



SASBAH

SUSSEX ASSOCIATION FOR
SPINA BIFIDA AND HYDROCEPHALUS

NEWSLETTER SUMMER 2022



Swoove Fundraiser at Framfield Way Co-op raised almost £800 – more photos inside

TRUSTEES

We are pleased to say that we have recruited 2 new Trustees. Tim McDermott-Roe joins us from West Sussex. Tim has been aware of SASBAH for a number of years having a relative who was one of our Service Users. Thanks to Tim for helping to organise Fundraising Events in West Sussex and also our Annual Golf Day. Our newest Trustee is Ian Wooler who is no stranger to SASBAH having served on the Saspire Board of Directors for a number of years.

We welcome both Tim and Ian to the Board. Should you feel that you or someone you know would like to become one of our Trustees, please email office@sasbah.org.uk or rom@sasbah.org.uk



Tim McDermott-Roe



Ian Wooler

Office address:

5-6 Swanwood Park, Gun Hill, Horam TN21 0LL

Telephone: 01825 873045

Email: office@sasbah.org.uk

We regularly send out e-newsletters, If you don't currently receive them please email Lynne at office@sasbah.org.uk and you will be added to the contact list.

FUNDRAISING

In Memorium

Mason Betts

Family members have been making donations to SASBAH for 17 years in memory of their baby boy, Mason. £125 has been donated this year and we thank them all for this amazing support.

Sue Manuel

Sue was well known to many of our West Sussex Service Users. £175 has been donated through Just Giving in her memory. Thank you to Sue's friends and family for their support.

Fundraising Events



We had a stall at Haywards Heath Town Day and raised £111. Thanks to all who came along to give a hand.



On a lovely Easter Sunday morning we held a sponsored Swoove outside the Co-op in Framfield Way, Eastbourne. Thanks to the Eastbourne Co-op branches who have chosen us to benefit from their Local Community Fund this year. Thanks also to Jo from Swoove for her constant support. We had lots of fun and raised almost £800 at the event from sponsorship and a raffle.



The Woolpack in Burgess Hill once again hosted a quiz night for us—thanks so much to them for their continued support. We raised a fantastic £500 from this evening and thanks to Susan Chalkley and Tim McDermott-Roe for their hard work organising this event.



SASBAH RESIDENTIAL BREAKS 2022

We have a full programme of Residentials planned for this year. We have already had a visit to Norfolk at the beginning of June which was enjoyed immensely by 13 East Sussex families. This residential was funded by East Sussex Council which is why we couldn't open the invitation up to all. Here are a couple of photos from the holiday and below are details of the remaining breaks we have planned.

Mindfulness and Wellbeing Residential Break

Friday 8th July to Sunday 10th July 2022, Sefton Place, Arundel*

This will include a series of workshops, treatments and classes to help you with your mindfulness, relaxation and wellbeing. This break will cost £50 per head and this is for full board accommodation and all activity costs included. This does not cover the cost of transport. Most activities will be on Saturday 9th.

Breakaway

Friday 23rd September to Sunday 25th September 2022, Lodge Hill Outdoor Activity Centre, Pulborough.

Outdoor Activity residential break for which there will be no fee charged thanks to the generosity of the funders. Transport will be provided to leave Gun Hill Office on the Friday and to return there on the Sunday.

Family Break

Friday 21st October to Monday 24th October 2022, Sefton Place Arundel*.

The aim of this break is to support families and a few individuals.. Activities will take place over the weekend mainly to entertain any children that are there. Cost of this break is £50 per room that will cover accommodation, food and entertainment but not travel costs.

To book on any of these residential breaks please contact either Rom on 07779038542 or rom@sasbah.org.uk or Lisa on 07725433136 or lisa@sasbah.org.uk. Priority will be given to those that have not been before but hopefully we can accommodate everybody that shows an interest. If you want to visit any of the residential breaks as a day visitor you would be made to feel very welcome and you can book in the same way as above and the charge for day visitors is just £10 to cover the costs of food and refreshments.



