



# SASBAH

SUSSEX ASSOCIATION FOR  
SPINA BIFIDA AND HYDROCEPHALUS

## NEWSLETTER SUMMER 2024



Getting together with Ant and Dec at Madame Tussaud's in Blackpool.  
More on our Residential Breaks on page 8.

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We currently send out a regular enewsletter.

Should you not currently receive this and would like to  
please contact Lynne on 01825 873045 or  
[office@sasbah.org.uk](mailto:office@sasbah.org.uk)

# CEO UPDATE

## *Greetings to all the SASBAH family and friends*

Hope this newsletter finds you as well as you possibly can be. This newsletter will be an introduction to Tim our new Chair of the Trustee Board and you will read a little about him later on. Tim has made a great start as Chair to the Board and has been very positive in his support for SASBAH service users, staff and volunteers and we welcome you warmly.

I am pleased to report that we are in a very stable position as a small local charity – thanks to Laura our fundraiser who has supported our financial security and the biggest thanks must go to all the staff and volunteers that have ensured that our services continue to be run for the benefit of all of our lovely organisation.

We are currently looking for a new head office to move into, although this is not an emergency I ask if anybody sees any buildings that you think we may be interested

in to contact me directly – not too far away from where we are currently based. I do not want to panic anyone though, the service of Saspire will continue just in a different location not too far away.

Lastly, I look forward to seeing lots of you at the Summer Activity Programme that is shortly upon us and of course very much look forward to Breakaway which will take place on the weekend of the 20th September this year.

If anyone wants to talk to me then please feel free to contact me directly on [rom@sasbah.org.uk](mailto:rom@sasbah.org.uk) or call me on 07779038542.

**See you all soon I hope – Rom**



**Rom Sanglaji**  
07779 038542  
[rom@sasbah.org.uk](mailto:rom@sasbah.org.uk)

# TRUSTEES

In January 2024, I took on the role of Chair of the SASBAH Board of Trustees. I have a very hard act to follow, Hilary Lewis has been superb in her two stints as Chair during the last twenty years. Photo below shows Rom presenting Hilary with a bouquet of flowers at the recent Charity Dinner to thank her for her many years of service. Hilary will continue as a member of the Trustee Board.



My link to SASBAH is through my wife and her parents (Christine, Tony and Eileen Balsdon) and her brother David who had Spina Bifida and Hydrocephalus. Unfortunately David died at an early age. Tony in particular was heavily involved with SASBAH for over 40 years, serving many years as a Trustee.

Over the next year you will see me attend meetings and groups across both East and West Sussex so that I can see first hand all of our activities and wonderful work our staff and volunteers do. I am always interested to hear from the SASBAH family on your experiences and how SASBAH can help you. The best way to contact me is on [tim@sasbah.org.uk](mailto:tim@sasbah.org.uk)

We are also looking to increase our Board of Trustees so if you or anyone you know may be interested, please get in touch.



**Tim**  
01825 873045  
[tim@sasbah.org.uk](mailto:tim@sasbah.org.uk)



# UNIVERSAL CREDIT

Some benefits and tax credits are ending and being replaced by Universal Credit (UC).

The following tax credits and benefits are ending and are being replaced by UC

- Child Tax Credit
- Working Tax Credit
- Housing Benefit
- Income Support
- Income-based Jobseeker's Allowance (JSA)
- Income-related Employment and Support Allowance (ESA). You can check on your ESA entitlement letter to see if you receive either Income-related or contribution-based ESA.

Some of you who claim working tax credits and or child tax credits may have already received a migration notice letter inviting you to apply for UC as your tax credit(s) are ending.

You will receive a letter called a Universal Credit Migration Notice from the Department for Work and Pensions (DWP) explaining what you will need to do and when. **It is important that you do not do anything until you receive your letter.** You will not be moved automatically and you must claim Universal Credit by the deadline date given in your letter. The deadline date for applying is 3 months from when the date of the letter is sent out. The letter will give you instructions to follow.

Please bear in mind your current benefits will end as soon as you submit your claim for Universal Credit. You will not be able to go back to your existing benefit once you have made a claim.

If your Universal Credit entitlement is less than your previous tax credits or benefits then you may be eligible for financial protection when you move to Universal Credit. This additional amount is known as 'transitional protection'.

To be eligible for 'transitional protection':

- you must only apply for Universal Credit once you have received your Universal Credit Migration Notice letter
- you must apply before the deadline date in your Universal Credit Migration Notice letter
- there must be no changes in your circumstances

If you are migrating from Employment and Support Allowance (ESA), you will not need another Work Capability Assessment (WCA) unless you have a change in your health or health condition.



