

Bardet-Biedl Syndrome UK

Registered Charity No. 1027384 and SCO41839



BBS UK Winter Newsletter 2016 - 2017



Foreword

January and February can seem such a gloomy time of year, so we hope this newsletter is a welcome arrival, an excuse if you need one to grab a cuppa, put your feet up and catch up on all the BBS UK news.

This time of year is extra busy for the team, who are putting the finishing touches to the weekend conference programme. Bookings have been steadily trickling in since before Christmas, so if you haven't already booked your place, it really is time to dig out those booking forms. Forms can be downloaded from the BBS UK website, www.bbsuk.org.uk or you can email info@bbsuk.org.uk for a copy.

Inside this bumper edition, you will find reports from the BBS Adults Social Weekend and the Avon Tyrrell Activity Weekend, both of which were a huge success. Both events will be repeated in 2017 and we hope to see more of you there. Also inside is some very timely healthy eating and lifestyle advice from Sarah Flack, Principal Dietitian at Great Ormond Street and an inspiring personal perspective from Helen Mainwaring.

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 hope to hear from you soon.

BBS UK Board of Trustees

CONTENTS

- 2 Foreword
- 3 BBS UK Attends Duxford Children's Party
- 3 BBS UK Events
- 4 Volunteering at BBS UK
- 5 Sleep Apnoea and Bardet-Biedl Syndrome
- 7 BBS UK Family Support Team
- 7 Cilia 2016
- 8 Diagnosing Bardet-Biedl Syndrome: a personal perspective
- 11 The Great South Run
- 12 BBS UK Activity Weekend at Avon Tyrrell
- 14 Winter Eating and Activity
- 17 Friends of BBS UK
- 18 Jeans for Genes 2016
- 19 Breaking Down Barriers
- 20 BBS UK Social Weekend at Cobden Hall Hotel
- 21 Fundraising Round-Up
- 23 Mailing List Update
- 24 Contact Details

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BBS UK Attends Duxford Children's Party

Chad and Shawna James, on behalf of 492nd Fighter Squadron based at RAF Lakenheath, invited BBS UK families to attend their Children's Christmas Party, held at Duxford Air Museum on the 10th December 2016. There were around 80 children at the party from five different charities; we attended with four very special BBS families and everyone had a magical day, thanks to the energy, effort and enthusiasm of the very wonderful 492nd Squadron. The Squadron are also known as the 'Mad Hatters' or 'Bolars', reflecting their unusual headwear.

While stationed at Chaumont Air Base, France in the 1950s, the Squadron wore berets, which they swapped for the traditional English bowler hat when they moved to RAF Lakenheath in 1960. The practice of adopting

local headgear has continued with every Bolar deployed to Turkey issued with a blue fez hat.

On arrival we were greeted by so many welcoming people and the biggest spread of food; we were told that although we should usually try to make healthy food choices, party day was different and we could have whatever we wanted. Fingers in ears mums and dads!

There was a candy floss and popcorn stand, craft tables, funfair sideshow games, a balloon artist and we had full access to the air museum. During lunch we had a Christmas sing-a-long followed by the arrival of Santa Claus in a fire truck. We really did have a wonderful day and can't thank Chad, Shawna and the fantastic 492nd Fighter Squadron enough for inviting us and making the day so special.

BBS UK Events



BBS UK Weekend Family Conference 21st-23rd April 2017

Planning is well underway for the biggest event in the BBS UK calendar, the weekend family conference! The programme is yet to be finalised and confirmed, but will include:

- Professor Beales with an update on the latest research and developments in BBS
- Sarah Bullen, Clinical Psychologist, GOSH BBS Clinics Team, with a presentation about challenging behaviour in children

- and young people who have BBS
- Jeremy Tomlinson, Endocrinologist, QEH BBS Clinics Team
- Workshops: Q&A with Professor Beales, Benefits, Puberty & Sexual Health, BBS Dietitians, Parents Supporting Parents, Transition Support and more...
- Children and young people's outing to Drayton Manor
- Bowling and lunch trip for adults and young adults (alternative to formal programme)
- Family Quiz and Raffle, crafts and activities and so much more...

Booking forms can be downloaded from the BBS UK website, www.bbsuk.org.uk or email Tonia or Julie if you would like a form emailed to you:

tonia.hymers@bbsuk.org.uk
julie.sales@bbsuk.org.uk

Spaces are filling up fast, so we advise delegates to book as soon as possible to avoid disappointment.

We look forward to seeing you there.



London Zoo
TBC May 2017

Whipsnade Zoo
TBC June 2017

Your BBS UK Family Support Team will once again be attending the Special Children's Day at London Zoo in May and at Whipsnade Zoo in June. We look forward to this very special event every year; with increased specialist facilities and number of staff, as well as special interactive events and discounted entry, the London Zoo and Whipsnade Zoo Special Children's Day is a great day out, not to be missed. Further information will be available nearer the time.



Family Activity Weekend
TBC September 2017

We are in the early stages of planning the next BBS UK Activity Weekend which will be held in September 2017 at a venue to be confirmed. We are moving the event to a more central

location and hope to see lots of you there. Further information and booking forms will be available over the coming months.

If you would like to be added to the BBS UK Children's Activities and Events Mailing List, email Tonia: tonia.hymers@bbsuk.org.uk.

BBS UK Adults Social Weekend
TBC September 2017

After a very successful weekend in Birmingham in September 2016, we are aiming to arrange another weekend full of activities for September 2017.

Everyone who attended the event in 2016 agreed that Birmingham was a good central location, and the activities were well received. We would again like to enjoy an evening meal on the Friday night, which provided an ideal opportunity for everyone to get to know one another or catch up with old friends. Saturday bowling and the meal at Frankie and Bennys was also great fun.

We will soon be contacting our members for their location and activities preferences which will enable us to put together a programme that suits all. If you have any suggestions, please contact either Julie Sales or Angela Scudder:
julie.sales@bbsuk.org.uk
angela.scudder@bbsuk.org.uk

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 experiences to be gained whilst volunteering at BBS UK such as:

- Valuable work experience in support and health services
- Gaining knowledge about BBS
- Good communication skills
- Networking

- Working with diverse groups
- Team working
- References (positive for C.V)
- Meeting like-minded people

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.

- You can work directly with the BBS clinics support team to offer vital help during our clinic days. You can volunteer at either the Children's clinics at Great Ormond Street Hospital, London or Birmingham Children's Hospital or at the Adult clinics at Guys Hospital, London or Queen Elizabeth Hospital, Birmingham
- Volunteer at our Annual Family Weekend by helping with our conference day programme, running stalls or evening workshops or becoming a trip carer or crèche support worker
- 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 London or 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.

