

# Bardet-Biedl Syndrome UK

Registered Charity No. 1181244



## BBS UK Winter Newsletter 2019-2020



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# Foreword

Welcome to the BBS UK Newsletter, Winter edition 2019-2020.

2019 was a busy but fun-packed year at BBS UK and inside you will find reports highlighting some of the activities we have enjoyed across the year.

The Birmingham Social Weekend and Family Activity Weekend were both enormous fun and a great success and we urge anyone who hasn't yet joined us on these events to sign up in 2020. Planning is well under way for the highlight of the BBS UK calendar, the Annual Weekend Family Conference, which this year will be held across the weekend of the 17th-19th April, once again at the Hilton Hotel, Northampton. Booking forms are enclosed with this newsletter and can be found on our website and Facebook page.

Also inside we have a report from Graham Daff about his experience on a Seable holiday, charity and fundraising news, a directory of useful resources and different ways of providing support through volunteering.

This newsletter is only possible with your support and we look forward to hearing from you over the coming weeks and months, but in the meantime, on behalf of everyone at BBS UK, we wish you a very Happy New Year.



# A Day at Sight Village, Birmingham

In July 2019, Amy Clapp visited Sight Village, Birmingham along with Aneeba, Luke, Graham and Sian.

Amy reports, “On arrival we joined the first seminar for the **Amazon Alexa**, a fantastic device that uses voice recognition and wifi to perform an ever-growing range of tasks including playing music or radio, accessing the internet, calendar services and other organisational tools. Additional support may be required at set up but Amazon provide a free help line.”

The following technology was also on display:

**Oxsight** smart glasses, which use intelligent image interpretation technology to enhance the user’s remaining vision.

**Orcam My Eye 2.0**, an artificial vision device with a lightweight smart camera that reads text aloud from any surface, and recognises faces, products and money in real time. The Orcam snaps onto any eyeglass frame magnetically.

**The Sunu Band**, a smart band that can guide you around obstacles using sonar or echolocation to detect objects up to 16 feet/5.5 meters away. Haptic vibration feedback informs how close (or far away) you are to obstacles.

**We Walk**, a smart cane which connects with the user’s phone via the WeWalk app, integrates with apps such as google maps and uber and also features obstacle detection.

Amy said, “We all really enjoyed the day, the



atmosphere was great and there were lots of friendly and informative stalls.”

In September, BBS UK Trustees, Rachael and Dianne enjoyed a day representing BBS UK at Manchester Sight Village which they reported was also well attended. Their stand was visited by many interested visitors including rehabilitation officers, VI teachers, VI charities and BBS UK members and they had a busy day raising awareness and offering information and support. They also met individuals who had received a diagnosis but hadn’t yet accessed BBS UK services. Many of the professionals were interested in learning more about the syndrome and taking information either to help those they already work with or may work with in the future.

There is a vast array of technology, equipment, information and support services available for people living with sight loss and we highly recommend that members go along to an exhibition near them to find out more. BBS UK also aims to invite exhibitors to Conference 2020 which will provide delegates with a snapshot of what is available.

# Birmingham Children's Hospital holds its first BBS Telemedicine Clinic



Joshua and Ryan Eccles, aged 15 and 11, who both have Bardet-Biedl Syndrome recently 'attended' their consultation appointment with an expert multi-disciplinary team at Birmingham Children's Hospital (BCH), from the comfort of their home in Wednesbury thanks to the use of digital technology.

Consultants from across the BBS clinics service worked with NHS commissioners to look at ways of extending the regular multi-disciplinary clinics service. Telemedicine clinics will benefit those who may not need a full clinic appointment, those who find travelling to hospital difficult or simply provide an interim check-up between the regular 'in-person' clinic appointments. Telemedicine clinics have been introduced across the four centres, however it is early days and this innovative service will continue to develop over the coming months.

Joshua and Ryan accessed the telemedicine clinic via Zoom video conferencing, set up by the BCH IT team, they were able to link with the team via an iPad on their kitchen table. Mum, Claire Eccles, felt the virtual clinic brought real benefit. She said:

"Joshua and Ryan normally attend a clinic, which is a whole day of appointments and it can be stressful for them and a tiring day for me. I felt the telemedicine clinic was really good for us as a family. We got as much done as we would have in clinic but in the comfort of our own home. The boys loved it and they were also able to do some of it independently, which was brilliant. We are so lucky to have such a great team of specialists and we'd like to say thanks to all involved."

BBS Service Lead, Professor Timothy Barrett said:

"The clinic was a huge success. It was delivered with specialists in endocrinology, diabetes and dietetics, along with BBS UK Support Officer, Amy Clapp. Thanks to our NHS commissioners, and with great support from our fantastic IT department, we were able to see and hear Joshua and Ryan and Mrs Eccles, which helped us have important discussions around their medical, emotional and educational needs. This clinic model does not replace face to face appointments, but does offer an option for families who find travelling to Birmingham difficult. It also has the potential to address NHS waiting times for outpatient appointments. Both Claire and her boys found the experience useful. We were able to come up with a list of action points to take forward with their GP, school and other local services."

BBS UK is working with all four centres in the development and running of the telemedicine service and welcomes all feedback in this respect; contact [tonia.hymers@bbsuk.org.uk](mailto:tonia.hymers@bbsuk.org.uk).

