

BBS UK Spring Newsletter 2018

BBS UK Contact Information

Tonia Hymers
07591 206680
tonia.hymers@bbsuk.org.uk

Angela Scudder
07591 206788
angela.scudder@bbsuk.org.uk

Amy Clapp
07591 206787
amy.clapp@bbsuk.org.uk

www.bbsuk.org.uk

Foreword

With Winter now behind us and Spring firmly established, we hope you are all enjoying and making the most of the warmer days. At BBS UK we are in the midst of 'Conference Fever', finalising plans and putting the final touches to what promises to be another fabulous weekend.

BBS UK is about to undergo a significant change over the next few months as it converts to a Charitable Incorporated Organisation (CIO). Despite the growth and change, your Board remain protective custodians of the charity's original aims and objectives, which are to preserve and protect the health and promote the welfare of persons affected by BBS and their families and to advance the education of the medical and educational professions and the general public on the subject of BBS and its implications for the family. We always have been and always will be committed to this aim.

The charity has had another busy year planning, organising and supporting our various projects and events and in raising awareness of our syndrome. The charity continues to develop and the trustees are very proud of its progress in strengthening its governance, finance and fundraising activities. Tonia Hymers, Angela Scudder and Amy Clapp continue to work tirelessly in their roles within the BBS clinics and throughout the charity projects and the Board of Trustees value working with such a dedicated team of people who all share the same goal of ensuring BBS UK continues to go from strength to strength.

Tonia, who is also our newsletter editor, continues to ensure that members are supported in receiving information and resources and she single handedly creates these amazing newsletters every year for us all to enjoy, learn and be inspired by.

This newsletter is only possible with your contribution and support, so please keep in touch and keep sending your news and fundraising stories and anything else that you think will be of interest to our readers; we look forward to hearing from you soon.

We hope you enjoy this bumper newsletter, packed with inspiring stories, news and useful information. We are overwhelmed by the fundraising achievements of so many of our members and can't thank you all enough.

BBS UK Board of Trustees

Rare Disease Day 2018

St Thomas' Hospital showcased their wonderful newly opened Rare Disease Centre, the home of BBS Clinics for the London Adults Service, at an event to mark Rare Disease Day on 28th February 2018. BBS UK, together with two other patient groups who use the centre, were invited to exhibit posters, banners and leaflets to raise awareness about their rare disease and the new centre. Each table also had cakes for sale to raise money to develop an outdoor space into a garden for the new centre.

We were invited to meet Steve Brine, MP and Parliamentary Under-Secretary of State for Public Health and Primary Care, to talk about the experience of living with a rare disease. BBS UK Vice-Chairman, Stefan Crocker represented BBS UK along with BBS UK Support Officers, Angela Scudder and Amy Clapp, Stefan said:

"I was quite nervous as I wanted to represent the charity I love in the best possible way. I found Steve Brine to be very easy to talk to. Dr Shehla Mohammed explained the medical side of BBS to him and then he started talking to me about my experiences. I was able to make him laugh when explaining how I see someone with having no head but a body if I look straight at them. I managed to slip into conversation my politics degree when he was asking me about employment and my lack of paid employment. He mentioned a scheme I had not heard of that the Department of Work and Pensions run called Disabled Confident."

Later, the Minister visited the market place and BBS UK's information stand. He took copies of the BBS UK Medical Information Booklet and Conference Report. He was very interested in the glasses Amy had brought along, which gave the wearer the experience of various visual impairments, including Rod-Cone Dystrophy. Stefan reports:

"The Minister came to our table and we persuaded him to buy a cake but as a minister for public health he refused to consume it. He tried on the simulation spectacles and found them very interesting. I explained how the sight degenerates with age, other aspects of the syndrome and that this year we have a focus on health and wellbeing at our conference. I then seemed to bond with him over the topic of football as it turns out he is a fellow Tottenham Hotspur fan."

Members of the BBS Clinics Team, Dr Elizabeth Forsythe, Kath Sparks and Professor Phil Beales also joined us on the BBS UK stand and answered questions from other medical professionals; there was a great deal of interest from the medical community and especially from renal teams. After lunch, Stefan, Angela, Amy, Elizabeth and Kath walked across Westminster Bridge (in the snow) to attend the Rare Disease Reception at the House of Commons. Stefan reports:

"As beautiful as the Houses of Parliament are, they are not very accessible if you are visually impaired. Thankfully Amy Clapp did a stellar job guiding me on the way in and Kath Sparks was fantastic guiding me back out. On arrival we were offered canapés and a glass of wine. Whilst waiting for the speakers to commence we were able to do some networking and I chatted to a Trustee of the support group for Primary Cilia Dyskinesia. One of the speakers was a young person whose rare disease had given her multiple

tumours from a young age and who ended up needing a kidney transplant. She was a very inspiring speaker.”

Steve Brine was the keynote speaker and started by saying how delighted he was with his tour of the Rare Disease Centre and to hear about the amazing work of the patient groups and the difference they make to the patient journey. He went on to say that the highlight of his day was meeting Stefan. Amy and Angela headed back to St Thomas’ and the BBS UK stand while Stefan, Kath and Elizabeth continued networking at the reception. All in all a great day for Rare Disease, BBS and BBS UK!

BBS UK Family Support Team

2017 was a year of restructure and change as BBS UK said a sad farewell to Julie Sales who retired in July. Julie had been the Adults Service Lead for several years and had volunteered for the charity for around 20 years, so it was a big change for the charity, company and team. BBS UK presented Julie with gifts and flowers at the Annual Family Conference in recognition of her contribution over the years. We were very grateful to Julie for the advance notice given of her retirement, which enabled us to plan ahead to ensure a smooth handover; in June we welcomed Amy Clapp to the Clinics Support Team.