Sleep Apnoea and Bardet-Biedl Syndrome

The following article has been adapted from Dr Matthew Hind's presentation, 'An Update of the Lung Function Study' given at the BBS UK Conference 2010.

BBS patients commonly report experiencing frequent coughs, colds, asthma and wheeze, particularly in the winter, which alerted

researchers to a potential problem within the respiratory system in BBS. Dr Hind and his team looked at BBS mice and discovered that they also appeared to have some problems with their lungs, with a reduced gas-exchanging surface area and fewer, but bigger alveoli.

At Conference 2009, BBS patients were

invited to take part in a study, which involved having their lung function checked and it was discovered that many of them had a reduced lung function. There are two measures of lung function: the vital capacity, the amount of air that you can breathe out until your lungs are empty, and the FEV1, the amount of air that you can breathe out in a short period of time; both of those parameters were reduced in a few patients with BBS. It was also discovered that symptoms of obstructive sleep apnoea seemed to be very common. There was enough data to offer screening tests at the Royal Brompton Hospital, to enable the team to investigate some of these symptoms in some more detail. Dr Hind was keen to state that he didn't think there was anything serious going on with the lungs in those with BBS, however there is 'something' going on.

Obstructive sleep apnoea is common in the general population, however it is more common in people who have Bardet-Biedl Syndrome. Sleep apnoea is when the floppy bit (epiglottis) at the top of our breathing tubes, just below the nose and the mouth, collapses back and stops us breathing during the night, causing oxygen levels in the blood to go down. Fortunately the brain wakes us up, often repeatedly, which is why those affected don't feel as though they have had any restful sleep the following morning. Symptoms of Obstructive Sleep Apnoea include, unrefreshing sleep, daytime sleepiness, nocturnal choking and a loss of libido. Those affected may also get up to go to the loo many times, maybe three or four times at night and morning headaches may feature as well.

To measure the level of 'sleepiness' patients are measured according to the 'Epworth Sleepiness Scale'. There are seven questions which will indicate a patient's chances of falling asleep in certain situations: no chance, slight chance, moderate chance or high chance. The situations are: sitting reading, watching TV, sitting in a public place like a theatre, or a cinema, a passenger in a car for an hour or lying down to rest in the afternoon.

Dr Hind and his team at the Royal Brompton Hospital use a variety of measures, including the Epworth Sleepiness Scale, to test for Obstructive Sleep Apnoea. Oxygen levels are monitored

during sleep, snoring levels are measured and they also look at body position. In addition, if a patient is snoring and their airway is obstructed, heart rate and blood pressure can go up, so these are also measured; it is a very common cause of what doctors call difficult hypertension, where patients might need one or two different types of treatment to successfully treat high blood pressure.

Complications of obstructive sleep apnoea include excessive sleepiness, impaired concentration and poor memory. Sleep apnoea can affect the heart and the lungs and it can also affect diabetes and can cause changes to the blood count as well, so there are lots of reasons why doctors are concerned about this condition.

The treatment for sleep apnoea is called CPAP (Continuous Positive Airway Pressure). Affected individuals sleep with a nasal mask, mouth mask or even little nasal pillows that blow air in and keep the pharynx open. It restores normal sleep by preventing your oxygen levels from falling which, in turn, prevents patients from waking up at night. Snoring is abolished, sleep becomes refreshing, frightening nocturnal choking disappears, headaches can resolve, libido can improve and affected individuals are no longer falling asleep during the day.

If you feel you have obstructive sleep apnoea, speak to your GP and ask for a referral. You will be referred to one of the many sleep clinics dotted around the country for an assessment and if obstructive sleep apnoea is diagnosed, you will be issued with a CPAP machine. Being overweight exacerbates sleep apnoea, so those affected should consider positive lifestyle changes including increased exercise levels, a healthy diet and reduced alcohol consumption.

BBS UK Family Support Team

In addition to supporting families and individuals before, during and after their BBS clinic appointment, the BBS UK Family Support Team can provide information and support across the following areas:

- ✓ Disability Living Allowance/Personal Independence Payment applications
- ✓ Education Health and Care Plan applications
- ✓ Local Disability Service/Social Services referrals
- ✓ Occupational Therapy referrals
- ✓ Blue Badge applications
- ✓ Activities and Days Out

If you would like help and support from a member of the team, contact Tonia Hymers, Children's Service Manager, Julie Sales, Adults Service Manager, or Angela Scudder, Family Support Worker, their contact details are below:



Tonia Hymers
BBS Clinics Children's Service Lead and Family Support Worker
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tonia.hymers@bbsuk.org.uk



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BBS Clinics Adults Service Lead and Family Support Worker
07917 252585
julie.sales@bbsuk.org.uk



Angela Scudder
BBS Clinics Family Support Worker
07958 204414
angela.scudder@bbsuk.org.uk

Cilia 2016

Drina and Michael Parker

We represented BBS UK at the Cilia 2016 conference held in Amsterdam from 4th to 7th October 2016. From a technical viewpoint the conference was clearly a huge success, and it was incredibly heartening to see the many hundreds of clinicians, researchers and pharmaceutical companies engaged in cooperative analysis of all aspects of cilia. The science was way above our heads but the optimism about research leading to future therapies was infectious!

Also infectious was the enthusiasm of Dr Helen May-Simera. It was a bonus to be able to spend time with her and to hear about the research she is doing in Germany. Helen was encouraging us and anyone in the BBS UK 'family' to visit her lab. Aren't we fortunate to have such a bright and inspiring researcher so committed to all things BBS! Our son, Richard, was fascinated by Helen's conversation as she can communicate about her work on a personal, understandable level. She is truly a people person.

The next Cilia conference is to be held in Copenhagen in 2018 and we have already submitted ideas on how patient engagement goals could be achieved. Without such changes, we are unlikely to attend in future.



Diagnosing Bardet-Biedl Syndrome: a personal perspective

Helen Mainwaring

“You’ve had too much gas and air!” That was the midwife’s response when I tried to draw her attention to the fact that my newborn son had twelve toes. Admittedly, the gas and air had gone to my head, but Gareth had been born with twelve toes, and laugh as they might, I was right. Although I immediately felt concerned, the love that I felt for my little boy, and the relief that I was sane and wasn’t imagining things, gave me some sort of sense of security and a feeling that everything was going to be alright.