# My First 5K Big Fun Run

*Hamza Hassnain*

So this is my first time ever of doing a 5K Big Fun Run. I've never done this before so I was quite nervous but excited too. On the day, I got ready and around 10am I left the house. We got there for 11am and I got to the park. Furthermore, we then did 5-10 minutes of warm up. Now the work gets even more harder! The run has now started and it lasts for an hour! So I ran my first 5K lap and got to the finish line. I thought that my first lap was not very tough. So guys guess what I did next? I

decided to do another lap. By the time I had completed the lap and reached the

finish line, I was super tired and couldn't do any more laps. Finally, I decided to finish off my run and wrap it to an end. We ended it and finally went home. I really enjoyed my run considering it being a first experience. Hopefully I should do something like this again!



## BBS UK Social Weekend 2019

October 2019 saw BBS UK host the ever-popular BBS UK Social Weekend. The aim of the weekend is for adults from all over the country with BBS to meet up with each other, explore new towns and try new experiences. Every year we try to organise new opportunities and encourage members who have never attended to come along and experience the weekend for themselves. Two newcomers to the weekend, Joe and Alison, enjoyed their first BBS UK Social Weekend so much they agreed to share with us why they decided to attend and what they enjoyed. Joe states, "I was interested in attending the weekend as it sounded like the weekend was fun and quite action packed. Everyone always seems to have a good time so I decided that I wanted to have the same experience." Alison decided to come this year "to meet other people with BBS and to build my social life as a visually impaired person and share experiences."

This year's event was bigger, and more action packed than ever. Friday night saw our

welcome meal and drinks followed by a very competitive and closely fought quiz. Many attendees had not seen each other since conference or longer, so it was a fabulous evening of laughter, meeting new people and catching up with old friends.

On Saturday morning, we all set out early to visit the BBC Birmingham Studios and everyone agreed the tour was fantastic. The tour guides were specifically trained in ensuring that those with a visual impairment got the most out of their time there; the tour was tactile, studio/set based and a truly fascinating insight into the world of TV and radio. Alison said, "We had an excellent guided tour of the BBC Studios and enjoyed walking onto the studio floor of 'Midlands Today' and 'Sunday Politics, Midlands'. We entered and sat in the control gallery, understood the importance of timing, and, if you were lucky, perhaps you sat in the Director's chair pressing the buttons and calling the shots! We visited the Archers studio, felt the weight of the scripts, and saw

and learnt how the special effects were recorded.” Joe said, “I thoroughly enjoyed the tour of the BBC studios and learnt so much about how Midlands Today is made as I watch this sometimes when I stay with my parents and they were also fascinated when I explained to them how the presenters have to write their own headlines.”

We would recommend to anyone in the area to book a visit.



Following on from the BBC tour, we headed to the Hippodrome for afternoon tea and an audio-described performance of Blood Brothers. Many of our group headed straight for the 'Touch Tour', which is a tactile tour of the stage and the props. This can enhance our understanding of the play and provides an invaluable opportunity for those with a visual impairment to visualise the set and get a deeper understanding of the characters. Alison said, "It was an informative touch tour...we walked on the stage, learnt about the story more, saw and felt props and costumes, and we even named the teddy, Keith, who was in the pram for the afternoon performance." Joe said the tour gave him "a real sense of where the cast would be on stage and what they had used to make the various objects."

The staff at the Hippodrome supported us fantastically throughout our visit, ensuring everyone had the correct audio aids and our lovely guide dogs were well looked after for the duration. Blood Brothers did not disappoint, Joe told us, "I immensely enjoyed the production of Blood Brothers so much so that I told my family all about it and also haven't been able to get some of the songs out of my head, which would normally be annoying but they were such jolly songs that it hasn't bothered me." Alison said, "The afternoon performance of Blood Brothers was excellent and all cast members were outstanding. One highlight for me was the powerful and poignant rendition of the song 'Tell me it's not true', led by Mrs Johnstone, the narrator and cast."

We laughed and we cried, Blood Brothers was a two-hour roller coaster of emotion that finished with a well-deserved full standing



ovation.

After a well-earned rest it was time for everyone to pop on their party shoes as we headed out for an evening of Greek food and festivities at Santorini Restaurant. The food was fantastic and the restaurant had a very lively atmosphere. Full up and exhausted, it was fortunately just a short hop and skip back to our central hotel for a post evening nightcap and natter.

Joe told us he enjoyed everything about the weekend; Thank you to everyone who came along and supported this event, we all had a fantastic time and cannot wait to get planning for next year!



# Seable Holidays

*Graham Daff*



I first heard about Seable Accessible Holidays via a monthly news digest a few years ago. I looked them up on the internet and then spoke to Damiano who was very helpful. I have been to Sicily for the past two years with them and late last year I noticed that they were doing more destinations and found that Amsterdam was one of them, which was a place that I wanted to visit and try out on my own.

I contacted Damiano and booked to go to Amsterdam this May, he was very helpful in organising everything. When I arrived at Amsterdam airport the special assistance helped me through to the arrivals hall where my guide, Veroniek, was waiting for me. We got a taxi to the Hotel Motel One, checked in and I was shown where everything was in my room. Then after a bit of downtime Veroniek collected me to go for a Chinese meal at the Sea Palace, followed by a visit to the Anne Frank museum using the tram to get there. I was allowed to go through the door where groups go and had someone making sure that I was safe all the way around the

museum. We then went back to the hotel for a well-earned rest!

