

## Life during Lockdown

A personal perspective from Jacqui

**BBS UK  
completes  
the 2.6  
Challenge**



### Opportunities

Trustee and  
Director  
vacancies

Become a  
'Friend'  
of BBS UK

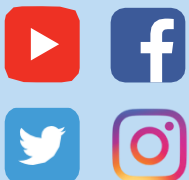
**BBS UK  
welcomes a  
new Office  
Manager**



## Fundraising

An update on BBS UK fundraising and  
how you can support

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# Newsletter

Summer 2020

**Welcome to the BBS UK newsletter, Summer edition.**

I write in unprecedented times, for the first time ever we had to cancel the BBS UK Weekend Family Conference. I would like to thank the Hilton Hotel, Northampton for being understanding and supportive in this difficult time. Hopefully this newsletter will bring a welcome distraction for many BBS adults and families that are shielding. It will provide a brief update of 2020 so far and some personal perspectives of living with BBS during the coronavirus pandemic.

At BBS UK we are working hard to keep everyone updated with the latest guidance and advice on the coronavirus. This includes the recent webinars led by Prof. Phil Beales and the coronavirus information hub which we launched on the BBS UK website in May. It is important to remember we are all in this together, we will get through this and eventually be able to come together and celebrate a return to normal life.

At the January BBS UK committee meeting the Board were tasked with shortlisting designs for a new charity logo. Following a consultation with our members, we decided upon the one that is currently adorning the Charity's Facebook pages and website. This is part of the Charity's rebranding project; the logo is currently on our leaflets and going forward we aim to rebrand our booklets and eventually merchandise. We are very happy with the logo as it is bright, vibrant and represents the genetic nature of the syndrome.

Please enjoy the newsletter, stay safe and hopefully things will slowly return to normal as the year goes on. If you have any comments on the newsletter or queries please email [admin@bbsuk.org.uk](mailto:admin@bbsuk.org.uk).

**Stefan Crocker**

Chairman, BBS UK Board of Trustees

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# Appointment of an Office Manager



**BBS UK would like to welcome our new Office Manager, Liz Loughery. Her contact details can be found on page 20.**

Liz joined us at the beginning of April and will be supporting all areas of administration and the general organisation of our office going forward.

## **Liz gives her thoughts:**

I am delighted to start my new role as Office Manager at BBS UK and I have already been made to feel very welcome. I have been fortunate enough to meet some of you at the Breaking Down Barriers conference and have had the pleasure of meeting the rest of the BBS UK team and Trustees via video call over the course of the last few weeks.

Before joining BBS UK, I worked for Alström Syndrome UK, firstly in an Office Management capacity and latterly as a Project Manager for their Patient Registry. Prior to working for charities, I worked as a Bid/Project Manager for private sector organisations.

I'm very excited to be given the opportunity to join BBS UK and happy to become part of the team but also, it seems to me, part of a family! I am really looking forward to meeting everyone soon.

# Membership Applications

As many of you are already aware, BBS UK are in the process of setting up the new BBS UK membership database. Whilst we are inputting a vast number of forms, it has become apparent that not everyone has had the opportunity or remembered to return their copy.

The membership form was circulated with the AGM paperwork in 2019 and also sent with the Conference report. If you do not recall completing one, please contact Liz Loughery at [liz.loughery@bbsuk.org.uk](mailto:liz.loughery@bbsuk.org.uk) and we will check if we have one for you. If we don't, we can send/email a new form to you, alternatively we are happy to complete one over the phone with you.

**WE MUST HAVE THIS FORM COMPLETED** for you to remain a member of BBS UK, and to ensure that you keep receiving important BBS UK information. Sadly, people who do not give us permission to contact them may stop hearing from us soon.