The team undertook a full service review which resulted in a restructure, with the service being split geographically: Amy became the Support Officer for the Birmingham Service, Angela Scudder the Support Officer for the London Service and Tonia Hymers the Service Manager. Angela and Amy have really enjoyed getting to know their patient group and the team are enjoying their new roles immensely.

The BBS UK Support Team attended the Annual Service Audit Meeting in November in London along with Service Leads from all four centres, NHS England and BBS UK. The increasingly stretched service and possible solutions were discussed at length throughout the day. BBS UK’s presentation outlined the service restructure, benefits of third sector involvement and the increasing demands being placed on the service. Much of our work is done outside of clinics: providing family and patient support, liaising with families, clinicians and local authorities, facilitating clinics, producing newsletters and organising events. We continue to be busy supporting families with Education, Health and Care Plan applications, PIP and DLA applications and local authority referrals; the ways in which we can support our families are many and the results are rewarding.

It was gratifying to hear Service Leads and NHS England express how important and valued BBS UK’s service provision is. Fitting the specialist multi-disciplinary service within the NHS is always going to present challenges, however good communication with patients and hospitals enables us to ensure the best possible patient experience and feedback also continues to be overwhelmingly positive. Patients and their families tell us how highly they value the service and the fantastic BBS UK Support Team, clinicians and support staff across the four centres.

Late summer, the Cambridge Rare Disease Network invited patient organisations to design and submit a poster about their Rare Disease and Patient Group ahead of their summit in November. Guidelines and suggested headings were given and BBS UK’s poster was based on content from the Medical Information Booklet. We were delighted to be one of five groups shortlisted and invited to give a five minute pitch at the event.

The theme we were given was ‘re-imagining the patient pathway’ and we were asked to come up with three wishes for our pitch. Most of the other groups wished for a specialised clinics service and as we did, a treatment for their condition. In the poster, our hopes and aspirations focused on a future where the

symptoms of BBS are treatable or manageable, that babies and children today won't go blind in the future and won't face a lifetime struggling with obesity.

For the BBS UK Patient Journey, we identified four stages: Pre-Diagnosis, Diagnosis, Treatment and Future Management. The poster describing the four stages has been well received and adopted by other groups for adaptation. You will find it within this newsletter.

We are currently working on the BBS Information Booklet for Schools, a Transition Handbook (titles to be confirmed) and an Introducing BBS booklet which will be made available in other languages. The Information Booklet for Schools and Transition Handbook are being funded by Genetic Disorders UK, within their Jeans for Genes programme and we are incredibly grateful for their support. All BBS UK information booklets are produced in collaboration with patients, parents and professionals with relevant experience and expertise and are produced within the NHS England Information Standard framework, which goes some way towards explaining why our booklets take so long to produce. We are so excited about these publications and hope to have them in circulation in the summer.

The family support team are working hard alongside your Board of Trustees finalising arrangements for Conference 2018, which looks set to be as successful and enjoyable as ever. We are incredibly grateful to the BBS Clinicians and other professionals who continue to support this event year on year, giving up their weekend to ensure our families have the most up to date information about the syndrome, relevant benefits and support; we are blessed to be so very well supported. Look out for the full Conference Report, due out in early autumn.

In November we held our second Adults Social Weekend at the Cobden Hall Hotel in Birmingham and we have been working towards a third Family Activity Weekend to be held in June 2018 at Whitemoor Lakes Activity Centre, you can read about both events elsewhere in this newsletter.

The most enjoyable and rewarding aspect of our role is attending clinic days, conferences and activity events and we look forward to seeing you all over the coming year. In the meantime, a very warm welcome to Amy, the newest member of the BBS Team:

Amy Clapp

BBS UK Clinics Support Officer: Birmingham Service

I'm Amy, married to Gary for 10 years and mum to Abi (17), Josh (16) and Sienna (4). We live in Swadlincote, South Derbyshire. Abi was diagnosed with BBS in 2012.

I enjoy going out for family weekends and meals. My hobbies are paddle boarding and going to music concerts with Abi. I was a volunteer for BBS UK within the clinics service for a year and have now been part of their amazing family support team for the last nine months.

I am still an active volunteer for Sight Support Derbyshire and as a family we join in all local activities. We enjoy supporting both charities and it's our chance to 'give something back'. At Conference 2017, myself and Abi had our very long hair cut off and donated to the Princess Trust to raise money for BBS UK. Recently, Josh and I have taken part in Cyclone24, a 24 hour cycling event for Sight Support Derbyshire.

I have gotten to know a lot of BBS families over the last few years by attending clinics, family days out and activity weekends set up by the charity and every family I have the pleasure to meet inspires me as we all travel this BBS journey together.

Ian Tolman: A Personal Perspective

My name is Ian Tolman and I am 40 years old. I was registered blind in 1997 and was diagnosed with BBS1 in 2007. I had cataracts in both eyes and had them removed in 2015 and 2016. I have been attending Highbury College in Portsmouth for a number of years as a student. The classroom for the Visually Impaired is equipped with all the facilities and software to enable me to access applications using speech software. My tutor has been working with the visually impaired for a number of years and she is dedicated to her work. I progressed from IT introduction courses, learning shortcut keys to achieving OCNLR ITQ Diploma Level 2 in 2016. I have also achieved ECDL – European Computer Driving Licence. This qualification enabled me to learn Windows application up to Level 2. I have used most Office applications for example Presentation, Word, Excel, Access and Internet up to Level 2. I can also access Outlook to keep me in touch with my friends. I was presented with an award for Academic Perseverance and Achievement at Highbury College in July 2016 when I achieved the OCNLR Level 2 Diploma in IT User Skills. Achieving the Diploma has meant a great deal to me as I have been working extremely hard to be one of the first visually impaired students to achieve this award in Highbury College.