On the second day I had a different guide, Roel, who showed me where everything was and helped me to get breakfast, after which we went for a tour of Amsterdam on foot. My guide had a wealth of knowledge of Amsterdam; we hopped on the tram and went for coffee at a street café, then we went and had croquettes which are famous in Amsterdam.

Following this we walked for a while to get to the canal boat where we had a long audio described tour which was very interesting and Roel took lots of pictures for me. We then went back to the hotel for a rest before going out to an Italian restaurant which was not too far away.

On the third day Veroniek joined me for breakfast and we had this together; we then went to a cheese farm and I made my own cheese (which I was allowed to take home with me) with assistance from a helpful assistant from the farm. Whilst the cheese was having the liquid squeezed out of it under a large press, we had a tour of the farm sampling lots of different flavours of cheese. We then saw how clogs were made and the different styles of them, followed by lunch provided at the farm. After this visit we went back into Amsterdam and did the Heineken experience which was great as we had a special key which gave us special access which helps to avoid the crowds. It was an amazing experience, I even got to go close to the shire horses, which is by special arrangement. I was worn out by the



end of the day, so we went back to the Italian restaurant for tea.

On the final day Roel met me for breakfast and we took the train and a taxi past the Hague to the beach where I did Power Kiting which was great fun; we had excellent weather for being on the beach. Following a snack we headed back to Amsterdam and in the evening Roel took me to a great steak house which was a brilliant end to my holiday.

When I returned home, Emma from Seable rang to get feedback as to how the holiday was and to find out if I would go back again and if the guides were up to standard. I would highly recommend going on holidays with this company.

For more information about Seable and the holidays on offer, go to [www.seable.co.uk](http://www.seable.co.uk)



## A new Chairman for BBS UK

After serving for two years as Vice-chairman of BBS UK, Stefan Crocker was elected as Chairman at the AGM in April.

“As Chairman I wish to increase the public knowledge of BBS and promote the work of the Charity,” said Stefan. “I was born and live in the market town of Bedford and due to a very late diagnosis I was educated in mainstream education. As BBS causes rod-cone dystrophy, I struggled at school in the mainstream sector. Thankfully nowadays there is a genetic test for BBS and additional needs support at school has much improved, although it is still not perfect.”

Stefan continued, “I had gone through my childhood seeing an optician at the Child

Development Centre in Bedford and was first diagnosed with astigmatism.

I received, periodically, ever stronger prescriptions for spectacles. I had heard that laser surgery could correct astigmatism, so in 2001 I attended a different Optometrist for further investigation. He noticed a retinal issue and referred me to the Bedford eye clinic, where they in turn referred me to Moorfields Eye Hospital, London. In April 2002 at Moorfields, I underwent numerous tests including sitting in a dark room for a prolonged period of time with electrodes



attached to my eyelids. Eventually the Consultant Ophthalmologist, Professor Bird, diagnosed me with BBS. Both my mother and I were very shocked and baffled by this information and spent a silent train ride home.”

Stefan had issues with bullying, had little confidence in his mobility and was unaware of his needs as a visually impaired person or how to articulate them. After diagnosis and assessment, he was given amongst other support items, text to speech software. Stefan always had a deep interest in politics, and eventually decided to undertake a politics degree, taking an Access to Higher Education course at Tresham College, Kettering. This involved travelling numerous times a week by train, which increased his confidence and knowledge of travel assistance and led him further from home. He graduated from the

University of Portsmouth in 2014.

Stefan reports, “During my time at Portsmouth I expanded my horizons and my tastes. I also learnt new visually impaired skills especially when I obtained my first Apple iPhone enabled with Voice Over. I discovered a love of travelling, helped by making many contacts through the BBS community. My extended time with visually impaired people made me realise I would like to work in the field of helping sight impaired people to be independent and maximise their lives.”

Stefan concluded, “I try to keep fit by regularly attending the gym, going for long walks and I have recently taken up visually impaired tennis. In 2016 I ran the 10-mile Great South Run in Southsea, Portsmouth to raise much needed funds for BBS UK and plan to do this again in October 2019.”

## BBS UK Activity Weekend 2019

Lots of adventures were had, and challenges conquered at the annual BBS UK Family Activity Weekend 2019. Families from all over the UK descended on Whitemoor Lake, Staffordshire in early July to partake in our yearly family-based event.

Friday’s good weather meant the weekend kicked off with the grown-ups enjoying the evening sun, while the children enjoyed the bouncy castle, arts and crafts and movie night. On Saturday, although the sun forgot to put his



hat on, all the families braved the drizzle to partake in numerous activities including, raft building, kayaking, sailing and archery.

A firm favourite at Whitemoor Lakes is the team games, where the families become super competitive and battle against each other to complete lots of wacky tasks and games. The evening saw the highly anticipated campfire with songs, games and most importantly toasted marshmallows.

On Sunday morning, grown-ups and children alike conquered their fear of heights by completing the high ropes and abseiling challenges, a perfect end to a wonderful weekend. After a well-earned Sunday Lunch it was time to award the children their medals for all their achievements, say goodbyes and go home for some rest.

The BBS UK Family Activity Weekend 2020 is set to be held at Whitemoor Lakes across the weekend of 26th-28th June. Activities will include sailing, kayaking, raft building, archery and team games. If you would like to register your interest, email Tonia at [tonia.hymers@bbsuk.org.uk](mailto:tonia.hymers@bbsuk.org.uk).