It was this same feeling of power in knowledge, and relief, that I felt nine years later when Gareth was finally diagnosed with Bardet Biedl Syndrome. Although I was concerned, as this was something completely new to me, there was a sense of relief that after nine years of perseverance and fighting for my son, and trying to convince both professionals and friends and family that I wasn’t insane and that there was some underlying issue with Gareth, I finally had the answer and I had been right all along.

It had been a long and frustrating journey and I had explored so many different possibilities. I had toyed with autism and experimented with Gareth’s diet, taking him off dairy and gluten and had even taken him to a private practice in Harley Street, London. I felt that nobody believed me. People thought that I was an overprotective mother and that I was in denial. We’d seen GPs, paediatricians, health visitors, education psychologists and all roads led to even more frustration. Nobody could give me any answers.

I lost count of the number of times that I’d carried Gareth home from my daughter’s school kicking and screaming for some simple reason, such as the fact that I’d broken his routine and gone to pick her up from school on the way home from somewhere rather than go home first and then walk from home to school. Eventually I became both mentally and physically drained. I didn’t

know why he kept himself to himself. Why he threw a tantrum if he couldn’t have the yellow apron to paint at nursery. Why he lashed out if anyone got into his personal space. Why he’d kicked the headmaster in his first week at big school. But I knew that there was some underlying frustration. There was something behind these irrational outbursts. There was a reason he was emotionally immature. He wasn’t a ‘naughty boy’. He didn’t need ‘anger management’. He was a lovely natured child. There was something causing these outbursts. Luckily, everyone at Gareth’s school was extremely patient, and although they couldn’t give me any answers, their patience and the way the staff bonded with Gareth and saw him for the loving and humorous child that he was, was a huge support.

I was at the end of my tether and didn’t know what other options to explore when, on the way out of an appointment in April 2015, Gareth’s Ophthalmology Consultant happened to ask, “Was Gareth born with extra digits?” “Yes”, I answered “Hmmm,” he muttered under his breath, “Bardet-Biedl”. He had been treating Gareth for Retinitis Pigmentosa and as he ushered us out of the door, telling us he’d like to see us again in three months, I couldn’t get those words out of my head. I was scared I’d forget them. I’d never heard them before. I said them over and over again in my head until

I reached the car and typed them into a search engine to try and find out more.

What I read changed our lives. The tears rolled down my face as I read about Bardet-Biedl Syndrome. Gareth ticked practically every box and I knew that I had finally got some answers. Immediately after arriving home I wrote a letter to the Consultant telling him that I'd read up on Bardet-Biedl Syndrome and that I was convinced that this was the underlying issue that Gareth had. I typed and typed and typed telling him exactly how Gareth matched the symptoms of Bardet-Biedl Syndrome. The three months couldn't pass fast enough until Gareth's next ophthalmology appointment. The Consultant was so supportive, he said he'd do everything possible to help; he wrote to the paediatrician and the geneticist and assured us that he'd get to the bottom of this.

By September 2015 we'd seen the paediatrician and the geneticist and had a clinical diagnosis of Bardet-Biedl Syndrome and by March 2016 we'd had genetic confirmation that Gareth had two mutations in the BBS1 gene. As the geneticist gave me the news I felt concerned and worried, but I also felt that same feeling of power in knowledge. I felt that after nine years of fighting, I finally had the answer. I wasn't insane. I wasn't a bad mother. I had trusted my instinct and not given in. It had even cost me my marriage, but I had been right and had done the best for my son.

Everything now made sense. I could see that the Retinitis Pigmentosa had been at the heart of a lot of issues when he was young. His insecurities, his desperate need to keep to a routine, his need to keep to his own personal space and his lack of trust of anyone unfamiliar getting too close to his personal space; these were all hugely linked to his eyesight and to BBS.

I was fortunate, and having that diagnosis opened the doors on a whole new world. We attended the BBS UK Conference in Northampton and met so many wonderful people and learned so much. The new BBS UK Medical Information Booklet has been a godsend. I've been able to give a copy to Gareth's teachers and his education psychologist, and being able to show someone in black and white what BBS is has made our lives so much easier.

I can't help wondering if things would have been different had I known earlier. Having said that, as a mother you instinctively know your child and I always felt the need to be patient. I didn't get angry at his outbursts. I was that much more understanding and lenient. But how many other children and parents are going through what we went through because they haven't had the diagnosis? How many will go through life not being diagnosed at all?

I can't thank BBS UK enough for the great work that they do and I'm sure that many, many more will benefit from this huge source of support and information. I finally feel that I can breathe again and that one journey has ended, and another has begun. While I realise that many challenges still lie ahead, we have become empowered to embrace these challenges and to face the future with a positive outlook.

Challenging Behaviour and Bardet-Biedl Syndrome

From talking with Helen, it was clear that she had developed some great coping strategies for dealing with her son's challenging behaviour and we asked her to write something down that we could share with other young mums who may be looking for support and reassurance. Our grateful thanks to Helen for sharing her story and coping strategies with us.

Patience: Although sometimes we all feel like screaming and feel our stress levels rising, I've found that confrontation just doesn't work. When Gareth is having an outburst, he needs to be brought back down to a calm state. Once he's calm, he can be reasoned with but in that instant, when his temper flares, there's no point trying to reason. Calming him down first is always the best option, and we discuss and deal with the issue later.

Distraction: It can be difficult and embarrassing to deal with the outbursts when you're out and about or when you're at someone else's house, especially if you don't know the people that well. Distraction works well, even if you have to compromise to get the situation under control, as long as you do deal with what has happened later on when all is calm! It's important to stay calm and not take things too personally. Most likely, people aren't judging you as much as you think, and if they are, well then they're not worth

worrying about. They probably feel for you more than they judge you. If I know that Gareth is going to be disappointed by something or someone, I'll always line up something positive to balance it - so if the Lego car set he's eagerly awaiting in the post hasn't turned up, there's always a "Never mind, let's build a garage tonight so that we have somewhere to park it when it arrives tomorrow." You've almost got to be one step ahead and foresee potential disappointment.

Reassurance: I always make sure that I tell him that I love him and that it's his behaviour I'm angry with and not him as a person. He does suffer from a lack of confidence and it's important not to dwell on shortcomings and to reiterate the fact that he is a sweet, funny, loving child and that it's just his behaviour I'm disappointed with, not him. It's also important to keep on reminding him what he's good at doing. When he is in a rage, even though I may feel angry, I find that giving him a hug helps to calm him down. As long as you discuss what has happened after all is calm, a hug can be reassuring and help resolve the situation and calm the frustration until you have reached a state where you're both calm enough to talk about it - this helps you as much as them! I have to remember that he doesn't like his behaviour either - it's almost beyond his control. It's just the way he reacts to disappointment, or it's his way of dealing with frustration. I've taught him to count to three and then walk away from the situation to a quiet space and then come back when he's calmed down - this works well too.

