



SASBAH

SUSSEX ASSOCIATION FOR
SPINA BIFIDA AND HYDROCEPHALUS

IMPACT REPORT 2019



**OVER 50 YEARS OF
SUPPORT IN SUSSEX**

www.sasbah.org.uk





Meeting the challenges

Our mission is to support all people in Sussex affected by spina bifida, hydrocephalus and other related conditions to achieve their potential, whilst promoting understanding of, and respect for, those with these conditions.

We achieve this by:

Offering life-long support for health, wellbeing and life opportunities, with a focus on increasing emotional resilience and quality of life.

Combating social isolation through building social and independent living skills, providing networking opportunities and offering inclusive services.

Supporting development and learning for children, young people and adults; meeting the challenges of living independently, developing skills for employment and coping with change.

Building awareness and understanding in our community, through events, fundraising activities and networking.

Providing information, expert advice and advocacy for those with the conditions, their families and carers.

Certain elements of our support services are also available to those with other physical, sensory or learning disabilities. Moving forward, in the uncertain times brought on by coronavirus, our mission is unchanged. Many of the challenges are magnified. We have had to adapt the delivery of our services and continue to review and develop all we do in response to identified need.

What is Spina Bifida?

Spina Bifida occurs very early in pregnancy, and is a defect in the development of the spine when one 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 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 a 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 age 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 of 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.

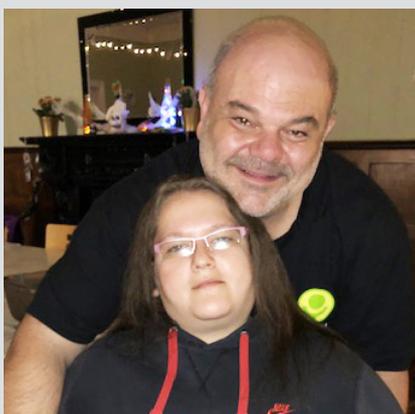
How did we do?

A year full of opportunities and threats – but SASBAH came out on top!

2019 began with what we then thought were difficult times, but through sheer hard work and determination, and with opportunities seized, ended on a far more positive note. Looking back, from the position in which we now find ourselves amid COVID restrictions and so much uncertainty, 2019 was a very “normal” year for SASBAH.

Financial concerns formed one of the threats we faced and sadly led to us giving up our Worthing Office. Prudence had also suggested that we should bring in-house our social enterprise, Saspire, formerly a wholly owned subsidiary and in 2019 that proved to have been the right thing to do.

Far more exciting were the opportunities which enabled us to make so much progress and help balance the books by the end of the year. Support for our awareness and fundraising efforts came from many directions. We were chosen to be Charity of the Year for Sainsbury’s in Heathfield, where a variety of opportunities for those gaining work experience through Saspire became a real bonus. Sax with a Twist, a local saxophone quartet, boosted collections at M&S in Bexhill and support from the store included a team of staff volunteering for a day to redecorate the SASBAH office. It had never been so spick and span! Jack Newman



ran the London Marathon and once again our trusty band of volunteers in Burgess Hill exceeded their fundraising target with quiz nights, stalls, coffee mornings and more. We ended with Battle Bawlers carol singing for the eighth consecutive year.

Looking positively to the future, and with thanks to John Eldridge Design, we launched our new branding, including a redesigned website. With support from Lloyds Bank Foundation, and following what felt like a great deal of detailed work, we were also able to set up a new database to keep safe all our service records and assist with monitoring and evaluation.

Throughout all the ups and downs our focus on service delivery was

steadfast. The highlights, as always, were the times when we brought people together. Participants in our hugely popular Drama Workshop chose the theme “Friends” (pictured overleaf) and explored what friendship means to them. You can see opposite some of the young people at Breakaway, our residential activities break, taking part in a sponsored Swoove - Sing It, Whoop It, Move It, Swoove It! Our monthly Local Support Groups, Family Break and Adult break were other opportunities we so readily took for granted and which we now wait to be able to return to.

Rom Sanglaji,
Chief Executive, SASBAH

Positive feedback:

“ SASBAH for me provides great support emotionally and mentally ”

“ Just wanted to say a heartfelt thank you for all the hours of work you gave to the outcome of my benefit tribunal. I couldn’t have done it without you. So grateful. ”

“ I cannot never ever thank you enough for all the help and support you have given me. ”



2019 At a glance

7	People from Saspire, SASBAH's training and work experience centre, moved on to employment
29	Personal development plans in place for young people
34	Children with special educational needs and their families received support
37	Individuals with disabilities regularly attending Saspire
46	Members at Bourne Free, SASBAH's disabilities group for young people
54	Individuals made a total of 289 attendances at 48 meetings of our Local Support Groups
57	Children and young people attended our residential breaks
93	Group social events attended by over 170 individuals
125	125 Volunteers contributed 20,960 hours of support
3,362	Individual case contacts made by SASBAH Advisers
20k+	Hours of respite provided for carers

How we help...

SASBAH has over 50 years' experience in supporting and developing the health, wellbeing and life opportunities of people with spina bifida, hydrocephalus and other related conditions. We don't take a 'one size fits all' approach. We consider each case individually, offering high quality options to meet our service users' needs.