# Fundraising Round-Up!

What a great year you have had, fundraising for BBS UK; you have been walking, swimming, running, crafting, cake baking, quizzing and partying and below is just a small sample of the fundraising activities from across the past year. We would love to share your stories with other members, so if you would like a mention in our newsletter, on our Facebook page or website, please email [fundraising@bbsuk.org.uk](mailto:fundraising@bbsuk.org.uk) and don't forget to include a picture!



We are grateful to Andrea Howlett for running the Manchester Marathon for BBS UK. Living and working in London with a family of her own, Andrea had great reasons to support BBS UK. "My Mum supported BBS UK as my cousin's granddaughter, Evie Swales has BBS, so I knew that was the charity I wanted to raise funds for. Evie is a fantastic little girl who is getting on with life and is bravely coping with BBS. Our whole family are so proud of her and the fantastic support she has from her lovely parents and sister. I know they have benefitted from the support of BBS UK since Evie's diagnosis." Thanks again Andrea.

Nicola Jordan is a mum of two children with BBS. With her whole family, friends and colleagues supporting her, she swam 22 miles in 12 weeks and walked 10,000 steps

each day. Her target for this challenge was £300 which she smashed raising £510. Fantastic effort Nicola!

Nik Oliver was raising funds for BBS UK when he received an unexpected donation. A donation of £150 came in via his sister in law from the Metropolitan Police Call Centre Tuck Shop!! A big shout out to the boys and girls in blue.

Ashley Wilkie and Emma Mitchell of Angus in Scotland rounded off an amazing year of fundraising by running the Virgin Money London Marathon 2019. A reprise of the Wilkie's fundraising efforts can be seen in this year's Conference Report.

Aneeba Ahmed has been fundraising for BBS UK and other charities for several years. She makes and sells colourful bracelets and takes part in sponsored walks.



Ollie Sloane's fundraising for BBS UK is going from strength to strength. Supported by friends and family, Ollie has organised a craft stall selling cards, up-cycled items and merchandise, a Quiz Night that raised a phenomenal £425 as well as an annual tea party. Great ideas there for others to copy. Thanks Ollie.

BBS UK was chosen by members to benefit from the recent Scottish Vintage Tractor and Engine Club (SVTEC) Annual Road Run in aid of charity. On Sunday 26th May 2019 a large selection of vintage tractors set off from



Huntingtower Quarry, Perth, on a circular route travelling 20 miles through the delightful Perthshire countryside. Organised by Duncan Heeps, the members generously raised £900. A public cheque presentation to BBS UK took place at Scone Palace on Sunday the 8th of September 2019.



Market Harborough couple, Michael and Ashley Hobbs put BBS UK forward as a beneficiary charity for Lounge Aid, an annual event where all the 128 Lounge Bars across England and Wales focus on raising money

and giving support to a local cause or charity. BBS UK were delighted to be supported by Mercado Lounge in Market Harborough for May and June and received an incredible £1,160, raised through Quiz Nights, Cake Bakes and several members supporting the Hobbs family in their Tough Mudder event. Could you do the same in 2020 at your local Lounge? Check it out.

Ashley and Michael, with their two children Oliver (4) and Charlie (18 months), were amazed at the support from local people in Market Harborough when they began to fundraise for BBS UK following Ollie's diagnosis of BBS. Whilst Ashley has her hands full as full-time carer and mother to the boys, Michael is a senior energy consultant at Utility Bidder, Corby. Michael organised a team for the Tough Mudder 2019 Challenge, held recently at Belvoir Castle, Leicestershire. Following a call for support, an incredible 44 people from the area joined the team and to date they have raised in excess of £10,980.00.

In a local press release, Michael said they wanted to increase awareness of BBS UK and the amazing support and information they provide for Ollie and the family. Their aim is to raise as much money as possible to give Ollie and the other young people and



adults with BBS around the UK, the best possible future.

Swimming 1400 lengths, Fern Walker (32) faced up to the hardest swimming

challenge of her life and smashed it, raising over £1250, which was well above her target; she was cheered to the finish by her family and friends. Elaine, her mother, thanked all concerned for their support in this undertaking, with her carers from Partners For Inclusion and the poolside staff at both Prestwick and Troon pools getting a special mention. The Ayrshire Post were on hand to capture the celebrations at the end of the swim. (Photo with permission and accredited to Stuart Wilson, Ayrshire Times)

#### Late News:

In October a team of BBS runners entered the Great South Run in Portsmouth. Running the 5k race were Laura Dowswell, Maria



Dowswell and her guide runner, while Stefan Crocker, Chairman and Emma Oates ran the 10k. They were inspired by talks at the Conference from Tom Oates and the Wilkies. All runners completed their race in good time and are recovering nicely!

We are immensely grateful to all of our supporters including those mentioned above along with their friends and family for coming together and supporting BBS UK in this way; if you would like to find a suitable challenge for you and your friends and family, contact Christine, BBS UK Fundraising Co-ordinator for ideas and support: [fundraising@bbsuk.org.uk](mailto:fundraising@bbsuk.org.uk).

## My Life, My Future!

BBS UK is excited to launch its new booklet, 'My Life, My Future: a young person's guide to living their life with Bardet-Biedl Syndrome'. The booklet has been funded by Genetic Disorders UK through their Jeans for Genes grants programme and produced in collaboration with the young people of BBS UK and members of the BBS clinics team.