In 2001 I was offered a place to sail on the sailing ship, The Lord Nelson with the Jubilee Sailing Trust, an organisation for all disabled people. I was able to climb the mast and do general duties on the ship which I enjoyed very much. Also, with the Jubilee Sailing Trust I completed a sponsored tandem sky dive with the Red Devils when I jumped from 13,000 feet, which was very exciting.

Besides my academic achievements I also enjoy playing tenpin bowling at my local bowling alley with my visually impaired friends. I also play in two leagues. I have been fortunate to compete in several national finals and have travelled to various cities in the UK to compete with other visually impaired and blind competitors. I am also responsible for the general running of the bowling club.

I enjoy listening to music and watching films and have an extensive CD and DVD collection. I enjoy going to watch films at my local cinema with my family and have visited many countries around the world. Without my friends and family I would not have been able to achieve everything which I have spoken about here, so I am very grateful for everybody's help; thank you very much.

Ian Tolman

Volunteering at BBS UK

Volunteering is a great way to share your enthusiasm, skills and ideas whilst having fun and meeting like-minded people. Volunteers have an important role and can enrich and extend our work and help us make services more flexible and accessible. By volunteering with BBS UK you will be making a positive contribution.

We believe strongly in the value of volunteering and seek to involve volunteers from across the community in order to provide the beneficiaries we support with a diverse range of supporters from throughout society who can contribute a wide variety of skills, experience and perspectives to our work. There are a number of benefits to volunteering at BBS UK such as:

- Improved knowledge of BBS
- Improved communication skills
- Improved team working skills
- Meet like-minded people
- Access networking opportunities

Volunteer Opportunities

You can volunteer for BBS UK in a number of ways and we have a range of opportunities for volunteers to get involved in. Here are some details of the opportunities and areas where experience can be gained.

- Volunteer at our Annual Family Weekend by helping with our conference day programme, running stalls or evening workshops.
- Volunteer and support our adults or children on activity weekends or day trips.
- Volunteer on the BBS UK stand at exhibitions such as Sight Village Birmingham.
- Contribute to our newsletter.
- Become a Trustee. We are always keen to hear from anyone who may be interested in becoming a Trustee. All of our Trustees are adults with BBS or parents of children with BBS. If you would like to help the charity continue to be a user led organisation, please think about joining us. We also welcome Trustees who can bring other life or professional experience to the management committee. For example, Trustees with experience of fundraising or human resources can be invaluable to a charity like BBS UK.

Becoming a Volunteer

We are very grateful to everybody who gives their time to volunteer with BBS UK. Some types of volunteering with us could involve a regular commitment, others are more informal. We hope you will be able to offer your commitment to us which will allow us to give you an appropriate level of support and plan our services.

If you are interested in volunteering, you will be asked to complete a simple application form. Once we receive your completed form, a member of our team will get in touch with more information on opportunities and we can decide together which option best matches your interests and time availability. Potential Trustees will be invited to come along as observers to management committee meetings first to get a better idea of what would be involved before committing themselves.

If you would like to apply or would like further information about volunteering or have any questions please contact Abbie Geeson by email at abbie.geeson@bbsuk.org.uk. You can also download and complete the Volunteer Application Form from our website www.bbsuk.org.uk.

Your help will be greatly appreciated and really will make a difference.

Flat Feet and BBS

Flat feet occurs when a person's arch collapses and is common in those who are obese or overweight. Some people don't experience discomfort straight away and the arch may fully collapse before the condition is noticed. The obesity that features in BBS puts additional strain on the feet, muscles, tendons and ligaments and over time causes them to become stretched and weak. If the foot is not sufficiently protected, the bones and joints in the foot can shift and even collapse, leading

to painful flat feet. The upwards effect of this change in structure and movement can lead to pain in the shins, knees, hips and lower back.

It is important that we protect the feet of children and adults with BBS, especially if they are overweight. If you suspect that you or your child may be developing flat feet, ask your GP for a referral to your local orthotics team. A simple set of insoles is all that is needed to protect the arch and relieve any discomfort.

Every Penny Counts

Thank you so much to everyone who has been fundraising for BBS UK.

We are immensely grateful that you organise activities and attend events that raise money for us.

We would love to share what you have been doing in our newsletters, on our website and through social media. If you would like to send us a photo and tell us about what you have been doing, please do get in touch. Your story could inspire and motivate others to fundraise too.

We are truly appreciative to those people who send us regular and one-off donations. Every penny raised is helping to make a difference to the lives of people affected by BBS and the more we can raise, the more we can do.

Ways you can help

- ✓ If you are full of energy, have you thought about taking part in a marathon, fun-run or bike ride?
- ✓ Do you know of anywhere where a BBS UK Collection Box could find a home?
- ✓ Would you like to make a regular donation through our Friends of BBS UK scheme?
- ✓ Could your workplace recycle ink cartridges to raise funds?
- ✓ Do you work for a company that would match-fund the amount you raise? We would happily give them a mention.

Read on to learn about some of the ways our members have been fundraising for BBS UK.

RBS Bowls Club: Raising Funds for BBS UK

Vera Scudder has a Grandson with BBS and as the Captain of The RBS Bowls Club, nominated the charity to be the recipient of the club's fundraising efforts during her three years as Captain. The club members have been extremely generous and across the three years they have raised over £3,000 for the charity. The photo shows Vera's last Captain's Day, during which they raised £350. They all wore bright coloured tops in aid of BBS and a great time was had by all! Vera said, 'We would like to wish everyone at BBS UK the very best for the future and hope that in some small way, we have helped by raising funds for such a worthy Charity.'