**Zoe Kane**  
01243 551976  
zoe@sasbah.org.uk

## WHEN YOU ARE LIKELY TO GET YOUR LETTER

YOUR CURRENT BENEFIT	DATE
Tax credits only	From now
Tax credits (pension age)	From August 2024
Tax credits with Housing Benefit	From April 2024
Income Support <ul style="list-style-type: none"> <li>– Income Support only</li> <li>– Income Support with Housing Benefit</li> <li>– Income Support with Tax credits</li> <li>– Income Support with Housing Benefit and Tax credits</li> </ul>	From April 2024
Housing Benefits only	From June 2024
Income-related Employment Support Allowance with Child Tax credits	From July 2024
Income-based Jobseekers Allowance	From September 2024
Employment and Support Allowance (ESA) only	You will not be asked to move to Universal Credit until a later date
Employment and Support Allowance with Housing Benefit	You will not be asked to move to Universal Credit until a later date

# UNIVERSAL CREDIT<sup>CONTINUED</sup>

In the latest edition of **Benefits and Work and DWP Touchbase e-newsletters** it states:

## ESA TO UC MIGRATION TO BEGIN IN SEPTEMBER 2024

The DWP have confirmed that they are planning to begin moving:

- income-related ESA claimants; and
- ESA with housing benefit claimants to UC from September 2024.

**All affected claimants will have been issued with migration notices by December 2025. This is much earlier than the previous timetable, under which migration for ESA claimants would not have begun until 2028.**

To make your claim for Universal Credit as quick and easy as possible, it is useful to have everything you need before you start.

To apply online you will need:

- your bank, building society or credit union account details
- an email address
- access to a phone

If you do not have these, you can call the Universal Credit helpline or go to a jobcentre. You can also get support from the Citizens Advice Help to Claim service (details are below).

You will also have to prove your identity. You will need some identity documents for this, for example your:

- driving licence
- passport
- debit or credit card
- payslip or P60

To complete your claim you will need to provide information about:

- your housing, for example how much rent you pay
- your earnings, for example payslips
- your National Insurance number, if you have one
- other benefits you get
- any disability or health condition that affects your work
- how much you pay for childcare if you want help with childcare costs
- your savings and any investments, like shares or a property that you rent out

You might need an appointment with the Universal Credit team if:

- they need more information
- you cannot verify your identity online

### Universal Credit Helpline

**0800 328 5644**

### Citizens Advice Help to Claim service

**0800 144 8 444**

They can help you with the early stages of your Universal Credit claim. You can talk to them on the phone, online over chat or using our British Sign Language (BSL) service.

Their advisers can help you:

- work out if you can get Universal Credit
- fill in the Universal Credit application
- prepare for your first Jobcentre appointment
- check your first payment is correct

### Source:

<https://ucmove.campaign.gov.uk/#jump>

<https://www.citizensadvice.org.uk/benefits/universal-credit/claiming/helpclaim/>

**To contact Zoe with any questions you may have, please ring her on 01243551976. If you can't get hold of her, leave a message and your name and telephone number and she will get back to her as soon as she can.**

**Alternatively, you can email her at [zoe@sasbah.org.uk](mailto:zoe@sasbah.org.uk).**

# SASPIRE

Dominic joined us in September 2023 as Work Experience Assistant. As a trained chef, Dominic has enjoyed passing on some of his experience to our Service Users who attend Saspire. They have helped to cook lunch using fresh ingredients helping some of them to overcome past negative experiences with food. They are now doing simple things such as making drinks



for the others, laying tables for group lunches, clearing up after meals, washing up and putting things away to increase their independent skills.

We are still working with Brewers processing their wallpaper samples and sample boxes for UK and US markets and their trade shows. When work is completed we have a program of board games, puzzles and quizzes.

We have an incredible outside space where we do group sports which helps with hand eye coordination and balance.

Chair aerobics helps with flexibility and healthy exercise.