** Sefton Place is an accessible building but it has limited accessible rooms so if the demand is high than we can book accessible rooms at the Premier Inn which is about a mile away from Sefton Place but you would have to have transport to get there and back or use taxis. Alternatively if you do not want to stay residentially you can just visit as a day visitor on any of the dates above.*

SASBAH ADVISER SERVICE

It is important to look after our informal or unpaid carers, who can be family members (of all ages) and friends. There is a range of help and support that is available for carers such as counselling, benefits, support groups, carers card (discount card), grants and equipment to help and support them in their caring roles.

The following are organisations across Sussex who provide support and help for unpaid carers, with a brief overview of the services they offer.



Zoe Kane
01243 551976
07789 616458
zoe@sasbah.org.uk

WEST SUSSEX

Carers Support West Sussex

provide the following services:

- Carers Assessments – carry out statutory Carer Assessments on behalf of WSCC
- Carer Health and Wellbeing Fund – can support you to access funds to support you in your caring role
- Counselling Service
- Relaxation and Respite
- Carer Equipment Service – equipment to help you in your caring role
- Online Carer Groups
- Hospital Teams – have teams based in all of the major hospitals in West Sussex and East Surrey Hospital in Redhill
- Carer Response Line – open 6 days a week
- Bereavement Support
- Benefits Advice Service
- Young Adult Carers support
- Carer Discount Card – for family and friend carers a range of discounts and offers across West Sussex
- Carer Emergency Card
- Digital Champions – 1:1 support with getting online and using IT equipment

Website - www.carerssupport.org.uk
Email - info@carerssupport.org.uk
Telephone - 0300 028 8888

TuVida (formally Crossroads)

provide the following services:

- Day Centres and Groups - A change of scenery for people receiving care and support, as well as the opportunity to meet new people in a fun and relaxing environment.
- Respite for Carers - Home care provision that enables periods of respite for carers. This is self-funded
- Emergency respite – This is for emergency's only which is funded by WSCC.
- Children and young people – Short Breaks Service, support for young people aged 11-18, who have medium to high needs and are socially isolated or not attending education. Available in the Arun, Adur, Worthing, Chichester and Horsham areas.
- Short Break weekends (Dementia) - Weekend breaks for people with dementia and their family or friend carers

Website - www.tuvida.org/westsussex
Email - westsussex@tuvida.org
Telephone - 01903 790 270

EAST SUSSEX

Care for the Carers East Sussex

provide the following services:

- Carers Hub - offers information, advice and support on a range of issues and acts as the first point of contact for all of their services.

- One to one support and advice
- Carers groups and activities
- Counselling
- Information for carers - fact sheets, CareLine Magazine, monthly newsletter
- Grants for carers – help to access grants for carers
- Digital resources
- Online help
- Carers Card – Identifies you as carer and someone depends on you in an emergency, option to connect to a back-up respite plan as is a discount card with businesses across East Sussex
- Young carers support

Website - www.cftc.org.uk/
Email - info@cftc.org.uk
Telephone – 01323 738390

BRIGHTON AND HOVE

Carers Hub

provide the following services for Adult Carers:

- Carers Assessment – carry out carers assessments
- Carers card – offers savings and discounts on leisure and well-being activities across Brighton and Hove
- CareLink Plus and Telecare
- Cares Reablement Service – Supports carers to achieve positive change and improve their health and well-being
- Dementia Carers Support
- Emergency back up scheme – help you set up a plan to include up to 3 people who could provide support in an emergency.
- End of life support for carers
- Advice and support for carers to people with a mental health condition
- Mindfulness based cognitive therapy (MBCT) for carers – this is a free 2 hours a week for 8 weeks course.
- My health matters – provide support to the person you care for whilst you attend health appointments and to attend training or courses that will help in your

caring role such as counselling or first aid training.