From Land's End to John O Groats for BBS UK

Keen cyclist, Mike Kear smashed his fundraising target to raise £6,500 for Bardet-Biedl Syndrome UK by cycling from Land's End to John O' Groats. Mike chose the charity in support of his friend's

daughter, Ellie Jones, 18, who has BBS. Cycling 969 miles over nine days in challenging weather conditions, Mike said it was an unforgettable experience, “We had apocalyptic rain in Bath, rain in Scotland and then breathtaking scenery.” Mike cycled more than 100 miles a day and camped overnight. Among many highlights was riding with cycling star Mark Cavendish, “It was a once in a lifetime experience that I will never forget.”

French Alps Cycling Adventure

In September 2017, Colin Barr flew out to Geneva to prepare for a gruelling 4 day, 550km cycle ride over the French Alps to Nice along with 30 others all riding for their own chosen charities. Colin chose BBS UK as the beneficiary for his challenging fundraising venture in support of his colleague whose young daughter had been diagnosed with the syndrome; he said, ‘There is much ongoing research into this condition including future gene therapies and I wanted to do as much as possible to try and support this worthy cause.’ Colin raised nearly £2,000 for BBS UK.

Aneeba takes on the Big Birmingham 5K

In September 2017, Aneeba Ahmed took part in the Big Birmingham 5k fun run in Cannon Hill park to raise money for BBS and RNIB. Aneeba was accompanied by Sarah Borrows, the Clinical Nurse Specialist for the BBS Service at Queen Elizabeth Hospital, Birmingham. Aneeba raised a fabulous £85 for BBS UK and £35 for RNIB and is looking forward to completing the event again in 2018 with Sarah and Amy from BBS UK. Aneeba is looking forward to attending the BBS UK Family Conference in April and talking about her experience of living with BBS.

Elsewhere in the newsletter you will read about the Wilkie family from Kirrimuir and their incredible supporters. Our heartfelt thanks to everyone who has organised, attended and supported fundraising activities for BBS UK, if there is any way we can support your fundraising activities, or if you have any fundraising ideas or questions, please contact dianne.hand@bbs.org.uk.

What’s the difference between healthy eating and a weight loss diet?

No this isn’t the worst joke ever! In the dictionary, the word ‘diet’ is defined as ‘a special course of food to which a person restricts themselves’. Why diets can fail is simply summed up by this joke:

‘The funny thing with a diet is the second day of a diet is always easier than the first. By the second day you’re off it.’

Diets tend to focus on restriction, true they can result in impressive weight loss but what happens when you stop restricting your intake or if it isn’t safe to maintain this eating pattern long term? The media seems filled with stories of people losing impressive amounts of weight on any number of diets but they don’t usually report the weight regain after they come off these diets. Often when we ‘diet’ and can’t have a specific food or drink, this becomes something we think about more than usual and it becomes even more tempting! When we give in and eat that chocolate bar, for example, we feel we’ve failed and often then give up on our attempts to eat more healthily altogether.

If we look at the definition for ‘healthy eating’ it simply means eating to promote good health which is clearly what we all want for ourselves, our family and our friends. The NHS has lots of fantastic healthy eating information on their website: www.nhs.uk/livewell/healthy-eating. Without clicking on this website, we all know for example that we need to eat more fruits and vegetables (at least our ‘5-a-day’), eat more fish and eat less salt. As some of these issues have been covered in previous

articles, I thought this time I'd focus on four tips that can help us adopt a healthier lifestyle without too much effort! Read on if you are ready to think about making some changes:

1. Reduce your energy (calorie) intake without altering the amount you eat

Sounds too good to be true, but it isn't, I promise! Many studies have shown that changing our drink choices can help us control our rate of weight gain. Typically, we eat the same amount of food whatever we drink, so by changing from a high calorie choice like sugary fizzy drinks or squashes to a lower energy alternative we can lower our energy intake at a mealtime. Water is calorie free and so is the best drink choice to have with your lunch and evening meal.

Tips to boost your water intake:

- ✓ When you're out take a water bottle with you.
- ✓ Most school aged children are only allowed to drink water at school, continue this at home by offering water with lunch at weekends and in the holidays.
- ✓ Hide any bottles of sugary squash or fizzy drinks so they can't be seen in your kitchen. Did you know you are most likely to want to have the things you can see or find easily? So just by putting it out of reach you are much less likely to drink it!
- ✓ Put a jug of water on the table at mealtimes.
- ✓ Experiment with different ice cubes. Get your children to fill ice cube trays with a selection of pieces of fruit to make drinks of water more interesting.

Changing to water can have other nutritional benefits; did you know that tea and coffee can limit the amount of iron you absorb from your meal? Sometimes drinks you think are healthy choices are actually making a significant contribution to your energy intake. Fruit juice and smoothies have a very similar calorie content to fizzy drinks and these calories can quickly add up. Just two small glasses of fruit juice a day would contribute about 1,000 kcals to your weekly intake.

If you'd like to drink fruit juice or a smoothie have it at breakfast time to help you absorb the iron from a fortified breakfast cereal. It is also worth diluting fruit juice with water and keeping to a maximum of 150ml a day. Remember to watch out for fruit juice based drinks as these contain only small amounts of diluted fruit juice but also have sugar added. As they contain so little fruit juice they are not a good source of vitamins and do not count towards your '5-a-day'.

As 'Dry January' is now long forgotten I thought it would be useful to remind adults how quickly calories from alcohol add up! The NHS Choices website gives two examples which may make you stop and think about what you're drinking. Did you know that the average wine drinker in England consumes 2,000 kcals per month from wine? If you drink five pints of lager every week of the year this will contribute more than 44,000 kcals to your annual energy intake.