**Dominic**  
01825 873045  
[dominic@sasbah.org.uk](mailto:dominic@sasbah.org.uk)

*Left: Preparing for Christmas*

*Below: A visit from Brewers*





# TRUSTS FUNDRAISER

**Hello All, Laura your friendly trusts fundraiser here, ready to tell you all about the exciting things that have been going on in my neck of the woods (actually, I work from home, not up a tree).**

Over the winter, for example, we were fortunate to receive extra funding towards the increased costs of our core services, a grant from the Police to buy an i-pad for Bourne Free, and a special grant to support people through the colder weather. Teddy, scourge of the local squirrel population, (pictured) believes summer is here already and that my work as SASBAH's Trusts Fundraiser is a bit boring by

comparison. "Well, Teddy" I tell him, "actually it's REALLY interesting. I sit at my desk and write to trusts and foundations, telling them why SASBAH is a great charity that works hard to support our lovely service users and actually, ..." But Teddy has fallen asleep in the sunshine, dreaming of the squirrels in the woods. I would like to add that we are hugely grateful to the forty-or-so trusts and foundations that support us every year and to the volunteers who give so generously of their time. I also know that my colleagues on the staff all work super hard, and suspect that Rom even works at SASBAH in his sleep.



**Laura**  
01825 873045  
[laura@sasbah.org.uk](mailto:laura@sasbah.org.uk)

Did you know, that apart from soaking up the sun's rays, summer is a great time to get outside and help raise money for SASBAH? ...there are as many possibilities as we can think of. Maybe, your local support group can take up your suggestions? The coming months promise a wonderful range of events, summer activities, residential breaks as well as the regular groups and services. If you use these services, do keep telling us what you like, what you need more of (not dog treats, Ted, you're round enough already) and what we can do to support you. Our work is all about working together with you, and I for one will carry on tapping away on my laptop in my quiet corner, endeavouring to help secure the funds to make things happen, while Teddy snores.

**Enjoy the summer, lovely people!**  
**Laura**



# FUNDRAISING

## In Memorium

Thanks so much to Clare Betts and family for their kind donations in memory of Clare's son Mason. Their continued support is greatly appreciated.

## 2024 Charity Golf Day



SASBAH held its golf day on the 19th June 2024. This was our 30th Annual Golf Day which was commenced by Mike and Tony Sandford in 1993. We were blessed with great weather and 52 players enjoyed playing golf whilst raising over £2000 for SASBAH. Congratulations to a team from Mid Sussex of Peter Marshall, Darren Burberry, Andrew Humphries and Graham Somerville that won the team prize with Mark Burnham winning the individual prize. Hannah Sandford did a great job of presenting the winners' prizes at a dinner following the event.

We wish to thank all our hole sponsors and Christine McDermott-Roe, Sue and Edward Barlow for ensuring the day went so smoothly.

We are already planning the 2025 event, which we will make a bumper tournament in our 60th year. If you know of any golfers who may want to attend or companies that may sponsor a hole please let Tim know at [events@sasbah.org.uk](mailto:events@sasbah.org.uk)

## Mid Sussex Group

The Mid-Sussex support group held a pub quiz at the Woolpack Burgess Hill on the 10th October 2023. We had 14 teams that enjoyed a challenging but fun quiz. The evening raised £413 for SASBAH. A second quiz was held on 26th March 2024 with this evening raising £520. Thanks to Tim and Christine McDermott-Roe for organising these events and to Fiona Davies for helping out.

## SASBAH Charity Dinner

On 27th April 2024 we held a dinner at The View Hotel Eastbourne. The entertainment included Helen Ward Jackson (Adele tribute) and Cherry Dance. DJs for the evening were our own Mikey and Perry!

Thanks to Amanda Saunders for organising the raffle which raised £620.



## Donations

There are several ways to make a donation to SASBAH, and all donations received go towards making our services run smoothly. **Friends donation** - Should you wish to donate to help cover the ever-rising costs of running our Services that would be much appreciated. Just fill in the enclosed form and return to the office with your donation or you can pay directly into the bank. **Regular donations** - we have a number of people who make regular donations every month and we thank them for their continued support. If you would like to make a donation in this way, the relevant form is enclosed.



# SASBAH RESIDENTIAL BREAKS 2023/4

## Mindfulness and Wellbeing

This break was held in July 2023 and included a series of workshops, treatments and classes to help with mindfulness, relaxation and wellbeing.



## Breakaway

Breakaway was held in September 2023. As usual, this was held at Lodge Hill outdoor Activity Centre in Pulborough. Breakaway this year is from 20th to 22nd September



## Butlins February 2024

This was the Family Break at Butlins Bognor Regis and was enjoyed by all who attended.



## Blackpool May 2024

We returned to the Bond Hotel in Blackpool after a few years break for our Adult Residential Break.