Plan Ahead: Always give a warning - Gareth doesn't like surprises. If there is a change of plan, he needs to be warned in advance. This also goes for everyday things like turning off his iPad and preparing for bed. Telling him sternly, "Right, turn off your iPad and go and brush your teeth ready for bed" doesn't work for him. However, telling him that it's time for bed but he can have 10 more minutes on his iPad if he promises to brush his teeth and get ready for bed afterwards does. That way, he has some degree of control over the situation and he'll happily tell me when his 10 minutes is up. He doesn't deal well with stress and rushing. You've always got to be well organised and plan ahead and think ahead. The way I say things also helps - requests are better than stern instructions and he responds better when he understands why I



am asking him to do something. Asking him to pick his toys up off the floor in case mummy falls over them works way better than telling him to pick them up off the floor.

Rewards: If it's a daily struggle to get your child to go to school, then a visual reward chart and stickers with a reward at the end of the week for good behaviour works well. Although, you can't be too harsh if the child has a bad day - unless the behaviour has been really, really bad, it's always better to discuss the child's bad behaviour and offer the child a chance to win back today's sticker tomorrow, rather than rule it out completely!

And finally, don't forget the siblings. It can be difficult dealing with siblings when you have one way of dealing with a child with BBS and then another way of dealing with a child without BBS, but they will come to understand. My eldest daughter is three years older than Gareth, and although it can be hard for her to understand why he gets away with more than she does, as long as I take the time to explain to her why I do what I do, she understands. It is hard for siblings and so important to take time out to treat them and reward them for their good behaviour too.

Hope this helps!

The Great South Run

Christian Bolton-Edenborough

On the 23rd of October I took part in the ten mile Great South Run. I arrived in Portsmouth the day before with my girlfriend Sian and good friend Stefan, so as to get familiar with some of the streets I would be running along. The original plan was that myself and Stefan would be running together with me as his guide runner. Unfortunately, a month or so just before the run, Stefan fractured his toe, thus preventing him from taking part, however he was kind enough to still come along to support me.

After a small breakfast I was ready to go, however getting to the start line proved more challenging than anticipated, as Portsmouth City Council decided to close all the roads of the city during the event, which meant no taxi could get us to the start line and so we had a two and half mile walk to the start line. Making it in time with just ten minutes to go before my wave of runners went, I attempted to de-stress during the warm up routines. Due to the amount of people waiting to start, warming up was challenging due to the lack of space to properly stretch.

I finally went through the start line at 11:15am. I tried to prevent myself from allowing the adrenaline from nearly missing the start to make me out pace myself during the first few miles along with the effort of running in a strong headwind. All along the race the views were spectacular. We passed the Portsmouth War Memorial and the grand Cathedral and I appreciated the horn toots of support from the Navy ships in the harbour. At half distance, after being spooked by a very loud bang that sounded like a pistol going off, I suddenly realised I was five minutes over my usual mile pace, and so set off on a mad dash over the last five miles. At times I was weaving and jiving around various men dressed in Ninja Turtle costumes along with the copious numbers of Macmillan Cancer and British Heart Foundation Research runners, at

one point even going behind the spectators to keep my pace up. I went past the one mile barrier and thought that I wanted to go as hard as possible with the



motivation of attempting to beat Stefan's time from the previous year. I made the silly decision to sprint, with various supporters shouting to keep up my strong finish. I could feel the lactic acid building in my legs, but I managed to get round the course in one hour 43 minutes which was 15 minutes faster than Stefan's previous time, so I have the bragging rights for now, until we decide to try something like this again.

The day finished with a meal in a very nice pub; the food was very satisfying after all my exercise. This was then concluded with a pub quiz, which myself, my girlfriend and Stefan did respectfully in. Many thanks to the Bardet-Biedl Syndrome UK members who sponsored my run.

On behalf of everyone at BBS UK, our heartfelt thanks go to Christian for his fantastic fundraising achievement. We would also like to take this opportunity to congratulate Christian on achieving a distinction in his Masters degree (LLM International Law of the Sea). Christian is still collecting sponsorship and donations for BBS UK via JustGiving.

If you feel inspired to make a donation, go to www.justgiving.com/fundraising/Christian-Bolton-Edenborough1.

BBS UK Activity Weekend at Avon Tyrrell

In September 2016, BBS UK hosted their second family activity weekend at Avon Tyrrell Activity Centre in the beautiful New Forest. We were so fortunate with the weather, the sun shone all weekend and the grounds and woodland looked stunning.

Following a hearty breakfast on the Saturday morning, the weekend's activities began with a swimming session in the outdoor heated pool. It is fair to say that the children were much more enthusiastic about this than the parents, it was a pretty chilly start to the day!

During the weekend, our families also enjoyed archery, hi-ropes, an assault course, zip-wire, orienteering and pedaloos. In the evenings we enjoyed crafts, table football and had a bonfire followed by a movie and popcorn! We also used the opportunity to have a second meeting of our Young People's group and with their help, work on the BBS UK 'education booklet' began.

Some of our young people requested more exciting and daring events this year and it was awe-inspiring to watch them tackle the zip-wire across the lake and take on the hi-ropes. Once again, the weekend's activities culminated in an obstacle course, which again was a fantastic testament to the determination and courage of our children and young people, a highlight of the weekend for everyone. None of this would be possible or as enjoyable without the fantastic Avon Tyrrell activities team,

they are a lovely group of young people, so encouraging and inclusive, our heartfelt thanks go to them all.

This very special weekend provides the opportunity for families to enjoy activities together, alongside other families who fully understand what it means to live with Bardet-Biedl Syndrome and it is fantastic to see everyone coming together and supporting each other. BBS parents really value meeting other parents who understand and everyone is able to just relax and enjoy being together in an accepting and non-judgmental environment for one fabulous weekend. The children and young people, both those who have BBS and their siblings, have an absolute ball; it was so lovely to watch them all looking out for each other and supporting each other with the activities and just enjoying being amongst friends for the weekend, we are so looking forward to next year's event, which has quickly become a highlight of the BBS UK calendar.

