



SASBAH

SUSSEX ASSOCIATION FOR
SPINA BIFIDA AND HYDROCEPHALUS

Impact Report 2023

Set up by families in 1965 for people in Sussex affected by spina bifida, hydrocephalus (SB&H) and other disabilities, SASBAH offers support, skills and opportunities to live a full and happy life. Working together with our community we create high quality options to meet the individual needs of service users.

We remain the only organisation in Sussex able to provide a range of condition-specific services and we are unique in committing to support people for their entire life.



Coronation Party May 2023

In 2023 we have continued to work with people to meet the range of needs that have arisen, especially with the continued rises in the costs of living. With additional training and support, we successfully ran a Winter Warmth campaign, helping ensure people could stay warm and safe during the colder months, whilst increasing awareness of heating homes and finding affordable tariffs and energy suppliers.

Family support and youth development have continued to feature strongly in our work, as we enable people of all ages to get together, make friends and access professional support. In addition, our residential breaks have provided opportunities for new and exciting adventures, to build independence and resilience in young and old, alike.

Saspire has continued to inspire and benefit a large group of younger adults to build their team skills and to take part in work, as volunteers.

'SASBAH plays a huge part in my emotional wellbeing and mental health'

I am always touched to learn how SASBAH is impacting on the lives of service users. It is easy to get caught up in a busy schedule, working hard behind the scenes to ensure the wheels keep turning. But at the end of the day, it is every person who takes part, contributes and shares of themselves, that makes SASBAH the success that it is.

We are grateful to the many volunteers, including our trustees, who give their time freely and contribute to the wealth of opportunities and to our funders who make it possible; to our dedicated staff team, and most of all, to our service users whose engagement and well-being forms the basis for all this work. As always, I am proud of the ways in which we continue to come together to develop and enhance SASBAH's services.

Rom Sanglaji – SASBAH CEO



Breakaway 2023

What is Spina Bifida?

Spina Bifida occurs very early in pregnancy, and is a defect in the development of the spine when or more vertebrae fail to close properly, leaving a gap. The spinal cord and nerves can be damaged, resulting in total paralysis below the defect. Many people with the condition rely on the use of a wheelchair or have severe mobility problems. Most will have serious bladder or bowel conditions. Although spina bifida is itself a physical disability, a high proportion of people with the condition will also have hydrocephalus.

What is Hydrocephalus?

Hydrocephalus is an excess of cerebro-spinal fluid in the head, often, but not necessarily, present at birth. Excessive swelling can cause accelerated growth of the baby's head and damage to the brain. Hydrocephalus can also be acquired later in life through trauma of one form or another, or through still unknown causes in people over the age of 50 (normal pressure hydrocephalus). The symptoms are often not recognised as requiring special treatment, especially if there is no, or only little, physical impairment. Known as the 'hidden disability', the condition typically gives rise directly to lack of motivation, concentration and spatial awareness, poor short-term memory, learning disabilities, problems with co-ordination and social difficulties. Later in life it can be associated with, and often mistaken for dementia. Babies are still being born with both conditions, though recently those with hydrocephalus alone are in the majority.



'SASBAH have become my extended family over the last 13 years. They are a huge part of my life socially and are always there if I need help or support. I enjoy meeting up with the friends I have made socially face to face or on zoom. It is reassuring to be with people who understand my conditions, and to share experiences with others who face similar difficulties and challenges to me. I am not sure what I would do without SASBAH – thank you!'

2023 at a glance

SASBAH supported over 500 service users and 500+ family / carers

"The support I receive is second to none."

224 people were supported to attend group **social events** across the county. SASBAH provided a range of fun, accessible and engaging activities ranging from bowling, meals out, walks and trips to tourist attractions.

"I have met lovely people and feel so included; less isolated."

68 people attended SASBAH **45 local support groups** held each month across the county in Bexhill, Burgess Hill, Crawley and Worthing.

'You are always there if I need help with anything as I find things can become overwhelming and complicated'

72 children and young people enjoyed **residential breaks** with SASBAH Youth Development programme, that included a Family Break and *Breakaway*, a young people's activity break.

32 adults, families and carers enjoyed a Well-being and Mindfulness residential, weekend.

26,000+ respite hours were provided for carers through our residential breaks, Bourne Free youth club, social events and SASPIRE.

66 volunteers supported SASBAH through community fundraising, residential breaks and at Saspire our work experience centre, to name a few!

3,209 individual case contacts made by **SASBAH Advisers** who provided advice and advocacy on issues such as welfare benefits, relationships, housing, care provision and any matters affecting everyday living for people with spina bifida, hydrocephalus and other complex disabilities. Our Advisers also hold an online, weekly Virtual Advisers session.

'Thank you sooo much, I could not have done this without all your help and support throughout, and am happy and relieved it is all over with and I got the benefit back.'

