

Sophie Lamb (left) and Vicky Mason take part in the photo shoot for 'Below the Belt' a teenage book produced by ASBAH, covering issues relating to continence, relationships and much more...



Connect

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

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Fortification faces delays

England's Chief Medical Officer has instructed the Food Standards Agency (FSA) to reconsider its recommendation in favour of flour fortification following a recent US study which claimed to show a possible link between high intakes of folic acid and an increased risk of bowel cancer.

Sir Liam Donaldson has requested further expert consideration before the government gives the final go-ahead for mandatory fortification.

This is disappointing news for ASBAH as this question was considered in detail by the Scientific Advisory Committee on Nutrition (SACN) last year.

There is considerable evidence that folic acid helps to prevent bowel cancer, but there may also be cases of pre-existing benign tumours where very large doses of folic acid might stimulate the tumour.

Flour fortification would not provide large doses and ASBAH believes the FSA review will confirm its advice in favour of compulsory fortification.

At the same time, voluntary fortification of products would be curtailed, to ensure that folic acid reaches the target population of women of child-bearing age without exposing other groups to any theoretical risks.

ASBAH's Chief Executive Andrew Russell said: "The intervention of the Chief Medical Officer is an unwelcome delay because there is no new medical evidence in recent reports.

"The FSA will convene an expert group in January 2008 and we hope it will quickly review the scientific evidence and confirm the advice issued in the summer.

We're in touch with the FSA and it agrees that recent press activity and the new research report don't give any cause to change the advice

"We're in touch with the FSA and it agrees that recent press activity and the new research report don't give any cause to change the advice. SACN looked closely at all the evidence, including cancer incidence, and unanimously recommended fortification."

In early November Andrew attended a Flour Fortification conference in Brussels organised by the International Federation for Spina Bifida & Hydrocephalus (IFSBH).

The two-day meeting saw leading health professionals discuss the development of a plan to influence European authorities to support the mandatory fortification of flour with folic acid and iron.

A full report will be included in the next issue of *Link*.

"Below the Belt is an extremely good book. It is factual and is written in language that young people can understand and accept."



"ASBAH have published continence pamphlets and leaflets before, but this is really targeted at the individual themselves rather than at the carer."

"The House of Commons launch went very well and I was delighted to see that several MP's and outside agencies were able to attend."

Austin Crowther, Chair of North & West Yorkshire Local Association, an ASBAH Trustee and Vice Chair of National ASBAH



The ASBAH and Hollister team responsible for 'Below the Belt'



Below the belt

ASBAH's brand new book for teenagers, *Below the Belt*, was launched in style at a special House of Commons reception.

The event, on 31 October, was attended by 50 guests, including health professionals, representatives from ASBAH and Hollister and several MPs.

Several families who have contributed to the content of the 32-page book were also among the party.

Below the Belt covers many issues faced by teenagers with spina bifida and/or hydrocephalus and is packed with practical advice.

Continence issues form a large section of the book, from the physical problems which may occur to psychological and emotional issues which can follow.

Stewart Jackson, MP for Peterborough and keen supporter of ASBAH, hosted the House of Commons launch.

Mr Jackson said: "ASBAH does tremendous work in helping individuals and families affected by spina bifida and hydrocephalus so I was delighted to be able to help with the launch of this fabulous new book.

Below the Belt is an ideal starting point for children approaching their teenage years.

Frank Lee

"Below the Belt is a great new resource for young people who have spina bifida."

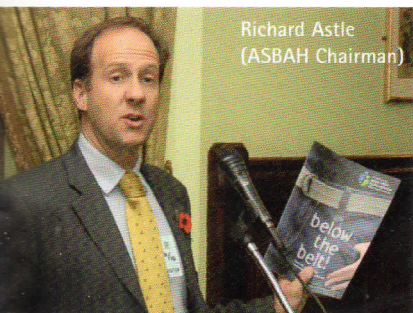
ASBAH Chairman Richard Astle welcomed the guests and thanked those who had been involved with the production of the book.

Below the Belt was written by ASBAH advisers Rosemary Batchelor, Angela Lansley, Lisa Raman and Gill Yaz and was sponsored by Hollister, a healthcare company which provides the Advance range of intermittent catheters.

The book's foreword was written by Frank Lee, Consultant Urological Surgeon at St George's Hospital, London.

He said: "*Below the Belt* is an ideal starting point for children approaching their teenage years, or anyone wanting to know more about spina bifida. The transition from childhood to adolescence is enjoyable, but can also be stressful.

"I hope the topics covered will stimulate further questions and encourage people to talk to ASBAH about any issues which they may feel uncomfortable raising."



Richard Astle
(ASBAH Chairman)



Lisa Cain
(ASBAH Trustee)

"I think there was a real need for the book. We have found that any extra information is a great help.



"The teenage years are difficult and unsettling for anyone, and it is doubly hard for anyone with a disability. Below the Belt should really help to answer some of their questions."