If you found 'Dry January' unachievable or just unthinkable, consider setting a positive, more achievable goal as you may find this easier than trying a total ban. An example of a more positive goal might be: 'I'd like to cut back on my drinking so I will only have an alcoholic drink when I'm out in April.' This allows you to set a different goal in May or extend the timeframe if you have found this has helped reduce your alcohol intake.

2. Spend some time planning what you are going to eat

We plan so many aspects of our lives, what we wear, how we will get somewhere but we often forget to spend time thinking about our food choices and this can negatively affect our dietary intake:

Do you buy more when you are hungry? Most of us would say yes! Food choices are less well controlled when we are hungry and more 'treat' foods end up in our basket.

Do you buy more if you shop with your children? Many of us will also answer yes to this question. Supermarkets are designed to sell their products so foods that are marketed specifically for children will be at their eye level. Plan to shop without your children whenever possible!

Do the offers tempt you to buy things you didn't intend to? Supermarkets often have lots of offers like 'buy one get one free' that make us buy more than we need or get us in to a store in the first place. The 'yellow sticker' reductions are often tempting too; I found myself nearly buying a big cake as it was only 45p! It is always good in these situations to stop and think whether you really need the 36 packets of crisps or the 45p cake – the answer for me was 'No' so it stayed on the shelf.

It is also worth planning your meals for a week so you can better control what you will be eating and this should also save you some time too. If you online shop you can order the same food regularly in just a few clicks. Try to work towards having a two or three-week menu cycle so you don't get fed up eating the same meals too often. Children however often like to eat the same foods regularly so do whatever works for you! Remember to update your menu choices throughout the year to reflect seasonal fruits and vegetables otherwise your shopping is likely to get really expensive.

Top Tip: Remember you can only eat the food that you have at home or buy when you are out. Avoiding the 'treat' snack aisles in the supermarket or internet shopping are good ways to help control your shopping choices.

3. Try some mindful eating rather than eating mindlessly

You may be very aware of mindfulness, but have you considered mindful eating? Mindfulness is defined as the practice of being aware of your body, mind and feelings in the present moment. Mindful eating follows on from this and involves paying full attention to your eating and drinking experience, for example, thinking about the smell and texture of the food whilst also thinking about how your body feels, does it feel hungry or full. Mindful eating means enjoying the eating experience without distractions. Perhaps you'd like to consider eating a little more mindfully, to get you started why don't you try:

Eating all snacks and meals sitting down at a table and without any distractions so you appreciate what you are eating! If a snack or meal is quickly eaten on the way home from school or whilst watching television, you don't realise how much you're eating and you may very quickly be looking for more food or have eaten a larger amount than you intended.

Try to eat more slowly as you will be more likely to notice and appreciate the different flavours and textures in your meal. Slowing down your eating may also help you identify when you feel full. To make your meals last longer you could try a combination of any of the following methods:

- ✓ Use smaller cutlery (I'm sure this is something Alan Sugar does!)
- ✓ Put your cutlery down for at least 10 counts between mouthfuls.
- ✓ Chew each mouthful for longer (if you chew only a couple of times now, try increasing to 10 times per mouthful)

- ✓ When you are serving your food, cut it up into smaller pieces.

Stop and think about whether you are actually hungry or whether you could be thirsty? Really think about how you are feeling and then make your choice! Remember children often mistake thirst for hunger so will ask for more food when just a drink would make them feel better.

4. Try to build some activity in to your day

Many of us start each New Year with great exercise goals but if we set too hard a target we may not succeed in achieving this. It can be daunting to start exercising if habits have slipped, so it is important to start doing something you like and that you can easily fit in to your life. Start slowly and build the activity up over time. Remember to first chat to your family doctor or clinic team if you haven't done anything in a long time, they might have some good tips to help you get moving too. Here are some ideas that you might like to consider:

- ✓ Plan your active time and stick to it! You're more likely to find time to be active if you do it consistently, for example walk to town at 10am every Tuesday and walk to the supermarket on a Friday.
- ✓ Split activity up throughout your day and count every 10-minute bout of activity towards your total goal.
- ✓ Add some walking to any of your regular journeys by getting off a bus at the stop before your destination or parking further away from where you need to be!
- ✓ Can you take the stairs rather than a lift?
- ✓ Find something that motivates you to move more! Activity trackers or a smart phone can allow you to monitor your step count and work towards the 10,000 daily step target. There are also a number of apps and ideas online which you may find motivating. Public Health England have launched a free app called 'Active 10' which is designed to encourage us to go for at least a 10 minute brisk walk each day. There is also a Couch to 5K app for running; interestingly the Visually Impaired Running Group in Bristol were offering a Couch to 5K course this January so it is worth finding out what is available near you.
- ✓ Be a good role model. If you can, walk your children to and from school. Try to regularly spend active time with your children: go swimming, to the park or try a dancing competition at home. The NHS Change4Life have some great Disney inspired 10 minute shake up ideas to get the family moving at home (www.nhs.uk/10-minute-shake-up). Do check these ideas out first so you know you have everything you need, enough people to make them fun and they are something you want to do! For example, Nemo and Marlin's Pass the Anemone needs a water balloon – so perfect for a warm day outside in the garden but not so suitable for inside!!
- ✓ Think about trying something new – trying a sport is a great way to make new friends. Check out the following websites for upcoming events near you:

- ✓
www.britishblindsport.org.uk/events
www.goalballuk.com/the-sport/get-involved

Feeling inspired but want more information or support? If you are a parent of a child attending the BBS clinics contact your dietitian or other member of your clinic team. If you are an adult your family doctor or practice nurse will be able to advise you of the support available where you live.