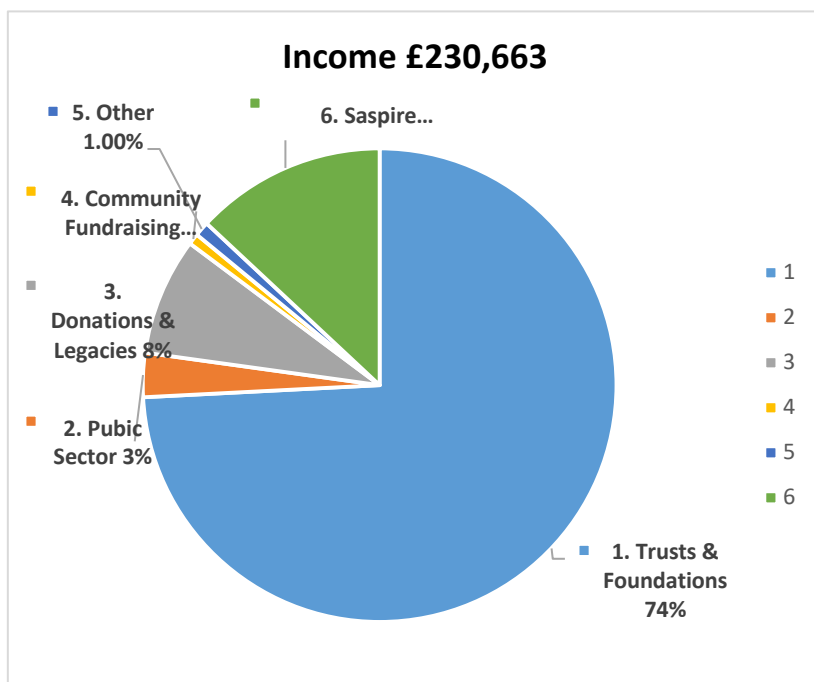
58 people attended **Bourne Free** our social group for young people that meets fortnightly in person, on a Wednesday evening for fun, activities such as sports, arts, games etc, and to make friends.

38 people attended **SASPIRE** our work experience and training project, that supports people with disabilities to volunteer, with support, in an accessible, structured workplace, to develop skills and confidence and increase future opportunities.

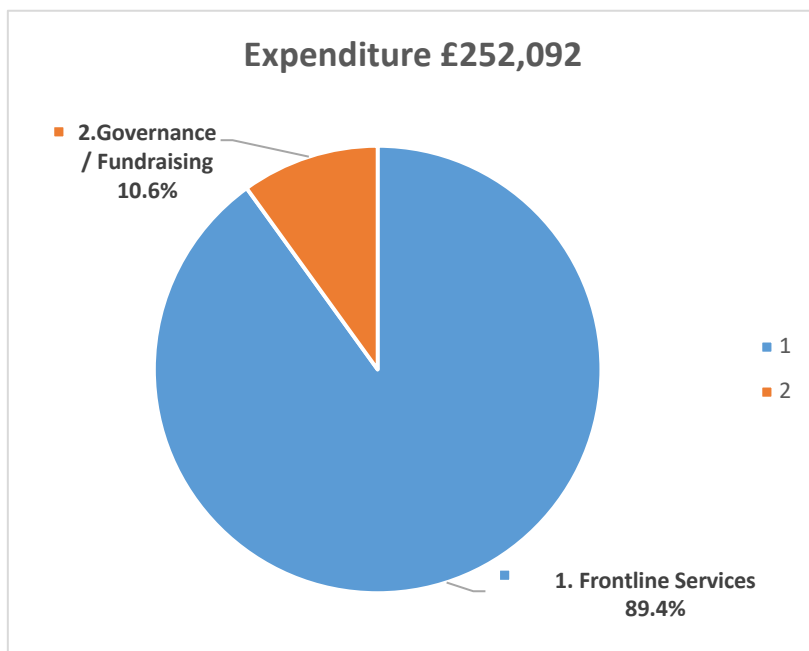
181 people attended our online **Digital Activities** – including fortnightly Bourne Free Digital, weekly bingo, hobbies, art, Swoove - dance and exercise sessions, Virtual Advisers, monthly guest speakers and social get-togethers.

'I enjoy meeting my friends socially with SASBAH and on zoom'

Our finances in 2023



In 2023, SASBAH attained a level of income below £250k signalling a return toward financial normality, although expenditure was just above this level. Due to unusually high levels of reserves previously created by the pandemic, we were able to raise our expenditure on frontline services in response to an increased need for support around the rising costs of living and a challenging economic environment for service users.



This increased expenditure in relation to income allowed SASBAH to reduce the levels of our reserves, whilst maintaining our resilience and supporting over 1,000 people during the year.

Our working efficiency is reflected in our ability to keep organisational costs such as fundraising and governance low, at around 10%, while supporting high levels of expenditure on

delivering much-needed, professional, frontline services.

We are grateful to the many funders who generously support this work and to our dedicated staff and volunteers.

SASBAH financial year runs from 1st January to 31st December and our full accounts and trustees' report are available on our website and on that of the Charity Commission for England and Wales.

2023 Music and Drama 4-day Workshop

“I overcame my fears of performing in front of a live audience!”



How you can help

SASBAH needs volunteers – with your support we achieve so much more! We are always on the look-out for people to join our Board of Trustees, or to support with community fundraising and other activities. If you can bring enthusiasm and commitment to help us reach our goals, we would like to hear from you. Please do get in touch using the details below.

Contact us SASBAH, 5/6 Swanwood Park, Gun Hill, Heathfield, East Sussex, TN21 0LL

Tel: 01825 873045 Email: office@sasbah.org.uk website: <https://sasbah.org.uk/>

www.facebook.com/SASBAHOffice www.justgiving.com/sasbah

Registered Charity no 1175032



SASBAH Trips and Activities in 2023