- Online help – digital resources and app's
- Young carers project
- Young adult carers support

Website - carershub.co.uk
Email - info@carershub.co.uk
Telephone – 01273 977000

Carers Centre for Brighton and Hove provide:

- Family carers with emotional support
- Activities for young carers
- Emotional support for young carers
- Activities for adult carers
- Emotional support for adult carers
- Carers reablement project
- Memory assessment service
- Working carers

Website - www.thecarerscentre.org
Email - info@thecarerscentre.org
Telephone - 01273 746222

ACROSS SUSSEX

Amaze

provide support for parent carers for families with disabled children and young people in Sussex:

- Compass card – a leisure discount card for 0 to 25 year olds with significant special needs or disabilities
- Carers card – discount card to help look after health and wellbeing of carers
- Face 2 face befriending groups
- Workshops and courses
- SENDIASS helpline – help with special educational needs and disabilities for 0–25's
- Help with claiming DLA / PIP for a young child

Website - amazesussex.org.uk
Email - infor@amazesussex.org.uk
Telephone - 01273 772289

SOCIAL ACTIVITIES & LOCAL COMMUNITY GROUPS

We have a variety of outings that will hopefully appeal to lots of different members. It's a great chance to catch up with old friends, make new ones and to get out of the house and try something new. We are always happy to arrange things that you want to do, so if you have any new ideas please get in touch. You can reach us by phone or text Lisa on 07725 433136 (for West Sussex activities) or Rom on 07779 038542 (for East Sussex activities) or email us or send us a message on Facebook. We look forward to seeing you!

WEST SUSSEX

JULY

Mon 4th Lunch at Munch, Worthing, 12-2pm

Weds 13th Crawley Support Group, 12-2pm Starbucks, Queen Square, Crawley.
We meet in the meeting room at the rear of the café.

Mon 18th Bowling at Out of Bounds, Angmering, 12-2pm. Booking essential.

Tues 19th Lunch at Harvester, Crawley, 12-2.30pm

Thurs 21st Pub Quiz at The North Star, Worthing.
Quiz starts at 8.30pm and costs £1, but join us from 7.30pm if you want to eat first.

Mon 25th lunch at Toby Carvery, Crawley, 12.30-2.30pm

Weds 27th Mid Sussex Support Group, Cyprus Hall, Burgess Hill, 12.15-2.15pm.
We meet in the Starford Hall at the front of the building. Tea and coffee are provided.
Please feel free to bring your own packed lunch.

AUGUST

Fri 5th Worthing fish and chips and seafront walk 4pm onwards

Weds 10th Crawley Support Group, 12-2pm Starbucks, Queen Square, Crawley.
We meet in the meeting room at the rear of the café.

Thurs 11th Pub Quiz at The North Star, Worthing. Quiz starts at 8.30pm and costs £1, but join us from 7.30pm if you want to eat first.

Mon 15th coffee/lunch and a walk at Marine gardens, Worthing, midday onwards

Thurs 18th coffee/lunch at Bake Out, Hassocks 11.30am-1.30pm

Weds 24th Mid Sussex Support Group, Cyprus Hall, Burgess Hill, 12.15-2.15pm.
We meet in the Starford Hall at the front of the building. Tea and coffee are provided. Please feel free to bring your own packed lunch.

Mon 30th lunch Crawley, venue to be confirmed.

EAST SUSSEX

JULY

Fri 1st Hastings & Rother LSG, The Pelham
12.30 – 2.30pm

Sat 2nd Midday at Beacon Centre, Lunch at Nandos

Sat 9th Wellbeing Day Sefton Place, Arundel

Wed 13th Bourne Free, Ratton School 6-8pm

Sat 16th Eastbourne Pier and Lunch, meet Midday

Sat 23rd Crazy Golf, Sovereign Harbour, Meet 11am

Wed 27th Bourne Free, Ratton School 6-8pm

Sat 30th Lunch at Rodmill, Midday

AUGUST

Fri 5th Hastings & Rother LSG, the Pelham 12.30–2.30pm

Sat 6th Lunch at Sovereign Harbour – Midday

Weds 10th Bourne Free, Ratton School 6-8pm

Sat 13th Cuckoo Trail walk and lunch. Meet Polegate Community Centre 11.00am

Sat 20th Lunch at Rodmill, Midday

Weds 24th Bourne Free, Ratton School 6-8pm

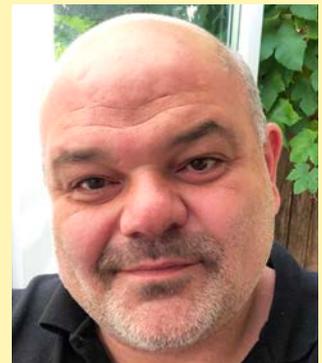
Sat 27th Fuscuardi's Ice Cream Parlour, Eastbourne - Midday