# Postponement of the BBS UK Annual General Meeting (AGM)

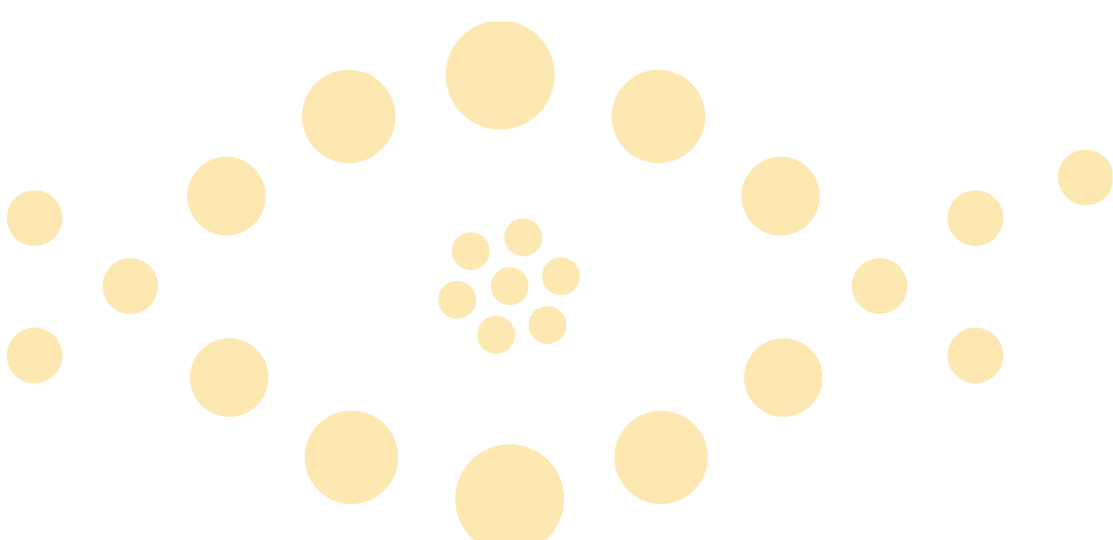
As you will all be aware the 2020 BBS UK Annual Family Conference had to be cancelled due to the COVID-19 pandemic.

We would normally hold our annual AGM on the Saturday morning at the conference, but due to the conference being cancelled, the AGM could not take place.

After consultation with the Charity Commission and the Board of Trustees, we have been advised to postpone the AGM until further notice, due to the exceptional circumstances and our responsibility to safeguard our BBS members, beneficiaries and board members.

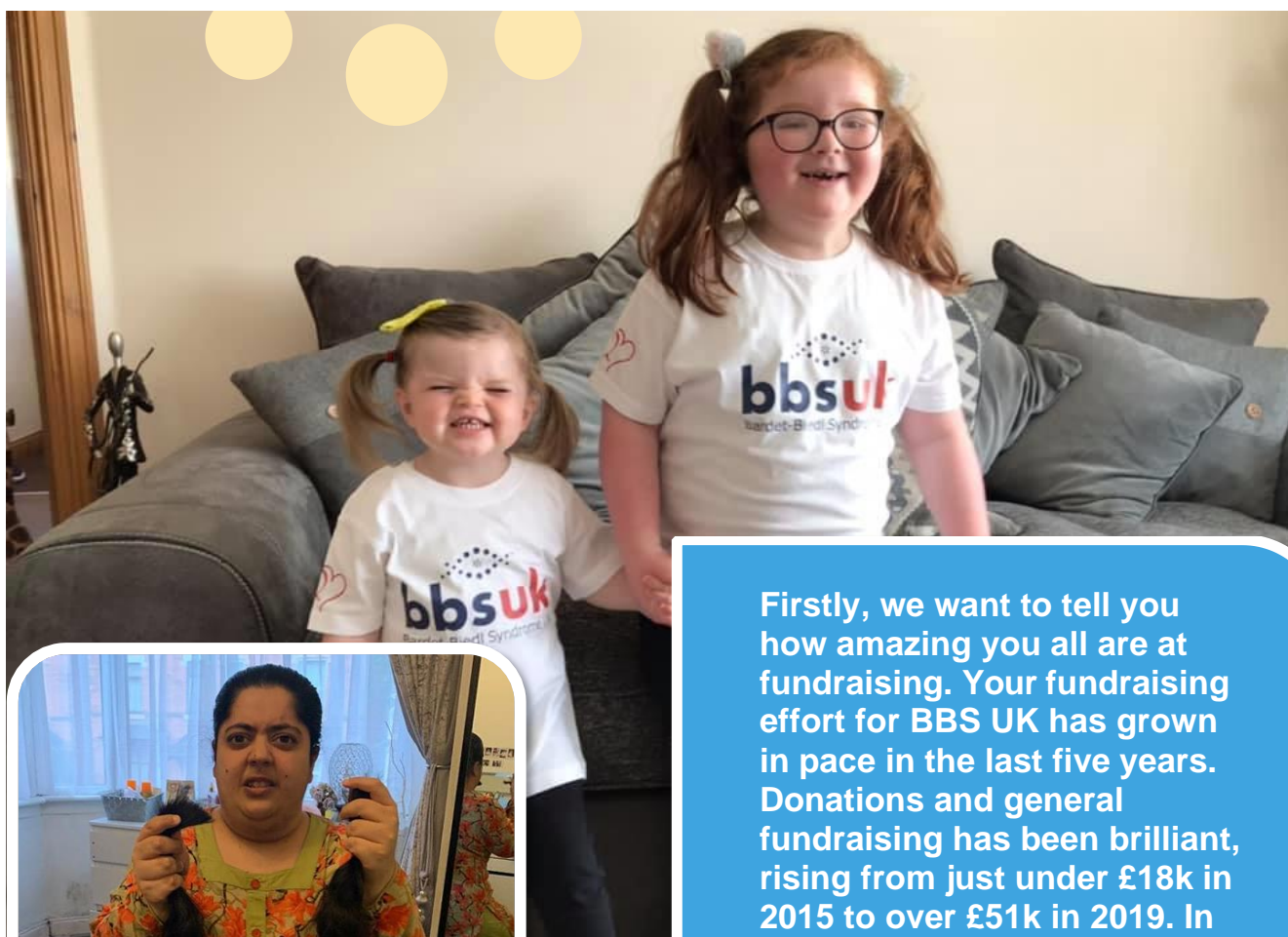
On current government advice we are unable to hold a face to face meeting, and until we are given notification that it is safe to hold meetings without restrictions, the AGM has been put on hold.