The booklet is aimed at young people of secondary school age to help them prepare for their eventual transition to adult healthcare services. My Life, My Future is a

Supported by



useful toolkit of information to help young people on their way to becoming more independent and get them thinking about how they would like to live their lives.

The booklet is designed around the ten symbols of 'T-KASH' (Transition: Knowledge and Skills in Healthcare) created by the young people of Alstrom Syndrome UK, to help healthcare staff

and other people in their lives understand what was important to them. Our thanks go to ASUK for the use of these resources and to the young people of ASUK for their invaluable contribution. Throughout the development of this booklet, we have called on the young people of BBS UK to ensure it remained focused on their needs, via workshops and meetings. We are incredibly grateful for their invaluable ideas, suggestions and comments which informed the booklet and can be found throughout. Their honesty and willingness to share has been inspiring.

A copy of the booklet will be posted out to families with young people in the appropriate age group and will be made available in clinics and at the Conference in April. If you haven't received a copy and would like one posted to you, please email [tonia.hymers@bbsuk.org.uk](mailto:tonia.hymers@bbsuk.org.uk).



## Healthy Living

**Sarah Flack, Principal Dietitian**

This year the government has published two interesting reports that aim to help us all live healthier lives; they have updated 'Physical Activity Guidelines' and published the 'National Diet and Nutrition Survey', which shows us what we actually eat. Read on to find out if you are meeting these healthy living goals and if not, how you could start to make some changes.

### Are you Eating Enough Fruit and Vegetables?

I'm sure you've heard the '5-a-day' message before, but as a nation, most of us aren't changing our diets. The latest results from the National Diet and Nutrition Survey showed that average fruit and vegetable intake still remains less than this recommen-

dation for all age groups surveyed. Previous surveys reported only about 30% of adults and 10% of young people aged 11 to 18 are eating enough fruit and vegetables; with teenagers eating on average just 2.7 portions a day.

### What is a portion?

For adults and children over 11 years, one portion is 80g of any fruit or vegetable, this equates to:

- ✓ One banana, orange, pear, apple or similar sized fruit
- ✓ One slice of large fruit such as melon or pineapple
- ✓ Two satsumas, plums or similar sized fruit
- ✓ A handful of grapes, cherries or berries
- ✓ One heaped tablespoon of dried fruit e.g. raisins, sultanas
- ✓ Three heaped tablespoons of fruit salad or stewed fruit

- ✓ Three heaped tablespoons of vegetables (raw, cooked, frozen or tinned)
- ✓ Three heaped tablespoons of beans and pulses e.g. baked beans, kidney beans (only one portion of beans and pulses can count towards your five-a-day)

For younger children a portion is best estimated by the amount that fits into their hand. Portions should increase as they grow until they are achieving the full 'adult' amount.

### **Do fruit/vegetable juices and smoothies count?**

One small glass (150ml) of smoothie or 100% fruit or vegetable juice can count as a portion, however if you drink more, it is still just one portion. If you have fruit juice as one of your '5-a-day', try to drink water, sugar free squash, diet fizzy drinks or tea/coffee with low fat milk at other times.

### **Do potatoes count?**

No! Potatoes, yam, plantain and cassava do not count towards your '5-a-day' because nutritionally these are classed as starchy foods like rice, pasta and bread.

### **Are you managing to meet this '5-a-day' goal?**

If 'Yes' well done and keep it up! If 'No' don't try to increase to 5 portions straight away, instead start with smaller achievable goals. A suitable goal would be to eat an extra vegetable or fruit portion daily, every weekday or on a specific day – think about what would be most manageable for you. Once you've done this for a few weeks, add in another portion, then increase again and keep increasing until you are regularly eating your '5-a-day'.

### **Top Tips!**

- ✓ Try eating one or two portions of fruit or

veg with each of your main meals and make fruit or veg your first choice for a snack.

- ✓ Add a piece of fruit to your breakfast.
- ✓ Not keen on vegetables? Try hiding vegetables in food; this has been shown to increase vegetable intake and reduce total energy (calorie) intake. You may be able to hide finely grated vegetables in homemade meatballs or pasta dishes. Mixing courgetti (spiralized courgette) and spaghetti can be a great way to boost the vegetable content of a pasta meal too.
- ✓ Bulk cook and puree vegetables to keep in the freezer to add to passata or canned tomatoes to make a vegetable packed tomato sauce. This can be used in home cooked meals such as spaghetti bolognese, lasagna or to top home-made pizzas.
- ✓ Help children grow their own vegetables or visit a 'pick-your-own' farm; they may be more adventurous about trying food if they have grown and/or picked it.
- ✓ Get children involved with cooking as they usually love eating food they have helped to make. Think about how they can safely get involved, i.e. older children may be able to help cut up vegetables with a suitable child-safe knife.
- ✓ Try to make fruit and vegetable choices as interesting as possible; a selection of different fruit or vegetable pieces can make a far more appetising snack than a whole apple, orange or banana.

My daughter loves to remind me that she has more taste buds than I do as I am much older than her! Our tastes can change over time and our tastes for stronger flavours develop



as we get older, so it might be time to give some foods a second go. Spinach and olives are both vegetables I found I liked later in life, so try not to think you don't like something, give it another go on your terms and you may just find that you now quite like it and in a few more weeks/months/years actually love it!