Wishing you all a happy and healthy 2018

Sarah Flack

BBS Dietitian

Great Ormond Street Hospital for Children NHS Foundation Trust

Sight Village

Sight Village is organised by Queen Alexandra College (QAC), Birmingham and showcases technology, support and services for people who are Visually Impaired of all ages. Sight Village is free to all and there are a number of events arranged for 2018 around the country. BBS UK exhibited at Sight Village Birmingham in July 2017 and Sight Village Manchester in September 2017.

The event attracts a wide range of exhibitors from accessible technology to Guide Dogs for the Blind. Visitors include those who have a visual impairment and those who support them, for example, social workers, teachers and support workers.

The BBS UK Team representing the charity at this year's Sight Village Events included Aneeba Ahmed, James Prendergast, Amy Clapp, Richard Zimler and Rachel Foley. There is always a great deal of interest in BBS UK's stand and the team were very busy handing out 'Who are We' leaflets, Newsletters and Conference Reports. Medical booklets were given out to a handful of professionals, SENCo teachers and rehabilitation workers. The team did a fantastic job of explaining who BBS UK are and what they do and spoke about their personal experience of BBS. They also took the opportunity to do some networking raising further awareness of the syndrome and charity.

Dates for Sight Village 2018:

- Sight Village South West (Exeter) 17th April 2018
- Sight Village Central (West Midlands) 10th & 11th July 2018
- Sight Village North East (Leeds) 26th September 2018
- Sight Village South East (London) 6th & 7th November 2018

For more information go to www.qac.ac.uk/exhibitions.htm

Fundraising for Caitlin

When we were given the news of our daughter Caitlin's diagnosis of BBS in March 2017, we were completely lost for a while. We knew basically nothing of this syndrome and to be fair, our hospital admitted the same, they had never diagnosed it before.

They did however issue us with the BBS booklet which is available on your website and we found this a great source of information. It was thanks to this and the website that we found out about the yearly conference which we duly attended in April 2017. Everyone there was so nice and welcoming and we learned so much from this weekend.

It was after this that we decided to do what we could to help the charity, which in turn would help our little girl over the foreseeable years ahead. Fundraising seemed the best way, so we drew up a battle plan throughout 2017 and made our JustGiving page live just before Christmas.

The response to date has been overwhelming with nearly £20,000 raised so far in only three months thanks to the generosity and kindness of family, friends and our little community here in Kirriemuir. The whole town has got right behind us and a number of other people now have fundraisers planned.

We have commenced our challenges this year and there are far more to come. This year has included and will involve:

Raising awareness with the Scotland Rugby team: We had some charity BBS wristbands made up in autumn last year which we sold for £2. We made just over £1000 from these and sales continue to amaze us. Royal Bank of Scotland are now on board with these and have taken 200 of them, they want to get their workers to wear them and they have promised donations throughout 2018 as one of their chosen charities. We had a bit of fun with them and managed to get the Scotland Rugby team to send pictures of them wearing them. A few of them actually kept them on as they were seen in the upcoming weeks in photo shoots and paper articles still wearing them!

Talk on BBS at the Kirriemuir Feel Good Festival: We were given a one hour slot to discuss BBS, the diagnosis and what the future holds. All talks on average got 10-12 people throughout the day, we were lucky enough to get 60 people through the door which helped raise awareness of the syndrome.

Race Night: This was always going to be our main fundraiser. We have done one before and raised £3,000, so we had hoped to match this, however, we managed to get £7,800 on the night which was amazing. We had over 100 people through the door, 17 race sponsors, multiple auction and raffle prizes and live music at the end of the night. A huge success if not slightly overwhelming.

Co-op Raffle: Our local Co-op held a raffle for St Valentine's day in aid of BBS and raised £600 across just two days of selling tickets.

Inverness Half Marathon: On 11th March 2018, three of our close friends ran the Inverness half marathon for BBS. They have raised approximately £300-£400 to date for their efforts which has included the sale of home-made fudge.

Wilkie West Coast Cycle Challenge: This is my next challenge. Myself and six of my friends are cycling 300 miles in three days over the west coast of Scotland, taking in the Island of Mull at the same time. Fundraising is well under way, again our hope is to generate £400-£500 with this challenge, which is booked in for 27th- 29th April.

Tombola and Cooking Kitchen, Bon Scott Weekend: In Kirriemuir, we have a music festival every May in aid of Bon Scott from AC/DC. Bon Scott originated from Kirriemuir and over the years, this festival has grown beyond belief with literally thousands of fans coming to Kirriemuir for the weekend. The organisers have allowed us to have a stall on the Saturday in the town where we plan to do a tombola. The local cafe is giving us full use of their facilities on the Saturday to make teas, coffees and make pots of chilli and rice etc to sell to the festival goers. Again this could be a great fundraiser considering how busy it always is.

Culloden to Clova for Caitlin: One of the Kirriemuir residents, Eck Robbie, read our story and was determined to do something. He is looking to re-create the route the Ogilvy clan took home after their defeat at the battle of Culloden. This is a 100 mile walk from Culloden to Glen Clova taking in some very remote areas which includes two nights of wild camping. They hope to do this in five days. There is a group of eight doing this and hope to raise £200-£300 each. Work is in progress with sponsorship of this, but we are hopeful to get Grants Whiskey Distillery to be a main sponsor and donate a substantial sum towards this.

Great North Run: In September, both myself and Caitlin's Mum, Ash, are running the great North run which is the half-marathon in Newcastle. We have had t shirts made up with the BBS logo so we can raise awareness.

On top of the above we have other community members doing various runs and walks throughout the year with all proceeds being donated to BBS. Our initial target for fundraising was £5,000. Realistically this is more likely to be £25,000 by the end of the year.