After two wonderful weekends at Avon Tyrrell, we are looking to move the weekend to a more central location for September 2017, further information will be made available over the coming weeks. If you would like to be added to the activities mailing list, contact Tonia Hymers: tonia.hymers@bbsuk.org.uk. We look forward to seeing you soon.



Winter Eating and Activity: ideas to help survive the winter weight gain pitfalls

Sarah Flack

Principal Dietitian, BBS Specialist Clinics, GOSH

At this time of year, when it is cold and wet, it can feel impossible to maintain your usual activity level and harder to choose healthy meal options. Salad isn't going to warm you up on a cold wintry day. Sometimes it can feel far more tempting to curl up on the sofa in your pyjamas in front of a screen whilst eating high calorie comfort foods or a take-away, but if you do this regularly the only result will be weight gain. Another hazard at this time of year is that food appears to be a central part of most winter celebrations. This can make managing weight gain even more challenging. If you feel you or your family are slipping into some winter related bad habits, read on for motivation and some ideas to try.

Winter weight gain isn't just an urban myth. Research has shown that many of us will gain weight this year and the amount of weight we gain is linked to our starting weight. Typically more weight is gained by those who are overweight before the winter period. Winter weight gain can be difficult to shift; many adults find their weight just creeps up a little bit year on year. Look in your wardrobe to see if there are things that used to fit and if there are, let's see if 2017 can be the year you get to wear them again.

Eating a little bit extra for more than a couple of days can really fool our bodies into believing it wants or needs this increased amount in the longer term. Sometimes we can kid ourselves that we have balanced the amount of extra calories eaten with increased activity as our weight on the bathroom scales hasn't changed. Remember if we eat too much today this won't be reflected on the scales for several days.

Overeating and/or reducing activity levels may affect your mood adversely. Many of us feel 'fed up' if our weight increases or we can't fit in our favourite clothes. Even more worryingly,

low mood can lead to a vicious circle of extra eating and further weight gain.

This may all seem a bit depressing so now it's time to focus on the positive things we can do which include:

- 'Winterising' your diet
- Ensuring you get enough sleep (without hibernating!)
- Thinking of this season as an opportunity to try new activities or join a club

Let's all try to make this the healthiest possible winter for ourselves and our families!

Below are some ideas and suggestions; some will be relevant to you but not all - some are aimed at adults only, children or families. Let's start with things to eat more of during the winter months.

Porridge (oatmeal)

Eating a warm bowlful of porridge or instant oat based cereal like Ready Brek, Scott's So Easy or supermarket own brand is a great way to start a cold winter's day. It is a great way to boost your intake of soluble fibre (important for heart health), zinc (important for maintaining a healthy immune system) and it is also low GI (glycaemic index). Foods with a low GI may help you feel fuller for longer so smaller meals and snacks later in the day may be manageable, which will help keep your weight in check.

Soup

Research has shown that eating a bowl of soup before a main meal can reduce your total calorie intake at this meal time in both adults and children. Using a vegetable based soup has also been shown to be a great way to boost your vegetable intake. Why not try changing to a two-course meal of soup followed by your evening meal and see if you can cut back your

portions of starchy carbohydrates (e.g. rice, pasta or potatoes) and protein-rich foods like fish, chicken or meat to a quarter of a plate each. This will help you cut back your total calorie intake. When choosing soup, avoid creamy, condensed or cheese containing types as these have more calories and usually more salt too. There is no need to add croutons or serve your soup with bread and butter as your main meal will contain plenty of the starchy foods to fill you up. If you eat additional bread and butter you won't be making an energy saving so your hard work will all be in vain.

Remember the best soup choice is to experiment making your own with a selection of vegetables (or to buy a vegetable based soup) so that this counts towards your 5-a-day target.

Try slow cooking

A slow cooker can be a great way of producing a hearty, filling winter meal to eat as soon as you get in from school or work. Using a slow cooker allows you to 'throw' all your ingredients in to the pot before you leave the house in the morning and return 8 to 12 hours later to a wonderful meal! Slow cookers can be great for stews, casseroles, chilli or curry loaded with vegetables to help fill you up. If your starchy carbohydrate food isn't included in the meal try serving with crusty bread, pasta or microwavable rice so that you can eat as quickly as possible.

Hot drinks

It is important for adults and young people to drink plenty of hot drinks like tea (including herbal or fruit tea) and coffee throughout the winter months as this can help you keep warm. However, watch out for the calorie laden coffee shop choices. Some of the seasonal options contain far more calories than you would imagine, for example, a medium-sized gingerbread latte at one high street shop contains around 320 kcals. Instead of this latte you could have enjoyed a breakfast of 2 Weetabix with semi skimmed milk, a banana and a cup of regular coffee or had a 2 egg omelette with tomato, mushroom and reduced fat grated cheese with salad for lunch. Stick to regular coffee or tea with skimmed milk, or herbal and green teas. These are usually

cheaper options too - so a win-win situation! Why don't you collect the money you save too for a big treat at some point in 2017?

Enjoy eating seasonal produce to meet your 5-a-day

There are lots of lovely fresh fruit and vegetables in season like clementines, satsumas, pears, oranges, brussel sprouts, carrots, leafy greens, parsnips, cauliflower and broccoli. Enjoy experimenting with different ways of serving or eating these delights. It is useful to fill your freezer with a good selection of frozen vegetables so you can quickly create a healthy meal. Look out for individual microwavable portions of mixed vegetables which can be a simple way to ensure you always have half a plate of vegetables at main meals. Eating this way allows you to eat a large and satisfying plateful whilst still controlling the total calorie content of the meal.

Eat regularly

It can seem an easy way to lose weight by skipping meals, but this can end in disaster as we either allow ourselves extra treats or grab a less healthy choice later on in the day, resulting in a higher overall calorie intake. If this continues this will lead to a gain in weight. Breakfast eaters tend to have healthier weights so try to have breakfast each day and then regular meals and healthy snacks too.

Drink enough fluid

Children will easily confuse thirst with hunger. Many adults can do this too so try a drink first! We all need to have at least 6 to 8 drinks each day. The size of the drink needed gets bigger as we grow up.

Now it's time to boost our activity levels. This can help lift our mood so it really helps our health and sense of wellbeing. The following ideas are only suggestions. Why not share your own ideas on the BBS UK Facebook page?