Wherever possible, please let us know if you're planning to join us on any of these events. (Lisa for West Sussex events or Rom for East Sussex). This is to make sure we have the right resources in place which should make your visit more comfortable and enjoyable. Although we try our best to avoid this, if we think an event is not going to be attended, we may cancel it and we would hate for anyone to turn up and find they are alone.

You can contact us by phone or text on the above numbers, email Lisa or Rom, or message us on Facebook, messenger or WhatsApp.



Lisa Keys
07725433136
lisa@sasbah.org.uk



Rom Sanglaji
07779 038542
rom@sasbah.org.uk

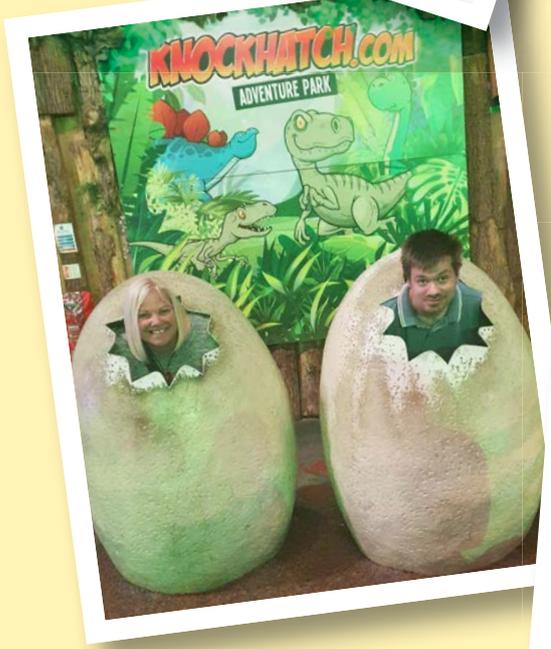
Please note that Lisa works part time, and much of that time is spent out and about at activities, so if you can't get hold of her, make sure you leave a message and she'll get back to you as soon as she can, but it may not be the same day. If your message is urgent, you can contact our office during the daytime on 01825 873045.

We welcome anyone connected with SASBAH, including service users, family members, carers, volunteers and friends. All the venues we use are accessible to the best of our knowledge at the time of printing.

SOCIAL ACTIVITIES & LOCAL COMMUNITY GROUPS

Here is a selection of photos from our groups and social activities.







DIGITAL ACTIVITIES

JULY/AUGUST 2022

Below are digital activities for July and August. We have added a couple of new groups which have been suggested by our Service Users. If you need more details on any of the groups or would like to join in please email office@sasbah.org.uk or check out our Facebook page.

JULY

Mon 4th	Virtual Advisors	1pm
Tues 5th	Time to Talk	1pm
Tues 5th	Swoove	6pm
Weds 6th	Bingo	5pm
Thurs 7th	Art With Hilary	5pm
Mon 11th	Virtual Advisors	1pm
Tues 12th	Swoove	6pm
Thurs 14th	Art With Hilary	5pm
Mon 18th	Virtual Advisors	1pm
Tues 19th	Swoove	6pm
Weds 20th	Bingo	5pm
Thurs 21st	Art With Hilary	5pm
Mon 25th	Virtual Advisors	1pm
Tues 26th	Swoove	6pm
Thurs 28th	Ladies that Lunch	1pm
Thurs 28th	Art With Hilary	5pm
Sat 30th	Quiz	5pm