Liam Wilkie

Birmingham Social Weekend

In November we held our second Adults Social Weekend at the Cobden Hall Hotel in Birmingham, with 25 guests and 7 support staff attending across the weekend.

On the Friday evening we had great fun bowling after a lovely, but noisy meal at Frankie and Benny's, catching up with old friends and meeting new; everyone really valued the opportunity to spend time with other adults living with the syndrome in a relaxed environment.

On the Saturday we went to the Birmingham Hippodrome to see Sunset Boulevard. Before the show we enjoyed a 'touch tour' and a fabulous afternoon tea, we couldn't fault the food or service. The staff and volunteers at The Hippodrome were incredibly helpful; we were given a private function room for our afternoon tea and while we were in the theatre, the guide dogs were taken by the Hippodrome volunteers for a walk, rest and drink while our guests enjoyed the show.

Following the performance we had dinner at a curry house before retiring back to the hotel for another evening of chat and laughter. We are planning another social weekend for 2018 and hope to include another visit to the fabulous Birmingham Hippodrome.

Sam wins Helena Kennedy QC Award

On a typical rainy Manchester day in March 2017 I travelled down to London with my mother to accept an award from Baroness Helena Kennedy QC for the achievement of overcoming many barriers to get into a prestigious Russell Group University (which happens to be my local university) The University of Manchester.

As a teenager, I lost my sight and with it my education. A combination of a high IQ and low vision led to many frustrations, and I left school at the age of 14 without any formal qualifications when the legal leaving age was 16. The consequences of losing my sight whilst being a teenager and going through adolescence meant I later developed depression, which wasn't treated until my mid 20s. I often joke that at that time I went downhill faster than an Olympic skier!

A combination of inpatient admissions for depression coupled with mild hearing loss and several eye diseases that are part of Bardet-Biedl Syndrome, led to me drifting through my later teenage years as I was let-down by the education services. Maybe if I had the support in my teenage years that I received recently at Bolton College and The University of Manchester, I am sure that I would have left school with dozens of GCSEs and A-Levels and maybe would have gone to Oxbridge. However, I wouldn't be the person I am today. My resilience is testament to the saying 'what doesn't kill you makes you stronger'.

I would like to put my life experiences to good use by becoming a lawyer specialising in mental health, so I decided to return to college and get some qualifications. In 2014, I enrolled at Bolton College with trepidation of what to expect based on my experiences of school. To my amazement I was looked after spectacularly by a visual impairment inclusion co-ordinator and a mental health inclusion co-ordinator, which is very rare in mainstream education. I left Bolton College in 2016 after gaining qualifications in Maths and English equivalent to GCSEs grade C and an Access to Higher Education Diploma that is equivalent to 3 A-Levels grade A. I was surprised to learn that such

prestigious universities would accept my application without formal GCSEs and A-Levels and was over the moon when I got into The University of Manchester.

Having formally applied to university and being accepted, my college, Bolton College decided to nominate me for the Helena Kennedy QC Awards, and with a personal statement and glowing references I learnt that I was to be a recipient of a Helena Kennedy QC Award.

On 21st March 2017 I was to attend a reception in The House of Lords along with the trustees, the press, and my sponsors along with other award winners. So, on a brilliant sunny day in London I got ready in my best clothes and jumped into a black cab and went to The House of Lords. Security wasn't that tight considering what happened the next day, the Westminster terrorist attack. After going through six different police manned barriers, I entered The House of Lords at Black Rod's Garden Entrance. I then went through internal security and had my bag and cane scanned and searched and walked through an airport style barrier to check if I had anything hidden – I hadn't I assure you! I picked up my identification badge, a third one no less and after several speeches by Helena, Ann Limb, (Chair of the Trustees) and Kirsty (the CEO of City & Guilds) the awards began; I was first up to receive the certificate that each award winner received.

Baroness Helena approached me and joked I was a Sister in Law as I am studying a qualifying LLB Law degree and will later be a practicing Lawyer. A set of professional photographs accompanying an afternoon high tea was the highlight of the ceremony and we were all duly kicked out at 5pm into the warm evening sunshine.

Breaking Down Barriers

The BBS UK membership and patient group is ethnically diverse, with approximately 58% identifying themselves as 'White British', so at BBS UK we are keen to ensure that our support services are reaching all aspects of our membership. To that end, in May 2016 we applied to take part in a three year project called 'Breaking Down Barriers', organised by Alstrom Syndrome UK and funded by the Sylvia Adams Charitable Trust and were delighted to be accepted onto the programme.

Funding, mentoring and workshops are provided across a three year period to help patient organisations join together to support families that have an increased risk of having children with genetic conditions within diverse backgrounds and who have difficulty accessing mainstream services. The project will enable BBS UK to develop a greater understanding of and provide greater support to ethnically diverse families and individuals and to facilitate greater access to the specialised BBS Clinics.

We really enjoyed working with the BDB team during Year 1 and benefitted from the experience and knowledge of other members and professionals involved with the project. In September 2017 we attended a workshop and presented our project to date, the presentation was well received as was our end of year report and successful application for Year 2.

We would love to hear from any BBS UK members from minority ethnic communities who would like to get involved with this project. Please contact Tonia, Angela or Amy for more information.

New Rare Disease Centre at St Thomas' Hospital, London

The UK's first dedicated centre for patients with rare diseases has opened at St Thomas' Hospital, London and is the new home to the BBS Clinics Adults Service in London including patients transitioning to adult services; the first BBS Clinic was held there on 10th January 2018 and the new Centre was a great hit with patients and professionals alike.