Get a pedometer or other step counting device

Studies have shown that step counts vary between summer and winter. It may not surprise you that step counts in winter have been found to be significantly lower than in the warmer summer. If you haven't got a

pedometer now may be the time to invest in one; it would also make a great gift idea so put it on your wish list for the next special occasion. Current recommendations are for adults to do 10,000 to 12,000 steps a day (12,000 steps roughly correlates with 5 miles for most adults). If you do get a pedometer start by checking out your usual step count and then set this as your minimum target. Aim to beat your target by a couple of hundred steps each day until you reach the 10,000 goal.

Try out new indoor activities

Winter can be the perfect time to try something new - either as a family, with friends or on your own. For adults, joining a sports club may be a great way to try new things and find new friends. Indoor activities to consider trying include goal ball, cycling, tennis, soft play, yoga, fitness classes, dancing or judo - there are so many options! Think about the things you enjoy doing, the ideal timing for you and the environment of the event. British Blind Sport have lots of ideas on their website: www.britishblindsport.org.uk

Why not share ideas with friends on the BBS Facebook page?

Embrace the cold and wet weather!

Wrapped up in a warm coat, scarf, hat and gloves, it can be great fun going for a bracing walk in the woods, on the beach or just around your local park. Children (and many adults secretly) love stomping in muddy puddles in their wellies, just like Peppa Pig, so don't let the rain put you off getting out and about.

The final area to consider is whether you are getting enough 'good quality' sleep. Sleep is known to be important for our physical health and wellbeing but some research shows that insufficient sleep can lead to weight gain in children and adults. Lack of sleep seems to be linked with increased snacking and a preference for energy-dense foods so it is easy to see why weight can increase. In children, later bedtimes and short total sleep times have been found to be associated with extra food intake, poor diet quality and increased body weight.

So how much sleep do we actually need?

Most adults require approximately eight hours of sleep; young children need much more than this. In adults, studies have shown that people who sleep less than seven hours a day tend to gain more weight.

Think you may need to increase your sleep?

Try a regular bedtime routine to help you or your child get ready for bed e.g. a warm bath, read a book or listen to the radio or a relaxation CD. Check you are not having too much caffeine (found in drinks like tea, coffee and cola) as this may affect your sleep. It can help to change to caffeine free drinks during the evening e.g. herbal tea or warm skimmed milk. Exercising regularly can actually help you sleep - so this is another great reason to try to be as active as possible during the winter. The NHS website is packed with lots of helpful advice if you need more information, or have a chat with your family doctor or clinic team.

So in summary, winter is the time to enjoy more filling and nutritious foods like soup, porridge, casseroles and stews with plenty of vegetables and feel great about these healthy choices. Don't let the wet and cold weather curb your activity. Find something you enjoy doing inside and consider buying a step counter to make sure you really move at some point each day. Research has shown Sunday is most people's least active day of the week; a step counter can really help you change this! Enjoy celebrating seasonal events but remember they last a day or two only so we shouldn't overindulge for several weeks. Remember to also make sure you get enough sleep so you wake up with lots of energy so you don't look for extra snacks to help you make it through the day! If you do find you or your family go off track a little with either healthy eating or the amount of activity, don't lose heart, just start again as soon as you can! With very best wishes for 2017.



Could you be a Friend of BBS UK?

As a small but national charity, supporting over 500 people with BBS and their families and carers, BBS UK relies solely on fundraising, donations and grants to fund their work and the amount of income determines the information and support they can provide each year. The BBS UK annual conference, newsletters and leaflets cost a great deal to produce and the charity is finding it more and more difficult to raise the funds needed to ensure future activity and growth.

Like most charities, financial stability relies on *regular* donations and we are often asked why we don't charge for membership to BBS UK. This would indeed provide that much needed regular income, however it has always been our policy that membership is entirely free to ensure that everyone who needs our support is able to access it.

Examples of support we have been able to provide this year:

- Helping a family get the benefits they were entitled to
- Assisting a young person to get a buddy so that they could get out and about
- Ensuring a family who were struggling with a new diagnosis receive regular support

Several years ago, we set up 'Friends of the LMBBS', now 'Friends of BBS UK', a fundraising initiative, giving those members who wished to regularly support the charity, the means to do so and we have slowly built up a small, loyal band of 'Friends' to whom we are very thankful as they help us to continue to provide the much needed support and information.

If you or someone you know would like to become a Friend of BBS UK, it couldn't be easier. Simply complete the attached form and return to the address below. There is no minimum, or maximum amount you can give each month. If fifty 'Friends' completed a standing order for just £5 per month, the income of BBS UK would increase by £3,000 per year! That would make a big difference to a small charity! Of course you are free to start and stop the Standing Order at any time, as you remain in control.

If you feel you would like to become a 'Friend', but would like more information, please contact the BBS UK Finance Officer, Kevin Sales, who will be pleased to assist you.

Kevin Sales kevin.sales@bbsuk.org.uk 01892 685311



Friends of BBS UK

Name:

Address:

Post Code:

Tel No:

I would like to become a Friend of BBS UK:

I have completed the Standing Order form overleaf Tick

Please send me a collection box

I wish to organise a fundraising event and would like a Fundraising pack

Gift Aid Declaration

The Government allows charities to reclaim tax through the Gift Aid scheme at no extra cost to you. At the standard rate of income tax, your gift is worth 20% more to us if you allow BBS UK to claim Gift Aid. Please tick the box below and help us to do more with your donation.

I would like the BBS UK to reclaim the tax on any donation I make. I have paid an amount of UK income tax or capital gains tax equal to any tax claimed.

Thank You



Friends of
BBS UK

Standing Order Form

I would like to become a 'Friend' of BBS UK and make the following regular payment:

Please pay the sum of £

Amount in words:

To: Bardet-Biedl Syndrome UK 'Friends Acc'
Account No: 70901059 Sort Code: 20-88-13

With effect from: (Date)

And **monthly** thereafter.

Please complete the following in **block capitals**:

Name:

Address:

Postcode:

Name of Bank:

Address of Bank:

Postcode:

Account No:

Sort Code:

Reference:

Signed:

Date:

Please complete and return to:

Kevin Sales
1 Blackthorn Avenue
Southborough, Tunbridge Wells
Kent, TN4 9YA

Jeans for Genes 2016

SUPPORTED BY



BBS UK applied to Genetic Disorders UK in the summer of 2015 for a grant under the 2016 Jeans for Genes Programme to fund the BBS UK Information Project: Prepare, Support, Empower. The aim was to produce three booklets:

My Day at BBS Clinic: a booklet utilising pictograms and photos to enable our younger members to better prepare for their day at clinic.

BBS and Me: an information booklet to be used in an education setting, produced in collaboration with our young people and families to ensure their needs are met and their voices are heard.