AUGUST

Mon 1st	Virtual Advisors	1pm
Tues 2nd	Time to Talk	1pm
Tues 2nd	Swoove	6pm
Weds 3rd	Bingo	5pm
Thurs 4th	Art With Hilary	5pm
Mon 8th	Virtual Advisors	1pm
Tues 9th	Swoove	6pm
Thurs 11th	Art With Hilary	5pm
Mon 15th	Virtual Advisors	1pm
Tues 16th	Swoove	6pm
Weds 17th	Bingo	5pm
Thurs 18th	Art With Hilary	5pm
Mon 22nd	Virtual Advisors	1pm
Tues 23rd	Swoove	6pm
Thurs 25th	Ladies that Lunch	1pm
Thurs 25th	Art With Hilary	5pm
Sat 27th	Quiz	5pm
Tues 30th	Swoove	6pm
Weds 31st	Bingo	5pm



SASBAH

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STANDING ORDER REQUEST FORM

Complete this form and return it to **SASBAH** and we will do the rest:

Account Name: _____

Account Number: _____ Sort code: _____

Bank Name/Address: _____

_____ Postcode: _____

I would like to pay with a monthly standing order of:

£5.00 £10.00 £25.00 *Other, please state:* _____

I would like to set up a monthly standing order to:

SASBAH, 5/6 Swanwood Park, Gun Hill, Horam TN21 0LL
NatWest Account no: 24096652 Sort Code: 60-11-17

To be paid each month on: 1st 15th 28th

Signed: _____ Date: _____

Print: _____

You can make your donation achieve even more - 25% more at no extra cost to you!



If you are a UK taxpayer then you can help us take advantage of the Government's Gift Aid scheme. At no additional cost to you and simple by completing the form below, we can claim an extra 25p back from the inland revenue for every pound you donate. In order to be eligible you must pay an amount of income tax and/or capital gains tax at least equal to the amount that we reclaim on your donations within the tax year.

I want **SASBAH** to treat all donations I have made for the last seven years, but not before 6 April 2000, and all donations I make from the date of this declaration until I notify them otherwise as Gift Aid donations.

Alternatively, Please treat this and all future donations as Gift Aid donations until I notify you otherwise.

Signature: _____ Date : _____

Please complete and send this form to:

SASBAH, 5/6 Swanwood Park, Gun Hill, Horam TN21 0LL

Registered Charity No: 1175032



SASBAH

SUSSEX ASSOCIATION FOR
SPINA BIFIDA AND HYDROCEPHALUS

FRIENDS OF SASBAH CONFIDENTIAL FORM

Personal details:

Title	Address:
Forename:	
Surname:	Post code:
Date of birth:	Phone No:
Gender:	Mobile No:
Ethnicity:	Email:

I give my consent for the above information, and a record of future contact, to be held by SASBAH

Signed: _____ Date: _____

If the person whose name appears at the top of this form is under 13, please give parent/guardian's name to consent to the child's details being held on the SASBAH database:

Parent/Guardian's name: _____

PHOTO CONSENT. We often use photos for publicity e.g. in our Newsletter/Annual Review/Website. We need your consent to use any photos of you in this way so please indicate here whether or not you give your consent.

I give my consent for SASBAH to use photographs of myself/my child. Yes No *Please tick appropriate box*

All personal information is processed in line with the Data Protection Act 2018.

As a Friend of SASBAH we will keep you up to date with news and information – but please tick the relevant box if you do NOT wish to receive:

Annual Review: by post by email **Newsletter:** by post by email **Monthly E-news:** by email

We will Invite you to take part in particular events and projects – but please tick the box if:

you do not wish to be invited to events you do not wish to receive Draw tickets

Should you wish to make a donation to help cover the ever-rising costs of running our Services that would be much appreciated. You can pay by cash to a member of the staff team, by cheque made payable to SASBAH or by Standing Order. Should you wish to pay by BACS, please contact the office for bank details. If you are a UK Tax payer, you can use Gift Aid to make your donation worth more. This also applies to any donations you make in the future or have made in the last 4 years. Please complete and return the Gift Aid Declaration Form to enable us to make the claim to HMRC.

You will find the Standing Order and Gift Aid forms overleaf.

Please return all forms and donations to: SASBAH, Units 5-6 Swan wood Park, Gun Hill, Horam, TN21 0LL

For official use only

Status:

Received by:

Date: