



Connect

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

Nov 08

Lights... Camera... Action!

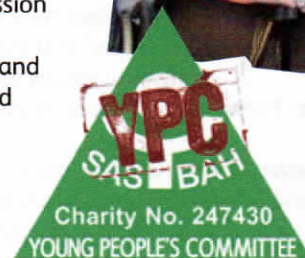
A short film about a group of young people with spina bifida or hydrocephalus, living in Sussex, was launched at a packed screening at Uckfield Civic Centre back in October.

BBC South East presenter Beverly Thompson, who is Vice-President of SASBAH, presented the young people with copies of their film. Beverly praised the film saying that it should win awards and she also commended the young people's hard work.

The young people in the film are all between the ages of 14-25 years and are members of the Sussex Association for Spina Bifida and Hydrocephalus (SASBAH) Young People's committee (YPC). The committee was set up in 2006 to enable young members of SASBAH to have an influence on how the organisation is run, the services it provides and ultimately its future direction. The lively group of 15 young people regularly hold committee meetings, organise events and take part in training throughout Sussex. The idea for a film project originated from a discussion at a committee meeting last year.

The film has been a collaboration between the young people from SASBAH and Khouse Media, a Brighton based film production company. The film was funded by the Big Lottery Fund as part of a three year project with SASBAH's Young People's Committee. East Sussex County Council Youth Development also provided funds for the project.

The young people involved in the film have high expectations about how the film can be used to promote SASBAH and raise awareness of spina bifida and hydrocephalus throughout Sussex. In particular, they want to make their own generation aware of what it is like being a young person with a disability. The group hopes to help eradicate discrimination and ignorance towards people with disabilities through increasing awareness and understanding.



(Above)
BBC South East
presenter Beverly
Thompson
presents Kristy
Baldock, Adam
Lovegrove and
Adam Moors with
the YPC Film.

update

hydrocephalus
action



Professional area

The Hydrocephalus Action Professional Area on the ASBAH website was launched last month and we've already had an influx of membership requests.

Open only to healthcare professionals who register with ASBAH, it aims to become a recognised reference area for those dealing with patients with hydrocephalus.

The area includes medical information relating to hydrocephalus and spina bifida including shunt surgery and continence procedures. Users can download medical teaching materials, including case studies, published articles, videos and information sheets for professionals.

All material submitted will initially be viewed by the Professional Area's consultative panel and ASBAH's medical advisory committee before being posted on the website.

If the Professional Area is to become a really useful resource, as many health professionals as possible need to be made aware of it, so please let people in your area know about the Professional Area so they can pass the message on to their GPs, surgeons, OTs, physios and nursing staff – hopefully this will lead to more understanding and better treatment for everyone with hydrocephalus and spina bifida.

Keeping in touch w



Tony Bassett, Cheryl Emmanuel
and Erik West at the
celebration lunch

Eastern Region Forum

ASBAH's Eastern Region has been holding forum meetings twice yearly for the last five years. Dave Isom, ASBAH's Eastern Region Manager, told Connect: "It's a good opportunity for local associations in the region to get together and share ideas, problems and solutions."

The latest meeting took place at ASBAH house in October. The guest speaker was Colin Roberts, ASBAH's Fundraising Director, so this meeting had a particular focus on fundraising. Each time there is a different guest speaker (chosen by the group) plus a standing agenda - including news about recent ASBAH publications, a round-up of what's happening in the region, from Dave, and each Local Association also gives an update on their activities.

As well as lunch, a 'paper buffet' is provided with copies of any new leaflets and information sheets to which attendees can help themselves.

The meetings are open to all local associations and support groups as well as interested individuals, from the region, and Your Voice is also represented.

The next one will be on April 4th 2009 – so if you're in the Eastern Region and don't want to miss out – make a date in your diary and watch out for more details in Link Diary Dates and on the website Events page.



David Isom



Colin Roberts

ith... Jersey (JASBAH)



40 Years of Caring

On Saturday 11 October, over fifty people gathered at Les Ormes restaurant to celebrate the 40th anniversary of the formation of the Jersey Association for Spina Bifida and Hydrocephalus. There was a nostalgic feeling in the air as they welcomed their guests and exchanged stories from "times past" whilst looking at press cuttings and photographs from the early years of the Association.

The event had been organised by Ursula Dingle, retired Secretary of the Association, as a celebration of our 40 years of caring in Jersey, but also as a "thank you" to the members of the 1968 Lions Club of Jersey whose members had been instrumental in getting the small group of parents organised into a thriving association. Many of the Lions had served as officers and committee members for many years, and some of them, together with their wives, and other supporters, were guests at the lunch. Other guests were Erik West and Tony Bassett, formerly of Staines & Hounslow ASBAH, who had helped service users and their families with transport from Heathrow to hospitals in London, providing a much valued support service for many years.