Transition Handbook and Workshop(s): a booklet and workshop aimed at preparing our young people for the transition to adulthood and the transfer to the adult BBS clinics.

We were shortlisted and presented our project to the panel in November 2015 and are delighted to report that J4G have awarded part funding; work has begun on the new 'education booklet', we will soon have the transition booklet underway and in 2017 we will seek additional funds to complete the project.

Our thanks go to all the young people and families who have helped with the 'education booklet' to date, your support and contribution is invaluable. Our most grateful thanks also go to all the families who supported Jeans for Genes Day in September 2015, in particular to those who told their story to raise awareness of Bardet-Biedl Syndrome and genetic disorders in general.

Breaking Down Barriers

BBS UK are contracted by NHS England to provide facilitation and support services to the specialised BBS clinics held in London and Birmingham and every year we are required to send a report of the year's activity, highlighting any issues and including evaluation data collected through the year. We also have to collect, collate and send Service User Data, which includes the age, gender, location and ethnicity of our patients. The BBS UK membership and patient group is ethnically diverse, with approximately 58% recording 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 BBS UK 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 will be 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 Sylvia Adams Charitable Trust was set up in 1996 with money left from the sale of Sylvia Adams' personal collection of antiques, in line with her wishes. From 1996 to 2015 grants have been given to projects supporting children and young people, those with a disability, those living in poverty or socially excluded. In 2011 The Sylvia Adams Charitable Trust contributed funding towards Alstrom Syndrome UK's Asian Mentoring scheme. This funding enabled ASUK to work within the South Asian communities to develop a greater understanding of their cultures and beliefs, the barriers and challenges they face and to raise awareness of Alstrom Syndrome, a rare autosomal recessive condition causing childhood blindness, hearing loss, heart failure, kidney failure, type 2 diabetes and many associated problems. The project was a great success which led to The Sylvia Adams' Charitable Trust committing funds to the Breaking Down Barriers project.

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. It is important to BBS UK that we give all families and individuals informed choices about the importance of ongoing health management and that all of our members feel fully understood and heard whatever their ethnic background.

The project runs across a three year period and our Year 1 Action Plan has been accepted:

In the first year BBS UK aims to:

- ✓ Ensure all newsletters contain relevant information for the entire BBS UK membership demographic
- ✓ Ensure all information leaflets are recorded in an appropriate language for South Asian members for the BBS UK YouTube Channel
- ✓ Plan small gatherings in an appropriate central location to encourage families to meet for mutual support

In years two and three, in addition to the above, BBS UK aims to:

- ✓ Identify a member of BBS UK to be a point of contact for our Asian families and to attend the BBS UK Clinics in the Birmingham area
- ✓ Organise an information day at a Birmingham hotel for local families and patients
- ✓ Engage an Asian Mentor to provide support alongside BBS UK staff and volunteers at the BBS Clinics

We are very excited to have been accepted onto the Breaking Down Barriers Project and look forward to working with Kerry Leeson-Beevers (ASUK) and the Sylvia Adams Charitable Trust. We will keep members updated with the project and developments over the coming newsletters. In the meantime if members would like to get involved with the project or would like further information, please contact Julie Sales: julie.sales@bbsuk.org.uk or by telephone: 07917 252585.

BBS UK Social Weekend at Cobden Hall Hotel

Denise and Alan Nice

The BBS UK inaugural adults social weekend was organised by Julie Sales and Angela Scudder and was specifically designed to give likeminded adults the chance to get together to meet up with friends, old and new, for a fun weekend.



Cobden Hall Hotel in Birmingham is a BBS UK favourite and is used for patients attending the BBS clinics at Queen Elizabeth Hospital; it proved ideal for the group's needs with the staff being extremely helpful and friendly.

It was arranged that everyone would meet inside the hotel on the Friday afternoon, where myself and Alan and later on Julie and Tonia would meet and greet and show people to their respective rooms and then meet later for drinks and a chat. After the evening meal in the hotel, details of our weekend were discussed, and menus were finalised for our meal in Frankie and

Benny's on Saturday. Teams were also drawn up for the ten pin bowling session which was to take place prior to the meal.

Saturday arrived and we all had breakfast and then chatted before our departure to the bowling alley in pre arranged taxis. As we had arrived before our allotted time, we all had drinks and the conversation flowed. We had two games of bowling each and we all managed to complete both games. It was great fun. I lost count of the number of strikes people were getting. Our thanks go to Sarah Lardner who came along to provide extra support, and fun, with the bowling.

We had certainly worked up an appetite for our meal at Frankie and Benny's. The staff were amazing and delivered the meals to each person by name; the staff were congratulated for the speed and courteous manner in which our meals were delivered. It was then back to the hotel. Some of us needed a rest whereas



others carried on to the small hours.

After breakfast on Sunday morning (a few of us still not quite awake) we all made our way back home. The feedback from everyone was very positive and we all thoroughly enjoyed ourselves. We are hoping that we could do something similar next year and would welcome and encourage some more people to join us, and hopefully make this into a yearly event. If anyone has any ideas for suitable pursuits we would love to hear from you.

Myself and Alan enjoyed the experience immensely, and our thanks along with those of everyone who took part, go to Julie, Angela, Tonia and Sarah for making this weekend so



successful.

Bye for now and look forward to seeing you at the next conference.

Fundraising Round-Up

First of all, a huge 'Thank you' to everyone who has raised funds or donated over the past year, you have been running, organising parties, making cards and crafts and so much more to raise funds for BBS UK, what a year you have had, you are all stars!

Your support really is so very much appreciated, if you want to try something new or are looking for new fundraising ideas, we have put some ideas together below; there are so many fun ways to help BBS UK.

Be a 'Smartie' and help BBS UK raise some money!

Treat yourself to a tube of smarties and then fill the empty container with any spare change. Bring it with you to Conference or Clinic and hand it in to one of the BBS UK Team. All coins will be gratefully received and will make a difference to what we can do.

Stand Up Bingo!

This is a very easy thing to organise - all you need is a book of raffle tickets.

If you are at an event or a party, ask people to buy a raffle ticket for £1 (they can buy as many as they want). Once all the selling has been done, everyone needs to stand up and the raffle tickets will be drawn one by one. When

someone's number has been drawn, they sit down.

When three people are left standing, the 3rd person receives £5, the second person receives £10 and the last person standing receives £20. You just need to ensure you sell enough tickets to cover the cost of the prizes and then the rest of the money raised goes to BBS UK!

Make sure you have someone marking off which tickets are drawn out to help clear up any confusion at the end if more people are left standing. (This could be done using a number square).

And lastly, make sure you insist that the winners keep their money - some people may want to donate it to the charity but if this happens people will be less likely to join in if you do this activity on another occasion because they will think there is no point if no-one actually wins the money.

Active Challenges

Some fundraising may take you to great heights or stretch you to your limits. Are you looking for a challenging way to raise funds? Why not sign up for something different next year. Take part in a sponsored cycle ride, walk, marathon run, sky dive or challenge of your choice to raise funds for BBS UK.

Become a BBS UK Hero

All sorts of people do heroic or just plain silly activities to help raise funds; whatever you do you are a BBS UK Hero.



Here are some ideas to inspire:

- Take part in a sponsored event e.g. fun run, adventure race
- Put on a fundraising meal or party for friends or family
- Give something up for a month (or two) e.g. chocolate, smoking or coffee!
- Host a quiz or games evening
- Take on your own personal challenge
- Swim-a-thon
- Car washing
- Fancy dress pub crawl....for the adults!
- Football knockout tournament
- Pancake race
- Sponsored silence
- Treasure hunt
- Teddy bears picnic
- Film evening
- Jewellery making
- Bingo
- Read-a-thon
- Carol singing
- Mulled wine and mince pie evening
- Eighties night
- Murder mystery evening

To raise money for BBS UK, simply decide what event you are going to do or organise, and then use our BBS UK sponsorship form. Alternatively you can set up your own sponsorship form or donate online at justgiving.com.

Just Giving

Online sponsorship is a very straightforward way to promote and collect funds and we recommend www.justgiving.com. It is so easy to set up your fundraising page and share with your family and friends.

You can also donate directly to BBS UK through our own fundraising page www.justgiving.com/lmbbs

Text Giving

Another simple way to donate is using Text Giving, simply text BBUK17 £5 or BBUK17 £10 to 70070 to make a donation.

Give As You Live

You don't have to dig in your pocket to raise money. There are loads of FREE ways that you can help us. You can now support Bardet-Biedl Syndrome UK every time you shop online through Give as you Live. You can shop online at over 4000 retailers where a percentage of what you spend can be turned into a donation for us, and it doesn't cost you a penny so you are helping us for free. Stores including Amazon, Debenhams, John Lewis, Sainsbury's and many more have all signed up with Give as you Live to turn your spend into a free donation for us.

It's easy to get started all you need to do is follow these simple steps:

1. Visit www.giveasyoulive.com/join/bbsuk
2. Click the big blue "sign up as a shopper" button
3. Enter your first name and email address

And then you can either shop at retailers by visiting www.giveasyoulive.com or you can install the toolbar donation reminder to your PC and laptop and you will never miss a donation visit. Sign up today to help us support people living with BBS.

Match Giving

If you are doing a fundraising event for us don't forget to find out if your place of work offers a match giving scheme. Many companies will offer to match pound for pound against what you raise. If they don't they might consider supporting you with a donation instead.

Gift Aid

Claim gift aid and make your donation worth much more – for every pound donated, BBS UK can claim an extra 28p from Inland Revenue*.

*To claim gift aid, we need the names and addresses of your sponsors and they must be UK tax payers. We will take this information from your paper sponsorship forms, or if you have setup online fundraising with Just Giving then gift aid is claimed automatically.

Corporate Giving

Do you run your own business or would your employer be interested in Corporate Giving? If so listen up or spread the word. Your company can make a real difference to BBS UK. Companies and their employees can support our charity in a range of different ways that not only help us to help children and adults with Bardet-Biedl

Syndrome and their parents and carers but also provide rewarding development opportunities for the staff that get involved.

We can work in partnership with employees and businesses in many different ways, for instance you could help:

- Encourage staff to get involved in fundraising events to support our work
- Make donations to help fund our projects and services with disabled children and adults
- Engage staff in a range of volunteer roles for the charity
- Choose us as your Charity of the Year

The benefits to your Company are that we can help you achieve your business and corporate social responsibility (CSR) objectives. Some of the benefits to you would be:

- Additional marketing routes for your brand and products

- Excellent opportunities for your employees to engage in team building activities and events, raising money to help children and adults with Bardet-Biedl Syndrome
- Enhanced image among your shareholders, customers and your community

We can work closely with you to determine the activities that will work best for your company. For more information on how your company could work with BBS UK, email us at fundraising@bbsuk.org.uk.

We can't wait to hear about your fundraising achievements over the coming months, so please keep in touch with us at **fundraising@bbsuk.org.uk**. We'd love to hear from you.

Finally, we really do wish we could name all of you who have done so much to help the charity but it would take up the whole of the newsletter! Without every single one of you, the charity could not continue the valuable work that it does. Keep up the good work!

Mailing List Update

Ever conscious of BBS UK's rising mail costs and environmental impact, we are asking our members and supporters to consider how they would like to receive their publications in the future. We will continue to produce a paper copy and send out to members unless they tell us otherwise, however some of you may prefer to receive a digital copy to read or listen to on your computer, tablet or smart phone. Enclosed with this newsletter is a data sheet so you can tell us exactly how you would like to receive your newsletters and other communications in future. Email is quick and free and at BBS UK, we use it to keep in touch with our members in between newsletters to inform of events and activities so to ensure you don't miss out, make sure we have your current email address.

It would also be really helpful to know if visually impaired members are eligible and happy to receive mail under the 'Articles for the Blind' scheme. Articles for the Blind is a scheme for blind and visually impaired people who

are registered as blind or whose standard of close-up vision, with glasses is N12 or less and certified by an ophthalmologist, doctor or ophthalmic optician.

The Articles for the Blind scheme enables blind or visually impaired individuals and registered charities to send 1st Class and International Standard letters, large letters and parcels for free; mail should be addressed to the blind or visually impaired person at that address.

There are considerable savings to be made, which will make a huge difference to BBS UK so please complete and return the enclosed data sheet as soon as possible.

The data sheet should be returned to Julie Sales, 1 Blackthorn Avenue, Southborough, Tunbridge Wells, Kent, TN4 9YA.

The data sheet can also be downloaded from the BBS UK website, completed and returned via email.

Contact Details

BBS UK General Contact

BBS Clinics UK Adults Service

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BBS UK General Contact

BBS Clinics UK Children's Service

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BBS Clinics UK

Family Support Worker

Angela Scudder
07958 204414
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BBS UK New Families Contact

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BBS Adults Focus Group

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www.bbsuk.org.uk