We will continue to keep you updated on the matter, and once a new date has been fixed, we will notify you accordingly.



# Fundraising update

The Wilkie Family supported the 2.6 challenge



Firstly, we want to tell you how amazing you all are at fundraising. Your fundraising effort for BBS UK has grown in pace in the last five years. Donations and general fundraising has been brilliant, rising from just under £18k in 2015 to over £51k in 2019. In any business this would be gargantuan growth but in a charity this is exceptional.

Aneeba kindly cut her hair to raise funds



In total you have worked hard through raffles, coffee mornings, summer fairs, sponsored walks, runs and extreme challenges to both raise our profile and funds for BBS UK. As you will read, this has helped our position now.

Many charities including BBS UK would normally expect to make significant proportions of their income from public fundraising events in spring and summer. This would set us up to support our activities through the summer and autumn.



The Hymers Family did a sponsored run and walk!



### **Hollie did a sponsored cycle for the 2.6 challenge**

With fundraising events from open gardens, quizzes and treasure hunts cancelled and sporting activities such as Kilt Walks, marathons and half marathons, bike challenges and other outdoor activities put aside, many charities find their reserves depleted and demand for services increasing; some charities are having to make immediate decisions about their financial viability. Through good governance, protection of the charity reserves and prompt decisions on cancelling the family weekend and Conference, we are fortunate to not be in that position.

Charity sector bodies have made initial estimates that charities will miss out on a minimum of £4.3bn of income over the next few months. Many will also face increased costs as part of their role in tackling the outbreak. The government support for charities, announced on 4th April, began to take applications for financial help towards the end of May and BBS UK are currently considering their approach. Our fundraising to April is around £12,000 down on last year. This is a cause for concern so we will be immensely grateful for support, no matter how small, to help us cut this deficit.

In response to the London Marathon being cancelled, the 2.6 Challenge was launched.



### **Judith made and sold some beautiful bags with all proceeds going to BBS UK**

This was a national virtual challenge event to help all small and medium UK charities. The Challenge launched on Sunday 26 April, the original date of the 2020 London Marathon and we were absolutely overwhelmed by the support we received!

There was a surge of fantastic and original fundraising activities held over the last month ranging from cake baking, handbag sales, sponsored haircuts, runs and walks! The funds raised as a result surpassed £8,000 which is amazing. A huge thank you to you all for all your efforts – we are extremely grateful for your support and generosity!

Our marathon runner Tom Horn, from Utility Bidders of Corby is deferring his place to the anticipated running of the Virgin Money Marathon in October, we wait to see if this will happen. Other athletes planning to support us have also had their plans thwarted and we await to see how their future events pan out. They will no doubt be upset their extensive training and preparations have been forestalled so far, but the pledges of income and support they have already had from both family and friends should spur them on in the future. BBS UK remains grateful for all their efforts.