Michelle Goddard, whose son Carl is one of the models in the book, is Chair of the Sheffield Local Association.



Sophie Lamb (left) with mum Louise and dad Gary



Stewart Jackson MP



"We're not there yet"



Sir Bert Massie CBE, former Chair of the Disability Rights Commission, was the guest speaker at the ASBAH AGM. He delivered a talk on the serious issue of the struggle for equality which was spiced with humour to keep his audience entertained and listening.

Sir Bert told the gathering that disability equality has moved a long way from the 1960's approach of looking after disabled people and sending them to the day centre to make "very pretty baskets".

He explained that by the 1970's there was a realisation that a lot of the problems disabled people encounter are a result of the built environment.

Instead of seeing the wheelchair as the problem that's preventing the person from getting into the office, maybe the stairs should be considered as the barrier and one that could be overcome, he suggested.

As a result MPs began to call for new laws and environmental changes after research showed that there were lots of inaccessible places such as taxis and buildings among others.

Further studies in the early 80's highlighted that patronising attitudes of non-disabled people were also impacting on the lives of disabled people.

But it was to be another decade and a half before the Disability Discrimination Act (DDA) was passed in 1995 and a further five years until we got the Disability Rights Commission (DRC) to help enforce it.

What has the DRC done?

It provided advice on disability law through its Helpline and fought to get changes made to the law itself.

All schools and universities are now covered by the DDA and the definition of

disability has been strengthened.

The success of the Disability Rights Commission can be measured by real changes to the lives of disabled people with improved access for wheelchair users – in all aspects of life.

That includes everything from taxis, shops and housing (all new housing now has to be accessible), through to education and employment.

Many thousands of disabled people now have more qualifications and are in employment.

But what has changed most is not only the public's perception of disabled people but disabled people's perception of themselves.

This increased confidence was illustrated by Sir Bert, using a quote from a disabled young person, "I'm me and if you don't like it that's your problem."

But despite pointing out many of the DRC's achievements, he didn't paint a totally rosy picture. He told the AGM that for some companies, it would still pay to discriminate because the cost of bringing a discrimination claim could add up to much more than the fines imposed.

More battles ahead

Although the DRC ceased to exist shortly after Bert Massie spoke to the AGM, he assured the audience that their work would carry on through the disability section of the new Equality and Human Rights Commission, including updating important codes of practice.

continued overleaf

There would still be a helpline to raise important questions and gain advice on disability discrimination and he urged people at ASBAH to make use of this and give feedback.

Sir Bert ended his talk with a look at how disabled people's legal rights in law are not yet backed up by social, educational and housing services to make sure they are enforceable.

Some of the battles ahead, which the Commission will continue to fight, will be to achieve better social and health care and the basic right to life for disabled people.

To find out more about the new Equality and Human Rights Commission (CEHR), visit their website at www.equalityhumanrights.com

The following helplines offer information and guidance on discrimination and human rights issues.

The CEHR dedicated Disability Helpline for England - tel: 08457 622 633. The Equality and Human Rights Commission Helpline for Wales, tel: 0845 604 8810.

You can also find out more about what the DRC achieved by reading their recent publications: *Celebrating the Journey - Impact Report 2000-2007*, and *DRC Legal Achievements 2000-2007* (both of these can be downloaded from the recent publications section of the CEHR website).

Helpline Update



The new Helpline and Information Service Development Group met for the first time in September to monitor the effectiveness of the ASBAH service.

The group is made up of six representatives who will attend regular meetings to review the data collected by the Helpline and focus the promotional campaign.

The types of calls and callers will be analysed to give a clearer idea where new services are needed and to enable a detailed evaluation of the service to be carried out.

Director of Services Mary Malcolm said: "The development group is vital to the forward planning and development of the Helpline and Information Service."

The Helpline and Information service team have praised the volunteers who helped with the huge publicity campaign carried out during the summer months.

In July more than 12,000 letters were sent to medical units around the country inviting them to sign up for helpline posters, dispensers and flyers.

Helpline and Information Service Development Group

- Parent Representative – Sue Tucker
- Your Voice Representative – Cathy Lunn
- Director of Services - Mary Malcolm
- Your Voice Co-ordinator – Barbara Robinson
- Fundraising Project Co-ordinator – Helen Dow
- Helpline & Information Service Manager – Linda Lewis



New look for information sheets

ASBAH's services have been working hard to update its series of information leaflets.

The content has been updated and the presentation revamped with a fresh, clear new look, made possible by the change of logo and style.

A new addition to the information library is a leaflet covering 'Depression and Disability'.

Two leaflets, 'What is Hydrocephalus' and 'What is Spina Bifida' are now available in Braille. It is hoped that these two leaflets will also be translated into several popular languages.

A new publication for teenagers, *Below the Belt*, has been launched recently, dealing with the subjects of continence and sexual health (see inside this issue of *Connect* for more details).

For help and information call our Helpline on 0845 450 7755

What would you like to see?

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