue The Spitz Bistro & Gallery in London's West End... in a stretch limo.

SASBAH's youth co-ordinator Rom Sanglai said: "Well they had done so well that we thought they all deserved a treat. It was also a very cost-effective means of transport!"

The group beat off stiff competition to pick up the award for the South East area and 14-year old Joseph Cooke was only too pleased to make an acceptance speech.

Rom explained: "The group have worked very hard for the past 12 months so we were thrilled that their work was recognised and rewarded. The award ceremony was a fantastic experience for them and it has given a huge boost to everyone's self-confidence."

The idea for the young people's group came when Rom, looking through the SASBAH database, realised that around one quarter of service users were between the ages of 11 and 25 years.

"Although we are a very proactive group, it seemed that we weren't involving our younger members enough in decision making," he explained.

"We sent out questionnaires and received a really positive response. The youngsters were very keen to be active within SASBAH and voice their opinions."

Fourteen members formed a committee and held regular, well-run meetings. They even enjoyed a consultation residential weekend thanks to an Awards for All grant.

Rom added: "The group has great ideas and has proved that it can put them into practice without too much help, so the Big Lottery funding will make a huge difference to what they can achieve. It's nothing less than they deserve."



really had to hit the ground running – the two operators initially started on a job share basis and at the moment this is working well to service clients' needs."

As the weeks and months have passed, patterns of call categories have emerged – for instance, an estimated 40 per cent of calls relate to medical issues, whilst many others phone to request shunt alert cards.

Linda added: "We've learned a lot since we started and every call we take helps prepare us even more for the next one. What I really enjoy is being able to point someone in the right direction to enable them to get the help they need – that's what makes the job worthwhile – making a difference."

ASBAH's Helpline can be called on 0845 450 7755 Monday to Friday, between 10am–4pm, at local call rates.

If you see opportunities in clinics and hospitals in your local association area where leaflet dispensers or posters could be displayed then do call the Helpline on 0845 450 7755 to tell us.

Leeds and Bradford reach out to North Yorkshire



It is always a sad occasion when local associations close and the demise of the North Yorkshire group was no exception.

But the service users in the area have been welcomed with open arms by the Leeds and Bradford association which is keen to make sure help is on offer to those who need it.

Leeds and Bradford, which celebrates its 40th anniversary in 2007, has gradually expanded its area in recent years following the closure of the Castleford and Pontefract, Huddersfield and Halifax associations.

As part of its 40th year celebrations a road show is planned for next year to promote itself around the areas and meet service users, old and new.

Deputy Chairman Jo Baxter, who has been with Leeds and Bradford for more than 36 years, told Connect: "It will be a great way to promote ourselves and get to know people in our new areas as well as our existing members.

"It is very sad when associations close down after so many years but we will do all we can to welcome their service users.

"Leeds and Bradford is lucky in that we have easy access to the Northern regional office and the advisers who are based there. The North Yorkshire Association may have closed down but the new ASBAH area adviser is making sure that good contacts are maintained there."

Although Leeds and Bradford is a thriving local association, Jo knows only too well how difficult it is for a group to keep its head above water.

Last year for example the group struggled financially and Jo admitted, "at one stage even I was getting worried.

"Luckily we have an extremely hard-working Treasurer, Anne Granger, who with our part-time employee Fiona Bryant, are excellent fund-raisers. They trawled the internet to find out



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where they could apply for funds to boost our bank balance."

The group keeps in regular contact with its 480 members via the bi-monthly Newslink newsletter.

There are several adult user groups and a youth group which meet regularly, plus drop-in sessions and family get-togethers which are held at various locations.