## Christmas Card Competition

Seasonal cards for Christmas time were suggested by a parent at last year's conference, and several other members over the last few months. Thank you so much for your ideas!

We are happy to announce we are launching a competition to design the cards which we shall produce and sell for BBS UK. We are hoping to have them available by late September.

We shall have four age groups: 5 and under, 6 to 11, 12 to 16 plus an adult category, and shall choose a design from each category.

The competition is open to all members and their families, designs can be landscape or portrait, up to A4 in size and using any materials. Some ideas are provided below.

Please scan and send your design as a pdf to [fundraising@bbsuk.org.uk](mailto:fundraising@bbsuk.org.uk) (with name address, age category and daytime contact details on the email itself.) or you can post in an A4 envelope with your details clearly on the back to:

**BBS UK Fundraising Office**  
**161 Finedon Road**  
**Irthlingborough**  
**NN9 5TY**

**Closing date is Friday**  
**28<sup>th</sup> August 2020.**

There will be a small prize for the chosen four designs, and every entrant will receive a certificate of merit. Good luck and we look forward to seeing your pictures.



# Become a BBS UK Friend



These unprecedented times unfortunately bring financial uncertainty and as a small but national charity, providing support and information to over 1,000 people including patients, their families, carers and professionals, BBS UK are reaching out for help so that we can continue to offer free membership to everyone who needs it.



Whilst one-off donations, fundraising initiatives and the many other ways in which people show their support are all vital and are hugely appreciated, like most charities, we also need people to become regular givers (or 'Friends' as we call them). This is because regular donations provide a reliable source of income that we can direct to where it is most needed, it also allows us to plan ahead more effectively, ensuring that we can continue to offer the best care and support for all those affected by BBS.

BBS UK currently has a small group of 35 'Friends'. These individuals very kindly donate on a monthly basis and for this we are immensely grateful. However, to sustain the Charity financially, there is an urgent need for us to increase our Friends income – if we don't take action now the future of the Charity and the support we provide will sadly be in jeopardy. We have therefore set ourselves a target of reaching **100 Friends in 100 days!** We really hope you can help us achieve this.



## What support does BBS UK provide?

Your contribution, however small, makes a huge difference to the individuals and families we help and enables us to continue to sustain a high level of support. Examples of what we have achieved over the last 12 months includes:

- Provision of newsletters and information booklets
- Support for BBS research programmes including those looking at mental health and wellbeing, kidney function and sight loss
- Organised subsidised events including the annual conference, activity and social events
- Management of the contract with NHS England providing support and advocacy services to the specialised clinics
- Support for families with accessing local authority support, benefits and housing applications and Education, Health and Care Plans
- Support for newly diagnosed families with information and regular contact
- Support for extremely vulnerable adult members during Covid-19
- A Covid-19 Information Hub on the BBS UK website
- Webinars to support members and their families during the pandemic
- Provision of support, advice and information via our social media channels

## What do BBS UK members say about us?

We are a lifeline to so many people and it is vital we can continue to offer this kind of support. Our members told us recently what the charity means to them; their words are testament to the impact we have and would like to continue to have in the future:

- “Fantastic support in the early days of diagnosis!”
- “The charity welcomed us in with open arms and it was the first time ever that we didn’t feel alone or judged”.
- “The warm supportive family network made me feel confident and accepting of living with BBS. It has also helped me develop many life skills. My life would not be as joyous without this charity”.
- “We were warmly welcomed, and everyone involved with the charity could not have been more helpful. The conferences are brilliant, really informative but fun as well. BBS UK has shown us that we are not alone, the charity and everyone involved and associated treat you like extended family and without all of you we would be lost”.
- “BBS UK helped me to not have to pay the extra bedroom tax and have my hours increased for my direct payments, I have always had great support from the BBS UK team”.

## 100 Friends in 100 days - how you can help us reach our target!

To become a ‘Friend of BBS UK’, please complete the form enclosed (or download from our website at <http://bbsuk.org.uk/friends-of-bbs-uk/>) and send to Kevin Sales (Finance Officer) either by post to 1 Blackthorn Avenue, Southborough, Tunbridge Wells Kent, TN4 9YA or take a picture/scan the completed form and email to [kevin.sales@bbsuk.org.uk](mailto:kevin.sales@bbsuk.org.uk) and remember there is no minimum, or maximum amount that you can donate 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 have any questions, please contact Christine Saxon on [christine.saxon@bbsuk.org.uk](mailto:christine.saxon@bbsuk.org.uk) or 07753 163 045.