Please note: If you regularly see a specialist renal (kidney) doctor or dietitian, please ask them if you need to take care with the amount and types of fruits and vegetables you eat before you make any changes to your diet. If you have impaired kidney function it is best to avoid eating star fruit.

Do you meet the new activity guidelines?

Recommendations vary for different ages but the underlying principle remains the same:

- ✓ Any activity is better than none!
- ✓ Some activity is good, but more activity is better!

The new activity guidelines stress that there is no minimum amount of physical activity required to achieve some health benefits. Previously it was thought that bouts of activity had to last at least 10 minutes to count but now any activity can count towards your daily total.

Age	Activity	Notes
Babies Pre-school children	180 minutes of active play <i>per day</i>	Periods of inactivity e.g. sitting in a pushchair should be broken up with active play as much as possible.
5 to 18 years	60 active minutes <i>per day</i> (minimum)	A variety of activities should be spread throughout the day to help reduce periods of inactivity and to allow your child to develop skills, muscular fitness and bone strength and hopefully also help them find something they love doing!
19 to 64 years	150 minutes moderate intensity activity <b>or</b> 75 minutes vigorous intensity activity (or combination of both) <i>per week</i>  <b>And 2 sessions muscle strengthening activity per week</b>	Moderate intensity activities include: brisk walking, cycling and swimming (you breathe faster but are still be able to talk).  Vigorous intensity activities include: running, sprinting and playing sports (you are breathing faster and struggling to talk).  Muscle strengthening activities include carrying heavy shopping, yoga, gardening or gym workouts

## Feeling confused?

The key inspiring messages from this report are:

- ✓ It is never too late to start being active
- ✓ Every minute of activity counts

## Getting started!

Have a look at how active you are now. If you have an activity tracker or a phone that measures your step count this is a great place to start; it can help show you when you move and also when you could possibly move more.

Set small, achievable goals e.g. walking up a flight of stairs rather than going in a lift so that your changes can last long-term. If you would like some support setting your activity goals think about who could support you to make some changes – it might be your family, a friend or your family doctor. Remember that your clinic team would be delighted to help too.

Sarah Flack

Principal Dietitian

Great Ormond Street Hospital for Children  
NHS Trust

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# BBS UK Conference 2019

April 2019 saw the 27th BBS UK Family Conference and 250 delegates descend into the Northampton Hilton to attend two days of presentations, workshops and activities for adults and children with BBS, their families and carers. Whilst a group of 80 children and their parents/carers were whisked off to Drayton Manor on the Saturday morning, the conference opened up with the yearly AGM.

BBS UK began in 1987 as the Laurence-Moon-Bardet-Biedl Society and through the determination of its volunteers and trustees continues to go from strength to strength. The charity continues to be driven by its original aims which are to preserve and protect the health and wellbeing of those with BBS and their families, and to advance the education of medical and educational professionals and public on the subject of BBS. With the departure of the current Chairman, Richard Zimble who stepped down after 10 years as a trustee on the Board, Stefan Crocker was appointed the new Chairman for the forthcoming year. Stefan who himself has BBS, has a strong vision of how he would like the Charity to move forward in the

forthcoming year.

Following on from the AGM we had an update on the research and study of BBS from Professor Beales, followed by a plea for those who have BBS to donate urine samples to Dr Helen May-Simera and her team. Dr May-Simera is a research scientist based at Johannes Gutenberg University, Mainz and her presentation 'How your wee can help us understand BBS' was well received by delegates. The samples collected during the weekend were couriered to labs in London to undergo rigorous testing, which will further assist Dr May-Simera's research and will help them to further understand the



molecular mechanisms underlying ciliary dysfunction in BBS.

Dr Murray Stewart, Chief Medical Officer at Rhythm Pharmaceuticals, a small biotech company exploring genetic causes of obesity, joined the conference from the United States. Rhythm Pharmaceuticals currently have a treatment in phase 3 called Setmalenotide and Dr Stewart gave an update on this research and an insight into the process of conducting clinical trials. Questions followed and the afternoon workshops had queues of delegates out of the door!

Presentations continued by a wide variety of other medical professionals including the RNIB, The Maypole Project and Breaking down Barriers. To ensure that the delegates stayed alert, BBS UK supporter and Zumba Teacher Maria Dowswell got all delegates to stand up and enjoy an impromptu giant Zumba session, re-energizing the whole room. Rachael Foley, the newly appointed BBS UK secretary, gave an insight into living with BBS which inspired many in the room, and champion fundraisers, the Wilkie family,



shared their inspirational year of fundraising before they hopped in a car to get to the London marathon, running in support of BBS UK.

Following on from a full afternoon of workshops, the evening as always was about relaxing, catching up with old and new friendships, supporting each other and of course a little bit of fundraising. Guests enjoyed a meal followed by a quiz, raffle and music. Members and attendees supporting each other on their BBS journey is central to everything that BBS UK do and year in year out feedback shows just how much people gain from the feeling of support and unity at this annual conference.

We are now planning BBS UK Conference 2020 which will celebrate 10 years of the BBS clinics service and looks set to be bigger and better than ever. Dr Bob Hawes from the BBS Marshfield Clinic in the States is a confirmed speaker and we are very excited to welcome him to our Conference and to hear about his work and research. Booking forms are included with this newsletter, we look forward to seeing you there.