At the Association's Annual General Meeting in July, Ursula Dingle retired as Secretary of the Association. She had been elected as Founder Secretary in 1968, a post which she held until moving to England in 1978. On her return to Jersey in 1993 she rejoined the

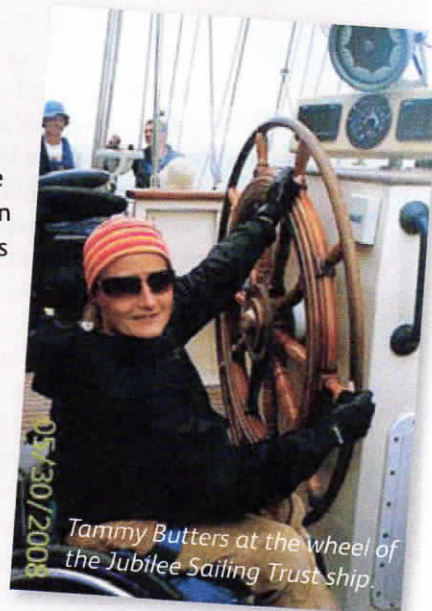
Association and was again elected as Secretary in 1999, on the retirement of Mollie Buesnel. Ursula was thanked for her 25 years of service to JASBAH by Chairman Terry McDonald, and presented with a bouquet and garden vouchers. Another founder member, Dot Picot, also retired from the Committee this year and was presented with a bouquet and an engraved cut glass bowl. Dot and her late husband Doug had been hard-working supporters of JASBAH since its formation, serving on the Committee and raising many thousands of pounds.

JASBAH is delighted with the achievements of their young members: Aaron Boschat and Melissa Alves in their sporting

activities – basketball, tennis and marathons. Alex Vinrace and Tammy Butters took part in the Jubilee Sailing Trust Day Sail, and had a terrific time. Jane Guicha has passed her driving test – first time, with full

marks – and is now enjoying the car JASBAH helped to provide and which enables her to take her daughter Katie out and about. JASBAH thanks the Driving for the Disabled association and the Harley Davidson Group for their sponsorship.

Fundraising has continued this year with collections plus individual donations, and is enabling the Association to maintain its support for our families in increasingly difficult times. Funds are needed for welfare and mobility help (Jersey does not come under the UK benefits scheme or Health Service). They also need support from local employers for permanent jobs for their disabled members.



Tammy Butters at the wheel of the Jubilee Sailing Trust ship.

Fundraising has continued this year with collections plus individual donations, and is enabling the Association to maintain its support for our families in increasingly difficult times

Share your Association's stories with Connect readers - fundraising, celebrating, or providing services. Contact Gill Winfield 01733 421321 email: gillw@asbah.org

Link... the next issue

Issue 226 of Link magazine is due out at the beginning of January.

Make sure your local association members don't miss out. Link is available on yearly subscription through the website, or by calling ASBAH's helpline on 0845 450 7755.

ASBAH AGM 2008

This year's AGM had a different feel with a mid-week slot at the John Foster Hall at Leicester University. Local Association representatives had the chance to meet up with ASBAH staff as the AGM was combined with the annual staff training event. ASBAH services staff also gave short presentations giving an insight into the day-to-day work of medical advisers, the scope of calls handled by the helpline and an update on the transition and employment project.

Andrew Russell presented a report of the last year's activities, stressing that the front-line support and advisory service would remain a priority. ASBAH's helpline, now in its third year, had been vigorously publicised and was dealing with many thousands of enquiries each year, 80 % of which were dealt with immediately, and the remainder referred on to appropriate services including our advisers.

ASBAH continues to communicate with government on many policy issues in social care, education and health services, as well as on important topics such as the primary prevention of spina bifida through the vitamin folic acid.

The Association is used to standing on its own feet financially, but faces particular challenges in the present economic downturn, so we are developing new fundraising approaches including internet shopping and sponsorship by companies such as 'charity of the year' deals.

User involvement, through the forum "Your Voice", has continued to develop, with their website, a newsletter, and two high-profile conferences organised by members in the past year, with more to come.

Andrew said that this would be his last AGM as chief executive, and listed some of the key future challenges for ASBAH, including pressing for improvements in inclusive education for disabled children, and working for better transition support for children as they approach adulthood. People with SB & H were living longer, with a generally better quality of life than in former years, but far more progress was needed. He was confident that the Association would preserve its status as the foremost national voluntary organisation in our field, thanks to the dedication of everyone including trustees, local members and the professional staff. He thanked the honorary officers and all these groups for their commitment through another successful year.

In the afternoon, our guest speaker was Caroline Bowditch who talked about expectations for disabled people and how she had challenged expectations to become a dancer and choreographer. Caroline urged the audience to 'expect more of ourselves and each other'. You can read more about Caroline's life and work in the next issue of Link.



Lauren takes to the skies to raise money for SASBAH

An eight-year-old performer who was told she may never walk has taken part in a sponsored glide.

Lauren Gander, who was born with spina bifida, took to the skies to raise funds for SASBAH.

The Bexhill youngster is a member of Eastbourne Operatic and Dramatic Society and has performed in Oliver! at the Congress Theatre.

Linda Gander, Lauren's mum, said, "She has battled with everything to come out the other side as a very talented dancer and performer.

"She lives for her dancing and has performed in London's West End production of The Wizard of Oz.

Lauren said, "The sponsored glide was very exciting and I am really happy about the amount of money we managed to raise for SASBAH."

Lauren was awarded the Gill Hamilton, young person of the year award at the 2008 Eastbourne Achievers' Awards in April.

Reminder – help available to raise your profile

In the last issue of Connect we mentioned that help is at hand if you would like some assistance in raising awareness through media coverage

Hannah Barrett, of Athene Communications, currently works with national ASBAH on a pro bono basis, helping to increase ASBAH's presence in the local press. and Athene Communications (whose Director is ASBAH's Chairman, Richard Astle) is offering to extend this help to local associations. Please contact Gill Winfield and she will put you in touch with Hannah, if you have any news stories.



helpline 0845 450 7755

Monday to Friday, 10am-4pm
Low Rate Call