# My life with BBS

a personal perspective by Joanne Newson

Joanne Newson has BBS and in May kindly agreed to tell us about her personal BBS journey. Joanne hopes it will inspire others to cope better with their BBS diagnosis. Joanne describes herself as “determined, resilient, amazing, motivated and stubborn”. The main areas of BBS that she finds most disadvantageous are sight loss, not being able to work on stage (drama is an area of interest for Joanne and she has a performing arts degree), not being able to drive, fighting the DWP, sorting out her tax credits and dealing with her local council.

## Diagnosis

Joanne was diagnosed in 2002 when Prof Bird at the RNIB noticed her large hands, that combined with her partial sight loss led to a BBS diagnosis. By 2004 Joanne was registered blind. It wasn't until Joanne was 32 that she was seen by Professor Phil Beales.

## Education & work life

Joanne attended a mainstream school. Following her schooling she went on to work for the Ministry of Defence as a Personal Assistant. After five years she took redundancy and re-trained as an actor and singer and gained a BA Hons in Performing Arts.

Joanne worked professionally as an actor and singer from approximately 2000 to 2007 in commercials, theatre, television and film; her favourite role was being part of The Magic Flute film directed by Sir Kenneth Branagh. She also attended the premier in Leicester Square.

In 2007, Joanne opened her own drama school for pupils age 5 years to adults and only a few years later in 2010 qualified as a LAMDA teacher. As part of her role at the school she coaches pupils for drama school auditions. Joanne is currently working on a LAMDA teacher's diploma and training with the Royal Shakespeare Company to enable her to teach Shakespeare.

Joanne has also completed and achieved:

- A LAMDA Performance Certificate in Speech and Drama
- ADPA - Associate Diploma in Teaching the Performance Arts

- LAMDA Grade 8 Gold Medal for Speaking Verse and Prose and in Musical Theatre.
- 18 months work at an actor's agency as an Office Manager
- LAMDA Grade 8 for Acting and Reading for Performance

## Helping others

Joanne is a trained and qualified disability awareness trainer. She works in medical schools helping doctors to learn how to communicate with VI patients. Her role involves sharing her personal perspective and experience on what it is like to lose your sight.

## A bit more about Joanne and her hobbies

Since the lockdown, Joanne has taken up cooking for her parents, family, front line workers in the local chemist and for nurses in a hospice in Kingston. Joanne told us that she may have gained some pounds due to the homemade cakes with rock cakes and cookies being the favourite!

Joanne supports the England rugby team and occasionally sees them at Twickenham. She also enjoys taking part in sporting activities, going to the cinema, theatre and on holiday.

Joanne is familiar with technology and has both an iPad and iPhone. She has won a number of disputes with the DWP, DLA and her local council which is testament to her sheer determination and willingness to carry on despite obstacles faced!

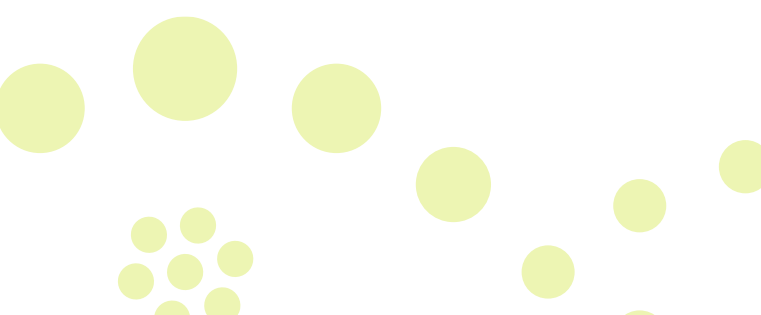
## Coping

Joanne has a good circle of friends, family and professionals who support her. She is also supported by her Church community, she says "they are on my side and have my back for when I need it".

There are a number of jobs that she can't do due to being unable to drive which she finds hurtful but does not let this dampen her spirits as "there are other jobs out there!" Joanne recognises that many of her friends have been through tough times too such as illnesses like cancer and this has helped her to put things into perspective.