ADVISER SERVICE

By understanding the conditions we can offer expert advice, advocacy and information on issues such as benefits, relationships, adaptations, care provision, education, housing, personal finances and any other matters affecting everyday life. Bringing a knowledge and understanding of the benefits system ensures the correct level of statutory support is in place, which in itself can reduce stress, anxiety and uncertainty. Our Advisers' support and encouragement help increase people's confidence and enable the ability to gain control over their lives through informed choices.

SOCIAL ACTIVITIES

In 2019 SASBAH's support for people with these challenging conditions aimed to help them participate fully in community life. We offered a range of fun and engaging activities, in local communities across Sussex. Trips out to go bowling, have a coffee and shop, a meal and pub quiz or visit historical places of interest or beautiful gardens were all popular and helped to combat social isolation and loneliness. New approaches, including interest groups and activities on Zoom, have since been introduced and moving forward we hope, in time, to be able to offer this alongside a return to in person activities.

LOCAL SUPPORT GROUPS

Open to all, our monthly groups offered regular social gatherings for like-minded people. For all those affected by the challenges of coping day in and day out with these conditions, including family and carers, getting together with others to share those experiences can be hugely beneficial. The mutual support, exchange of knowledge

and information and simply chatting with those who understand, all help improve wellbeing and build resilience.

COMMUNITY DEVELOPMENT ACTIVITIES

Our aim is to build awareness and understanding in our local communities, of both the specific conditions and the wide-ranging issues affecting those with disability. Through networking, fundraising activities and events we are able to involve many of those who attend our local groups, or benefit from other services, and wish to "give something back". This in turn contributes to social inclusion and provides opportunities for new experiences.

BOURNE FREE

This is a disabilities social group that runs fortnightly in Eastbourne, open to any young person. Group activities include sports, art and crafts, games, music and much more. The focus of this group is having fun, making friends and enjoying social time together. It helps to build self-confidence and esteem for those who attend and provides respite for parents and carers. Bourne Free has since had to move online, delivering weekly sessions of fun activities to keep this group engaged and socially active.

RESIDENTIAL BREAKS

In 2019 we ran three residential breaks. One for children and young people, one for families and one for adults. The first, "Breakaway", included a range of fun but challenging activities and gave the young people the opportunity for increased independence. The time away from home increases self-reliance and confidence, as well

as providing much needed respite for carers. The family break gave 15 families the chance to come together and share fun experiences, make friends and re-charge their batteries for the ongoing 24/7 caring duties they have to manage. And 8 adults enjoyed a "mini break" with others facing similar life challenges.

TRAINING & DEVELOPMENT

The continuing development of everyone involved is important to us. So, we provided one to one specific support to create a personal development plan, identify training needs and set appropriate goals, both for occupational aspirations and for life. We also researched training opportunities and potential work placements to meet the identified development needs.

SASBAH CLINIC

In partnership with the NHS, a preventative health care clinic is run at Chailey Clinical Services which gives adults with spina bifida and hydrocephalus access to a regular health check. This support is accessed by GP referral.

SASPIRE

Saspire is our work experience centre, providing a stimulating and fully supported environment for disabled adults to gain personal, social and work-based skills. There is a strong emphasis on personal development and promoting greater independence, which increases prospects of employment or other worthwhile occupation. Saspire fosters a strong work ethic, and also delivers structure, purpose and fulfilment to the lives of those attending. Contracts of work are fulfilled, working in partnership with local businesses, and in 2019 we were particularly grateful to Brewers plc for their continuing support.

Living with Hydrocephalus

Simon's Story

Simon has had hydrocephalus since birth. He is now in his early fifties, living independently, and has been volunteering in a local charity shop for 15 years. As a member of SASBAH's Hastings & Rother support group Simon is well known for his sense of humour and passionate support for Everton FC. On a good day he will come across as articulate and bright. But the issues are all too real and on a bad day, when his head, neck and back all ache, Simon is barely able to function. Hydrocephalus is by its very nature a hidden condition and it is this aspect that has had the greatest impact on his life. It gives rise to cognitive difficulties, a lack of motivation, anxiety, depression and paranoia. All of this affects Simon's emotional wellbeing but remains largely unseen.

When Simon was born his Mum, Julia, had never heard of hydrocephalus. As a baby his head grew large and heavy and, when she noticed that his eyes were rolling, it was time to get help. Over the years Simon has undergone surgery more than 30 times but Julia particularly remembers that first time, not yet certain of the diagnosis and having to return home with an empty carrycot, while he remained in

Julia and Simon (8) at The Smuggler, Pett Level, a summer holiday favourite.



hospital for weeks having the first of many shunts fitted. Simon's surgeon advised "no contact sports" but that otherwise Simon should be treated like any other child. There was no other information or guidance and no one else in their small village with the condition. Initially not knowing who to turn to, Julia was grateful to be put in touch with SASBAH, then itself only a couple of years old, and an Adviser came to visit them at home.

'SASBAH's Adviser became our lifeline as we learnt over the years how hydrocephalus was affecting Simon's physical and mental health.'