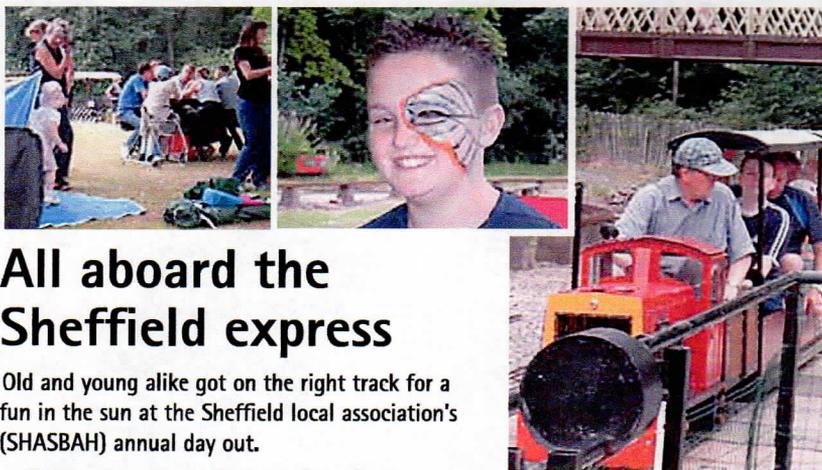
For younger members the Saturday Club is a great way to get involved with activities and make new friends.

"We do encourage children and young people to come along to these groups," Jo added, "because meeting others who have spina bifida and hydrocephalus builds their confidence and helps them to get out and about. It also gives some respite to carers as well."

Running such a large group is no mean feat, especially with a committee which is down to just five members.

But Joan remains positive and said: "We have a great committee and team of helpers but just need a few more people to help share the workload, particularly as our area has widened. We're keeping our fingers crossed that some volunteers will come forward at our AGM in March.

"But I still enjoy myself and I've made so many good friends over the years through the group. Most days it doesn't actually seem like work."



All aboard the Sheffield express

Old and young alike got on the right track for a fun in the sun at the Sheffield local association's (SHASBAH) annual day out.

The group was invited to spend an afternoon at the Abbeydale home of the Sheffield Model Engineers to enjoy rides on the miniature steam railway, a bouncy castle and try their luck on the giant games such as Connect 4.

The steam railway, tucked away in a pretty clearing in the middle of woodland, has been the venue for the association's annual events for ten years, thanks to Treasurer Shirley Everingham, whose husband is a member of the model engineering group.

And it was the perfect opportunity for the association to gather together and meet up with friends of all ages.

Shirley, who has been Treasurer for almost 20 years, told *Connect*: "It is the perfect spot for our Family Day and there is something to interest everyone.

"Everyone brought picnics and we served refreshments in the clubhouse. It really was a lovely day."

The children queued to have their faces painted by Chairman Michelle Gardener and area adviser Julie Turnbull caught up on all the news and gossip.

Committee member John Antoszkiewicz added: "Thank you to everyone who came along and made it all worthwhile and a special thank you to the Model Engineers again, for treating us to their steam engines and beautiful grounds."

40th anniversary celebrations at Bristol

While ASBAH has enjoyed an eventful 40th year, Bristol and District were holding their own anniversary celebrations.

The local association formed in 1966, the same year as ASBAH, and has helped and supported hundreds of people through the decades.

To mark the occasion the group held a party in May which was the perfect chance to meet up with friends, old and new.

Four of the founder members – Ray Mabbutt (Chairman), Gordon Egan (Secretary), Sheila Egan and Avis Brown – joined in the celebrations.

The fun-filled evening included the cutting of the cake by the oldest disabled member of the group at the party, Syd Ralfs, and the youngest, Gareth Picken.

But amidst the anniversary year celebrations there were low points, with the sudden death of Chairman Steve James and two parents who had been original members from the

1960's, Cliff Daniels and Ray Boon. The son of committee member Lyn Griffiths also died earlier in the year.

Spirits were lifted within the Bristol association by the welcome news from ASBAH that a new area adviser had been appointed, after a two-year absence. Ann Gillard, a physiotherapist, joined ASBAH on September 18, and is settling in well to her new role, covering the South West, including Bristol and Bath, and the fringes of south Gloucestershire, Dorset and Wiltshire.



Ann Gillard



Syd Ralfs cuts the anniversary cake

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