"I don't ask to be treated any differently or to be wrapped up in cotton wool". In December 2019 she fell off a stage but she carried on working for two shows before going home in a taxi. What scared her most was telling her parents and friends. Joanne also fell between the platform and train at Waterloo station about four years ago. She didn't break anything but badly bruised herself.

Joanne is in her 50's but is showing no signs of slowing down, she told us, "The reason I do so much is to make the most of the sight I have, plus I'm not good if I'm not working or doing things I like. Yes, I have had to fight to get things but hopefully things are now in a better place for the future. I hope this short article helps you to get up and do things, and remember, don't let BBS take over your life. I vowed that it wouldn't stop me doing things or work and I hope this comes across in what I have shared. Find a passion or hobby and don't stay isolated, as it really doesn't help!"



# Life during Lockdown –

a personal perspective from  
Jacqui Jones – McCarthy



On the 1<sup>st</sup> of January, I put the new family planner up on my kitchen wall, all the key dates neatly written in a bold pink sharpie. Hospital appointments, birthdays, a lad's trip to Tenerife for the husband, a school residential to Blackpool, BBS UK annual conference and most importantly the Pokémon Go Safari in Liverpool that Keira begged and pleaded with me to take her to.

Fast forward to March and the whole world has changed and every single date on that calendar is now postponed or cancelled. Half the world is in 'lockdown' as Coronavirus takes a hold. I speak to friends in Spain and Greece who can't leave their homes without official permission to do so. It's all a bit crazy!

Here in the UK we're told to wash our hands for 20 seconds but that's it for now. Keira G is distraught that the Pokémon Go event is now a 'no go!' 'They won't cancel Easter will they Mum?' 'No Keira, Easter isn't cancelled'. There might be a global pandemic, but all my girl is worried about is her chocolate Easter eggs! The husband on the other hand is taking this very seriously and has been hypnotised to give up smoking, he hasn't even been out to his local for a couple of pints on a Friday night since the end of February.

My best friend is a nurse, she's also Keira's Godmother, she rings me to give me the heads up. 'It's not good this thing Jac, in fact it's horrid – keep yourselves safe!'

I feel myself getting anxious, there's still no lockdown for us in the UK but on Monday 16th March, I decide to keep my girl off school; I want her at home with me where I can look after her. Turns out I made the right call as the Government closes all the schools the Friday after.

Along with the schools the pubs are shut and we're all asked to stay at home unless it's essential to go out. That weekend the weather is glorious, as a family we stay at home but I see on Facebook a friend has taken her daughter horse riding, another friend has gone to the coast for the day, the news shows queues of people walking up Snowdon, National Trust parks are packed with people. My blood pressure is rising 'what part of stay at home don't they understand? Argh!'

And so the lockdown officially begins at 6pm on Monday 23rd March 2020. 'Yes, finally!' Karl and I sit down and discuss what we will do, we make plans to decorate the house and finish all the jobs we've started but keep putting off finishing. Maybe my house will be in some sort of order for the first time in a long time! Sadly this isn't to be as Karl can still work, he's able to get materials and continue on the job he's on, he travels to and from work on his own and is able to be socially distanced whilst he's at work but I'd much rather he was at home with us.

I stop watching the news, I find it's too upsetting hearing the daily figures on Coronavirus. I'm fully aware of what's happening though as we live on one of the busiest roads in South Manchester, I only have to look out of my kitchen window and the only traffic I see, apart from empty buses, is ambulances, private ambulances and hearses. Week two of lockdown I have a bit of a wobble, cabin fever sets in and I have a bit of a cry when no-one's looking.



### Keira's wonderful 'lockdown' artwork

My girl is coping just fine though, she's happy to be at home, she feels safe at home and she didn't like school much anyway. We have managed to get a good routine in place where we attempt some schoolwork in the morning and she can do her own thing in the afternoon, but she needs to do a little bit of exercise too. Keira is happiest when she's drawing, playing Pokémon on her phone, DS or Switch or doing some Pokémon research on her iPad.

She has a little corner on the floor of our lounge where she keeps all her things, we call it her ever expanding office on the floor, it's organised chaos but she knows where everything is and I daren't move any of it for fear of a reprimand off my daughter!

As the next few weeks come and go, I get my food shop down to once a fortnight and I plan it like a military operation. I've learned to 'Zoom', we have virtual hospital appointments, BBS UK webinars, 3-hour long gin fests with old school friends on video call – it's quite amusing watching yourself get slightly socially relaxed on your iPad. My brothers and I look at old family photos together online and laugh and cry together as we remember our childhood and our parents who passed away a few years ago. I reconnect with my cousins – my dad was one of 10 children so there's LOTS of us, it's fun and we're planning a party/reunion just as soon as we are allowed.