Other rare conditions that will make use of the new centre include Epidermolysis Bullosa, which causes fragile skin that is prone to recurrent blisters and sores and Xeroderma Pigmentosum, which creates an increased risk of skin cancer and eye disease from exposure to UV light. Windows have been fitted with clear UV filters, without reducing the light and airy design, and none of the internal lighting emits harmful rays. A feature wall with an 'enchanted forest' theme brings the outdoors to patients unable to expose themselves to sunlight. Patients from across all services that are currently seen in the RDC have been involved in every aspect of the design from the layout, furniture and lighting to the colours used in the centre. The furniture is curved and relaxed by design lending a contemporary look to the Patient Area. The centre also includes a video conference suite to allow clinicians to work more closely with local health services across the UK and internationally.

Hannah Young, from Felixstowe in Suffolk, was one of the first BBS patients to use the new centre. Patients see up to seven specialists at each appointment; Hannah says, "Being visually impaired, it can be stressful finding where to go in a hospital and I feel disorientated going from one place to another. Visiting the Rare Diseases Centre is a more relaxed experience because I stay in one room for my appointments."

The new £2.3 million centre enables BBS patients to have access to the most up to date ophthalmic equipment and testing, increases capacity and was designed with the needs of the patients in mind. Dr Shehla Mohammed, Consultant Geneticist and Service Lead for the BBS Clinics Service at St Thomas' Hospital has been instrumental in gaining the funding and ensuring patients have been involved at every stage of development. Dr Mohammed said, "We are delighted that the centre offers a warm, welcoming and calm environment and is designed around the specific needs of our patients. Working with other specialities in the centre enables medical teams to learn from each other and share good practices to help improve the care we deliver to our BBS patients. Bringing the RDC to fruition has been a long journey and we are very grateful for the support and encouragement from the Executive Board throughout the process and the generous financial contribution from the Guy's Charity".

Kieron Boyle, chief executive of Guy's and St Thomas' Charity, which helped to fund the development, alongside a number of other charities said, 'It's been made possible by the incredible generosity of the public, and will make a lasting difference to the quality of care delivered to adults and children with rare conditions across the UK'.

New General Data Protection Regulations

Bardet-Biedl Syndrome UK takes its legal obligations and the protection of personal data seriously. The new General Data Protection Regulations (GDPR) is a new law to protect the privacy rights of individuals and comes into force on 25th May 2018. BBS UK are currently redeveloping their privacy notice which will be available at www.bbsuk.org.uk by Monday 21st May 2018. This privacy notice will provide information about the processing of personal data that BBS UK carries out. You can visit the UK Information Commissioner's website for more information on GDPR and your rights at www ICO.org.uk.

Resource Central

Amy, our newest BBS Family Support Team member has been collating a list of useful websites, support groups, Facebook pages and events which may be of interest to some of you:

IT BUDDY: Available across the country in local libraries to help support with the completion of online and paper forms. Contact your local council or library for more information and to make an appointment.

VICTA: Visual Impaired Children Taking Action (VICTA) supports children and young people who are blind or partially sighted and their families across the UK. If you are visually impaired and under the age of 29, or are the parent of a visually impaired child or young person then VICTA can help. VICTA also have an extensive events and activities programme. www.victa.org.uk

LOOK UK: LOOK UK supports young people up to the age of 29 and their families living with a vision impairment. www.look-uk.org

PHAB: PHAB's mission is to inspire and support children, young people and adults with and without disabilities to make more of life together - breaking down community barriers, reducing social isolation, and creating opportunities for disabled people to enjoy the same activities and challenges as, and alongside, those without a disability. www.phab.org.uk

CEA CARD: A national card scheme developed for UK cinemas by the UK Cinema Association (UKCA). The Card enables a disabled cinema guest to receive a complimentary ticket for someone to go with them when they visit a participating cinema. www.ceacard.co.uk

ACCESS CARD: The Access Card is printed with symbols to show your disability and to highlight the barriers you face and the reasonable adjustments you might need, so you don't need to keep explaining. Based on your rights under the Equality Act and providers' responsibilities, the card informs providers quickly and discreetly about the support you need and may gain you access to things like concessionary ticket prices and complex reasonable adjustments without having to go into loads of personal detail. The card costs £15 for three years. www.accesscard.org.uk

BRITISH BLIND SPORTS: The work of the charity enables blind and partially sighted people to have the same opportunities as sighted people to access and enjoy sport and recreational activities in the UK. www.britishblindsport.org.uk

SIGHT SUPPORT DERBYSHIRE: a charity providing services, support, advice and information to around 9,500 local people who are registered blind or partially sighted. Sight Support Derbyshire offer a range of support to adults and children, through a range of services, including: Hospital Services, Sight Loss Information Sessions, Low Vision Aid Services, Rehabilitation Services, Resource Centres, Sports and Leisure Activities, and Children and Young Peoples Services. www.sightsupportderbyshire.org.uk

FACEBOOK PAGES:

VI Talk

VI Talk Travel

Rare Disease Day

Rare Revolution Magazine

RNIB Library

Action for Blind People

If there are any websites, groups or Facebook pages you have joined that you think may be helpful or of interest to others, please share them with us for future newsletters!

Social Media

BBS UK has an open Facebook Page, 'Bardet-Biedl Syndrome UK', from which we share news and information. We also have two closed Facebook Groups for our members to communicate with each other and share information: 'BBS UK', for those living with BBS, their families and carers and 'BBS Adults Social Group', for adults living with BBS.

If you are eligible and would like to join one of the closed groups, put a request in and the team will add you.

BBS UK is also on Twitter, so look us up and get 'tweeting' @LMBBS1.

We hope you have enjoyed this newsletter, if you would like to contact us about any of the articles, or to submit an article of your own, contact Tonia Hymers at tonia.hymers@bbsuk.org.uk.

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