## BOURNE FREE

Amanda 01815 873045,  
office@sasbah.org.uk

Becky 01825 873045,  
office@sasbah.org.uk

Bourne Free sessions are held fortnightly on a Wednesday evening between 6pm and 8pm at Ratton School, Eastbourne. Amanda and Becky run the groups which offer a varied programme to suit all tastes. If you'd like to go along please contact the office on 01825 873045 or email office@sasbah.org.uk for more details. All sessions are detailed in the monthly newsletter and on our Facebook page.

Above: Craft Evening with Jen, making Easter decorations



Movie Night



Outdoor Games Night



Swoove with Jo



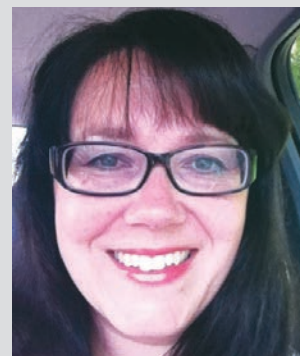
# SOCIAL ACTIVITIES

**Contact details: General enquiries –  
office@sasbah.org.uk – 01825 873045  
West Sussex**

Lisa organises all our West Sussex Social Activities and Local Support Groups. There is a very varied programme to suit all tastes and includes bowling, lunches, walks and museum visits. On the first Thursday of the month there is a quiz at the North Star pub in Worthing. The Local Support Groups are: Crawley on the 2nd Wednesday of every month, Worthing on the 3rd Friday and Mid Sussex on the 4th Wednesday. All activities are advertised in our monthly enewsletter and on our Facebook page.

Wherever possible, please let Lisa know if you're planning to join us on any of these events. This is to make sure we have the right resources in place. Although we try our best to avoid this, if we think an event is not going to be attended, we

may cancel it. You can contact Lisa by phone or text on 07725 433136, or email [lisa@sasbah.org.uk](mailto:lisa@sasbah.org.uk), or message me on Facebook, messenger or WhatsApp. 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.



**Lisa**  
**07725 433136**  
**[lisa@sasbah.org.uk](mailto:lisa@sasbah.org.uk)**

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.





## SOCIAL ACTIVITIES *CONTINUED*

All our East Sussex Activities are organised by either Helen or Rom and are advertised in our monthly enewsletters. If you don't already receive this and would like a copy please email Lynne at [office@sasbah.org.uk](mailto:office@sasbah.org.uk) and she will add you to her circulation list. Most of Rom's activities are held on a Saturday and include lunches out, shopping and walks.

Helen joined us in June 2023 and here are a few words from her.

### ***Hello there!***

My name is Helen and I am the East Sussex Events coordinator. I organise and arrange several events each month for our wonderful service users. I ensure they are inclusive. We are a lively bunch and there are many meals out, social gatherings,

crazy golf, movies, tenpin bowling, nightclubs etc. We all have a good time – no matter where we are or where we go. There is always a lot of fun, banter and laughing.

I also organise a support group for Rother on the first Friday of every month, which usually involves a lovely lunch. This group is for the service users, their families, and their parents. It's a chance for us to get together and see how we are all doing and feeling. There is always good food and big hugs! Everyone from anywhere in Sussex is always welcome.



**Helen**  
07899 801045  
[heleh@sasbah.org.uk](mailto:heleh@sasbah.org.uk)





# DIGITAL ACTIVITIES

We started our Digital Activities program in 2020 during lockdown. They proved extremely popular and so we have continued to run a number of them. Some of our Service users who are unable to get out and about for a variety of reasons have said they have been a lifeline to them and really enjoy the contact with others that attending the sessions offers to them. Details of all activities are in our monthly enewsletter and on our Facebook page.

## Art With Hilary

The group are happy to try anything and have covered a range of subjects. Anyone is welcome to join - the sessions are good fun and you don't need to be an 'artist' to enjoy. The weekly sessions are advertised on our Facebook page and if you would like an email invitation please contact Lynne at [office@sasbah.org.uk](mailto:office@sasbah.org.uk). Below are a few of our paintings.



## Swoove

Swoove is run by the lovely Jo Hardy fortnightly on Wednesday.

It's well attended and is a fantastic way to help people with limited mobility to get some exercise.



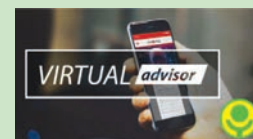
## Ladies That Lunch

This is a group hosted by Zoe or Lisa and is held on the last Thursday of the month. It's an opportunity for the ladies to discuss issues which affect them.



## Virtual Advisors

The Virtual Advisors session is held every Monday and is hosted by Zoe.



## Bingo

Bingo is held every Tuesday and is hosted by Lisa or Rom. It is very popular and such good fun.