And my girl Keira G is thriving at home, this is the most relaxed she's been in a long time. She speaks to her teachers on the phone, we agree not to force her education right now as she's 'on target', she's where she should be; we decide to focus on her independence skills instead which are just as important for her future. We have support from all the professionals involved in her care, we can phone them or email them which is reassuring. This lockdown thing is getting easier.

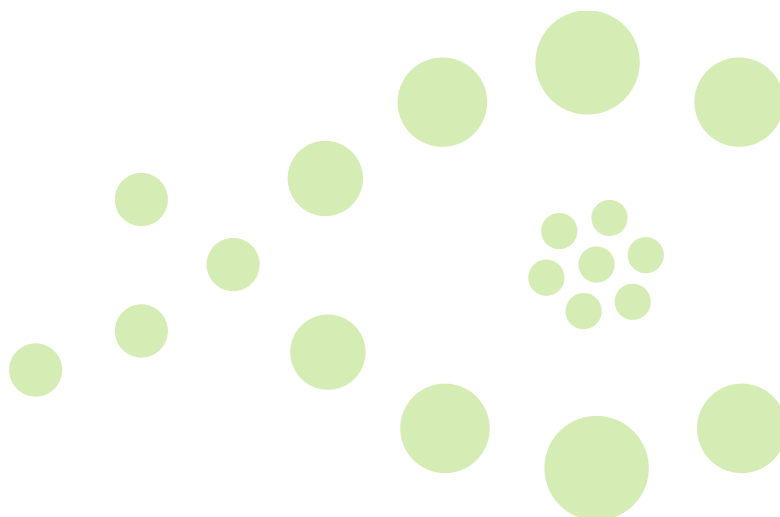
BBS UK asks for help, Christine wants us to take on the 2.6 Challenge, so inspired by the Wilkie Warriors and pinching the Hymers' idea, Karl and I agree to run, jog, walk or crawl 2.6 miles a day for ten days and try to raise a few £££s for our favourite charity, shouldn't be too difficult right? Days one to five were surprisingly easy but things get a little bit harder after that. My legs get tired and I need to really push myself, I mix it up a bit, do a day on the treadmill then

a day outside and finally complete the ten days with very tired legs but a great sense of achievement. I did it! This unfit 50-year-old did it! Yay! I've now vowed to finally complete the couch to 5k programme and the husband in his wisdom has purchased a new mountain bike for me so we can 'enjoy' cycling together. I've only fallen off it once in the last two weeks and I'm no longer saddle sore.

So here we are today eight weeks into lockdown and the restrictions have started to ease. We've had good days and bad days but it's ok not to be ok sometimes. I still have a fear of 'the virus' but I'm more relaxed than I was initially; I've learned to accept that I can't be in control of everything. Keira G is a superstar, she's resilient and taking it all in her stride, Karl and I are extremely proud of her. We're probably both going to come out of this a little bit fitter and a few pounds lighter than we were.

As I go out into my front garden at 8pm every Thursday to clap for our wonderful NHS, Frontline staff and all Keyworkers and I chat over the hedge to my neighbour, I long for physical contact with friends and family – just a coffee and hug; I miss all the little things that I took for granted before.

So, for now, stay safe all of you, I hope I'll see you at Conference 2021.



## Research study: Mental health and well-being in Bardet-Biedl Syndrome

The BBS research team at Aston University would like to say thank you to all the families that have taken part or expressed an interest in this research project exploring mental health and well-being in Bardet-Biedl syndrome so far! They are very grateful to have had the opportunity to speak to so many families and to meet some of you at the BBS UK Conference last year. Recruitment for the project is ongoing. If you have not yet taken part and are interested in this project, please read the information below.

### About the project

Individuals with Bardet-Biedl syndrome (BBS) report experiencing emotional difficulties in addition to physical health difficulties. Researchers at Aston University are running a research project to find out more about factors that impact well-being in BBS. The first stage involves a questionnaire study. The hope is that the findings will inform Doctors and healthcare services about person characteristics relating to well-being in BBS. For the first stage of the project the plan is to recruit 120 individuals with BBS aged 4 years and above and their parent/carer to complete some questionnaires.