# Volunteering

Volunteering can benefit the volunteer as much as the cause they choose to help and dedicating your time as a volunteer can help you make new friends, boost your social skills, learn new skills and use and enhance skills you already have.

People choose to volunteer for various reasons. For some it offers the chance to give something back to the community or make a difference to the people around them. For others it provides an opportunity to develop new skills or build on existing experience and knowledge. Regardless of the motivation, what unites them all is that they find it both challenging and rewarding.

Everyone has different skills which are suited to different volunteering opportunities. It is important that an individual is 'matched' to the right volunteering position to enable them to support their chosen organisation and so they benefit from the volunteering experience. BBS UK has a number of volunteers that help the charity; all of these volunteers have been given the opportunity to work with us to ensure their volunteering opportunity suits their needs.

BBS UK would like to take this opportunity to say a huge THANK YOU to everyone who supports BBS UK, your volunteering is greatly appreciated and makes a big difference to the work we are able to do.

BBS UK are always looking for new volunteers and volunteering opportunities. If you feel you would like to volunteer for the charity please contact us and we will work with you to see what volunteering opportunities are available. Volunteering doesn't have to be weekly or at a set time and day, it could be at an event, promoting BBS UK, or at the conference helping support the BBS UK staff team and delegates. BBS UK staff will support you through your volunteering journey and ensure that you

are confident and happy in the volunteering position.

We have identified some of the volunteering roles BBS UK currently has, this list is not exhaustive so please contact us with your ideas:

- ✓ Why not become a sighted guide, helping to support visually impaired delegates at the BBS UK Conference?
- ✓ Get fundraising on the Conference Weekend tombola and merchandise stall, a great way to meet new people and raise vital funds.
- ✓ BBS UK attends events all around the country, promoting BBS UK and often requires sighted guides to support visually impaired delegates attending these events.
- ✓ In your local community why not arrange a 'bag pack' or collection at your local supermarket or ask the local shop if they will have a BBS UK collection tin. This not only raises money but awareness of BBS UK too.
- ✓ Write a newsletter article for us, tell us about your experiences, what you have been doing.
- ✓ Are you a grammar whiz? Can you proof read and/or edit documents? We have a range of documents that need proof reading and editing, from newsletters to reports.
- ✓ Trustees are vital to enable the charity to continue; in particular, we need volunteers with finance, human resources and governance experience.
- ✓ Fundraisers help raise vital funds; you could sit in a bath of beans, hold a sponsored silence or jump out of a plane - the opportunities are endless!

Everyone has skills in different areas so please do contact us to see how we could optimise those skills to enable you to become a volunteer for BBS UK.

For more information about volunteering for BBS UK contact: [admin@bbsuk.org.uk](mailto:admin@bbsuk.org.uk).

# Calling All Members: Please ensure you have returned your Membership Applications

In September all members should have received a letter regarding a request to complete new membership forms in line with BBS UK's move to become a CIO (charitable incorporated organisation).

Thank you to all our members who have returned the forms over the last few months. We will begin compiling our new charity database very soon. As previously stated, we are unable to transfer old charity data so

require everyone to reapply for membership. If you have not received your forms, simply misplaced them or need support to complete them, please contact Rebecca on [rebecca.perfect@bbsuk.org.uk](mailto:rebecca.perfect@bbsuk.org.uk) If you just haven't got around to completing the forms, please do so as soon as possible. Membership remains free and ensures that members receive communications such as newsletters, conference reports, event information and a chance to vote for or to become a trustee.



RP Fighting Blindness rebranded to Retina UK in October 2018 which, Chief Executive, Tina Houlihan said 'marked a pivotal moment for the charity'. Retina UK is dedicated solely to working for people affected by inherited retinal conditions including retinitis pigmentosa and rod-cone dystrophy, a symptom of Bardet-Biedl Syndrome. The charity drives and funds medical research into inherited retinal conditions and provides information and support for those affected. It has invested more than £16 million into eye research since it was founded 42 years ago.

Chief Executive, Tina Houlihan, said, "Our aims remain unchanged; we simply want to do more of what we do best, which is funding and stimulating ground-breaking medical research and providing high quality support for those affected by inherited sight loss conditions. Our rebrand means we will be more relevant, recognisable and accessible to the people who matter most – those affected by inherited sight loss."

Retina UK offer helplines, information resources and local information and support events. To find out more go to [www.retinauk.org.uk](http://www.retinauk.org.uk).

# Directors Needed for BBS UK Clinics Ltd

BBS UK Clinics Ltd (the Company) was set up by BBS UK (the Charity) to manage the contract it holds with NHS England to provide support and facilitation services to the specialised clinics service. The day to day management of the Company is the responsibility of the Service Manager, Tonia Hymers. The Board of Directors meets once a year, usually in October or November, for the Company's Annual General Meeting. The developments and issues of the previous year are discussed and future planning is undertaken. Unless any significant issues arise, all other management and decision making is undertaken via telephone calls and email.

The role of Director is a voluntary one (non-remunerative) however all reasonable out of pocket expenses are paid. There are two

vacancies on the Board and these places must be filled by individuals who are not employed by BBS UK or BBS UK Clinics Ltd and who are not Trustees of BBS UK as these positions are already filled. In particular we are interested in individuals with good communication skills, the ability and willingness to attend meetings (usually held in London) and any of the following:

- ✓ Relevant business knowledge/experience
- ✓ Finance, human resources or legal knowledge/experience
- ✓ Knowledge/experience of the NHS and/or contract management

If you think you have the skills and experience needed to join the BBS UK Clinics Ltd Board of Directors, please email [laura.dowswell@bbsuk.org.uk](mailto:laura.dowswell@bbsuk.org.uk) for an application form.