Sadly, just like for so many children with this condition, bullying was an issue at secondary school. But Simon's worst experience was not due to his fellow pupils. Having completed a cross-country run "too slowly" he was forced by the teacher to run again. Dehydration upset the functioning of his shunt and Simon collapsed. Julia was more than furious.

After school Simon had a varied series of jobs but, worried that they wouldn't take him on due to a lack of understanding about hydrocephalus, didn't tell prospective employers that he had a shunt. Sadly, this led to a number of situations which put his health at risk, particularly through heavy lifting. Unable to cope with pressure and feeling there were just too many hurdles to overcome, Simon found it difficult to hold down a job. In complete contrast, at the Cancer Research shop where he now volunteers there is full understanding and acceptance that some days he is unable to go in.

At the age of 25 Simon began the transition to independent living, with SASBAH facilitating a move into supported living. Invariably it is a challenge to find suitable



Simon with his step-dad, Mike.

accommodation, but Simon has continued to manage to live on his own, with family and SASBAH's Adviser always there in the background for support.

There have been other health issues to contend with. A benign tumour on his adrenal glands, discovered during a shunt revision, caused dangerously high levels of adrenaline and consequent high blood pressure. More recently Simon was diagnosed with type 2 diabetes.

All of this, together with hydrocephalus, means some very complex form filling when it comes to securing the appropriate benefits. Short term memory difficulties, poor concentration and processing delays mean, in Simon's words, **'It would have been impossible for me to do it on my own.'** He is full of praise for the one to one support SASBAH provides, and hugely appreciative that, through rigorous attention to detail, all benefit appeals have been won.

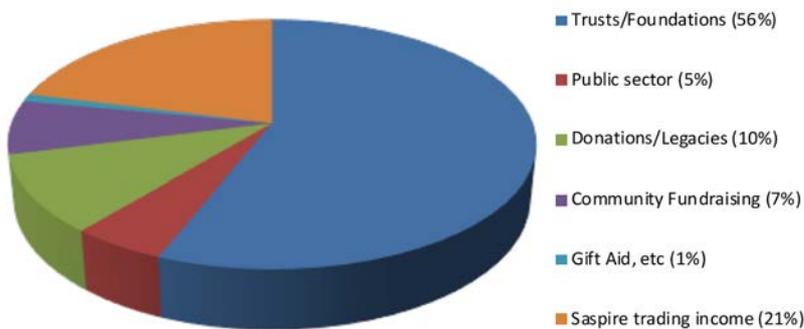
'There have been so many times when I don't know what would have happened if SASBAH hadn't been there.'

Julia and Simon agree - it is thanks to the regular support and reassurance, which alleviates his paranoia and anxieties, that Simon continues to cope with day to day life.

The Money Page

Our finances in 2019

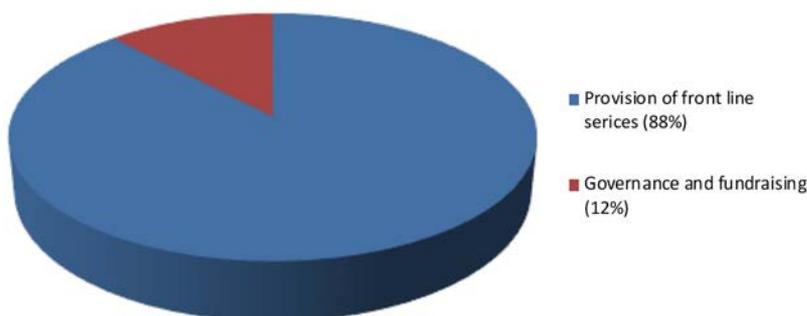
Income £239,746



- 34% increase, year on year, in funding received from trusts and foundations

- 76% increase on 2018 levels of donations

Expenditure £242,383



- 2019 saw a steady recovery resulting in income and expenditure being closely matched

Looking to the future, our challenges will include mitigating the loss of community fundraising income and a significant decline in our trading income, whilst our social enterprise is unable to operate, during the pandemic.

Our full accounts, which are available on request or to download from our website, have been independently examined and verified by our accountants, Ashdown Hurrey, and include details of the grants received from trusts and foundations.



We couldn't do it without you

Like all smaller charities we owe so much to those whose support enables us to maintain and develop our services. Sainsbury's in Heathfield provided the opportunity for work experience in their in-store bakery for Tracy and Sam from Saspire (seen above) and so many other individuals and organisations have made generous contributions, but sadly we just don't have the space here to acknowledge them all. Whether you have given your time as a volunteer, made a financial contribution, helped on stalls or at collections, undertaken a challenge, donated in memory of a loved one or organised an event to raise funds and awareness – ***we thank you!***

How you can help

SASBAH needs volunteers – with their help we can achieve so much more! The **20,960** hours of support contributed during 2019 (based on the real living wage rate) is worth an incredible **£194,928!** If you would like to undertake the challenge of a lifetime, organise a fundraising event, help out on a residential break or give your time as a Trustee or support worker at Saspire, our work experience centre, do get in touch using the details below.

Contact us

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