### How can I get involved?

If you would like to take part in the questionnaire study or learn more about what is involved, please email the Aston University research team, their contact info can be found below.

Registering an interest does not commit you to taking part. You will have a chance to make your decision about getting involved once you have read the information sheets.

### Who are the researchers who are working on this project?

This research project is being led by Dr Jane Waite.

Dr Joanne Tarver and Lauren Shelley are researchers on the project.



Dr Jane Waite



Dr Jo Tarver



Lauren Shelley

### To register interest, contact:

Dr Joanne Tarver: [j.tarver@aston.ac.uk](mailto:j.tarver@aston.ac.uk)

Lauren Shelley: [l.shelley2@aston.ac.uk](mailto:l.shelley2@aston.ac.uk)

The team would like to extend their thanks for your interest and support of the research.

# Trustee vacancy for BBS UK

BBS UK is looking for new trustees. Trustees play a pivotal role in setting the strategic direction of the Charity, as well as ensuring the Charity delivers the best service it can every day. For this voluntary role, the Board are looking for individuals who are motivated, passionate about the voluntary sector, with relevant professional expertise and experience, in particular across the areas of human resources, finance, management and leadership. It is essential that the Board is representative of the diverse population we support, with a diverse range of experience and skill-set to draw upon.

## BBS UK Trustee expectations

- Attend three board meetings a year as well as the Annual General Meeting (AGM)
- Engage with regular catch-up calls and via email
- Attend the BBS UK Conference

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

## How to apply

If you would like to express your interest in this position, please request an application form from Liz Loughery via email at [liz.loughery@bbsuk.org.uk](mailto:liz.loughery@bbsuk.org.uk). Applications will be considered by the Board and a response sent in writing.

## Closing date

Completed applications should be returned to us by 1<sup>st</sup> October 2020.

This role will require a DBS check to be undertaken.



# Director vacancy 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 is one vacancy on the Board and this place

must be filled by someone who is not employed by BBS UK or BBS UK Clinics Ltd and who is not a Trustee 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.

## Covid-19 Resources

We know that some of you might feel worried about the Covid-19 outbreak and how it could affect your health or the health of your loved ones. We understand you may have lots of questions so want you to know we are here to help. With the assistance of BBS Clinicians and the information provided on the Government website we have pulled together some information and resources which we hope will provide you with some support at this difficult time. For access to this information go to the BBS UK website using the link provided below.

<http://bbsuk.org.uk/coronavirus-information/>

# General 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.or.uk](http://www.retinauk.or.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)
- **Ipsa:** 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

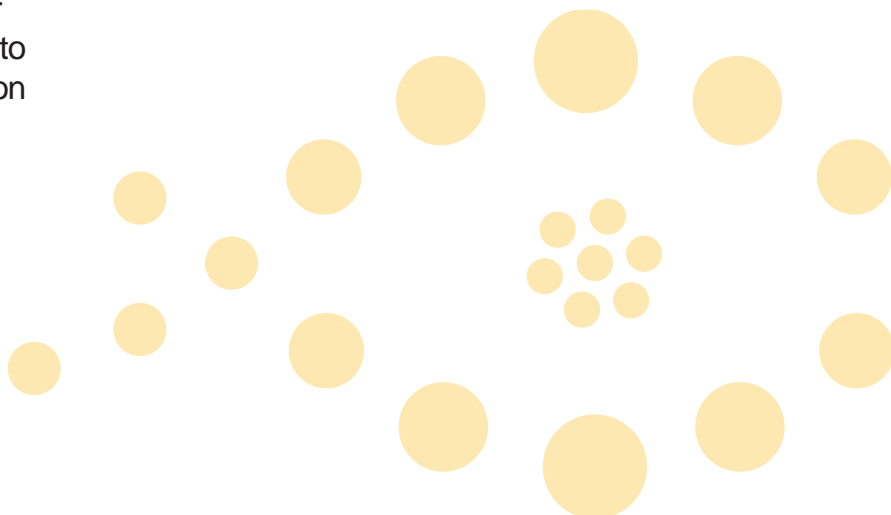
- **Natspec:** Natspec is the membership association for organisations which offer specialist further education and training for students with learning difficulties and/or disabilities. The website enables users to search for specialist provision by location and expertise: [www.natspec.org.uk](http://www.natspec.org.uk)

## 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

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