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## Useful Resources

### Information & Support

- **VICTA:** Visually 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](http://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](http://www.look-uk.org)
- **Retina UK:** Retina UK supports people affected by inherited progressive sight loss and also invests in medical research: [www.retinauk.org.uk](http://www.retinauk.org.uk)
- **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](http://www.phab.org.uk)
- **The Maypole Project:** The Maypole Project provides a lifeline of support for children with complex and life-threatening illnesses and their whole family. They provide a range of support to parents from diagnosis through treatment and beyond and provide emotional support to the whole family including siblings and grandparents. Tel: 01689 889 889 [helpline@themaypoleproject.co.uk](mailto:helpline@themaypoleproject.co.uk)
- **Mencap:** Mencap's aim is to improve the lives of people with a learning disability and their families now, and fight alongside them for a better future. They are part of a network of over 400 local groups reaching out to people across England, Northern Ireland and Wales: [www.mencap.org.uk](http://www.mencap.org.uk)
- **Through Scarlett's Eyes:** Through Scarlett's Eyes is dedicated to supporting parents and families of visually impaired children: [www.throughscarlettseyes.com](http://www.throughscarlettseyes.com)

## Sport and Activities

- **Art Through Touch:** Art Through Touch is an inclusive organisation which provides and promotes access to art for people with a visual impairment. Activities include workshops, seminars, monthly art talks, a monthly newsletter and gallery visits: [www.art-through-touch.org.uk](http://www.art-through-touch.org.uk)
- **Metro Blind Sport:** Metro is a London-based charity; their aim is to open doors to sport for all vision impaired people, regardless of age or sporting ability. They have sessions throughout the year for archery, athletics, bowls, cricket, cycling, football, goalball, rambling, sailing, skiing, swimming and tennis: [www.metroblindsport.org](http://www.metroblindsport.org)
- **British Blind Sport:** The work of British Blind Sport 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](http://www.britishblindsport.org.uk)

## Grants

- **Family Fund:** Family Fund is a registered UK charity which provides grants for low-income families, raising children aged 17 and under. It can help with essential items such as washing machines, fridges and clothing but can also consider grants for sensory toys, computers and much needed family breaks together: [www.familyfund.org.uk](http://www.familyfund.org.uk)
- **Disability Grants:** A directory of grants that are available to those living with a disability: [www.disability-grants.org](http://www.disability-grants.org)

## Holidays

- **Seable:** An accessible holiday company specialising in holidays for the blind and visually impaired: [www.seable.co.uk](http://www.seable.co.uk)

## Legal Support or Advice

- **SOS!SEN:** SOS!SEN offers free friendly, independent and confidential support for parents and carers of children with Special Educational Needs. Helpline: 020 8538 3731 (term time only)
- **Ipsea:** Independent Parental Special Education Advice: [www.ipsea.org.uk](http://www.ipsea.org.uk)
- **Coram Children's Legal Centre:** Coram Children's Legal Centre provides free legal

information, advice and representation to children, young people, their families, carers and professionals, as well as training and consultancy on child law and children's rights: [www.childrenslegalcentre.com](http://www.childrenslegalcentre.com)

- **Turn2us:** Turn2us is a national charity that helps people in financial hardship to gain access to welfare benefits, charitable grants and support services: [www.turn2us.org.uk](http://www.turn2us.org.uk)

## Useful Directories

- **Natspec:** Natspec is the membership association for organisations which offer specialist further education and training for students with learning difficulties and/or disabilities. The website enables users to search for specialist provision by location and expertise: [www.natspec.org.uk](http://www.natspec.org.uk)

## Discount Cards

- **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](http://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. The card costs £15 for three years: [www.accesscard.org.uk](http://www.accesscard.org.uk)
- **Max Card:** A discount card for foster families and families of children with additional needs. Families simply show their Max card upon entry to a venue in order to obtain free or discounted admission. Email [hello@mymaxcard.co.uk](mailto:hello@mymaxcard.co.uk) or phone 01133 947 951 or see your Local Offer.

## Travel Support or Services

- **Dial a Ride:** Transport for London's free door-to-door service for those with permanent or long-term disabilities: [www.tfl.gov.uk/modes/dial-a-ride/](http://www.tfl.gov.uk/modes/dial-a-ride/)
- **Ring and Ride:** Ring and Ride is a door-to-door service for those living in the urban areas of the West Midlands who struggle to use conventional transport: [www.ringandride.org](http://www.ringandride.org)

# Contact Details

## **BBS UK General Contact**

admin@bbsuk.org.uk  
www.bbsuk.org.uk

## **BBS UK Fundraising Officer**

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## **BBS UK Clinics Patient Liaison Officer:**

### **London Service**

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## **BBS UK Clinics Patient Liaison Officer:**

### **Birmingham Service**

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## **BBS UK Clinics Service Manager**

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## **BBS UK Adults Contact**

Stefan Crocker  
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## **BBS UK New Families Contact**

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## **BBS UK Adults Contact**

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[www.bbsuk.org.uk](http://www.bbsuk.org.uk)