

Book Now: BBS UK Online Conference

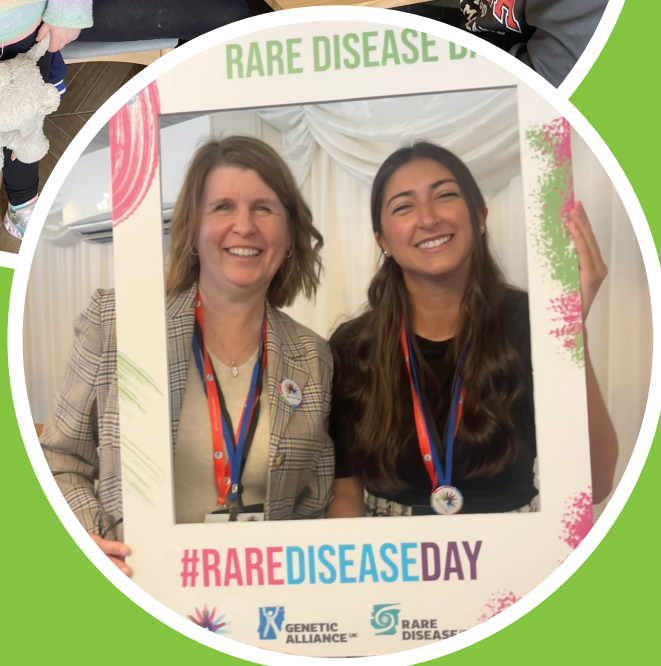
Saturday 8th June 2024

Registration information inside!

Plus: Research Updates

VI Cricket

Fundraising Heroes



Update from Ireland
Rare Disease Day
And much more!

- 2 Foreword
- 3 Fundraising Roundup
- 6 BBS UK Clinics Support Service
- 8 Advice Service Report
- 9 Social Care Student Visit to Great Ormond Street Hospital
- 10 Online Conference 2024
- 11 Are You a Member of BBS UK?
- 12 Service User Advisory Group
- 13 Medical Information Booklet
- 14 Ireland Regional Group's Meetup in Dublin
- 15 Healthy Eating Workshops
- 16 VI Cricket and Representing England at the IBSA World Games
- 17 VI Mentoring with LOOK
- 18 Sicilian Adventure with Seable Holidays
- 20 Research Round Up Spring 2024
- 21 Cilia Conference 2024
- 21 BBS UK Out and About
- 23 Upcoming Events
- 24 Contact Details

The views and opinions expressed in this newsletter are those of the authors of the articles. They do not necessarily express the views and policy of BBS UK.

Whilst every effort is made to check the accuracy of information reproduced, readers are advised to check with the original source before acting on it.



Foreword

Welcome to the 2024 Spring Newsletter

As I sit down to write this, the sun is shining, and I'm enjoying feeling its warmth – Spring really is here. This is a packed newsletter, with so many interesting articles, and I personally look forward to learning more about what our fellow members have been up to.



However, what I'm looking forward to the most is our online conference, which is only a few weeks away. As always, Team BBS UK have been working hard to bring us a varied and informative programme. Having an online conference provides the opportunity to reach so many more people, who might otherwise be unable to attend, and we will hear from speakers such as Professor Phil Beales and Dr Elizabeth Forsythe, along with other speakers and delegates joining us from the UK and overseas. I look forward to joining you all from the comfort of my sofa.

Meanwhile we have had some changes within our team. Last edition we introduced Samantha Serido, as our Fundraising and Communications Officer; Sam has really settled into her role and is already having a positive impact on our fundraising efforts. More recently, we welcomed another student social worker on a temporary placement with the Advice Service, which you can read more about in the newsletter. Lastly, the Board of Trustees said farewell to Azrat Mirza, and we send heartfelt thanks to Azrat for his contributions to the Board and BBS UK, during his time as a trustee.

Towards the end of last year, the Board and staff came together for a two-day workshop in London to start the process of preparing BBS UK's Strategy for 2025-28. We had very lively and interesting conversations and are now drafting a membership audit to enable you, our members, to tell us what you need and want from BBS UK across the next three-year period. This work will continue throughout this year.

I'm pleased to say that it has also been a busy time for fundraising, and I would personally like to thank you all for your fundraising efforts. As you know, our charity relies on donations and funding to provide the vital services that we offer for members and their families, including our Advice Service and BBS Clinics Support Service, which need to grow if they are to continue providing the support that is needed.

We continue to represent BBS UK in the wider community, with the team attending Rare Disease Day events at various locations. In September I will be travelling to Dublin for the Cilia 2024 conference for two days, to connect with other BBS groups and researchers, which I am excited about.

I hope that by the time this newsletter reaches you, the weather is starting to get a bit warmer, with summer just around the corner. I know that I'm definitely looking forward to getting out more, and to my daily walks on the beach. As always, please keep in touch with us, and with each other.

Happy reading!

Laura Dowswell

Chair of the BBS UK Board of Trustees

Fundraising Roundup

We Carry the Gene

Our We Carry the Gene campaign aimed to show just how far-reaching the BBS community is, as we set our minds to carrying the 'BBS gene baton' all the way from John O'Groats in Scotland, through Ireland, Wales, and finally to Land's End in England.

When we began the campaign, we set a fundraising goal of £10,000 to help continue our charity's services. Little did we know that your dedication to empowering our BBS community would far exceed our expectations, raising over £80,000 to support our cause. It is truly awe-inspiring.

Through our campaign fundraisers' hard work, over 587 people supported our BBS UK community through We Carry the Gene. Our amazing fundraisers cycled, walked, ran, and quizzed their way into raising awareness about BBS. We are so grateful to not only those who made immensely generous contributions to the campaign, but also those who thoroughly dedicated themselves to moving that baton from one end of the UK and Ireland to the other! Absolutely incredible efforts from everyone involved, and our team remains overwhelmed by your dedication to our community.

Introducing... Rare Not Alone!

Starting in late spring, 2024, we're thrilled to begin Rare Not Alone – a campaign where we celebrate connection and friendship, by supporting our Bardet-Biedl Syndrome UK community together. BBS is a rare, life-changing genetic disorder. But we're here to show that even though it's rare, those affected are definitely not alone.

Much of our charity's work is focused on supporting and 'being there' for our community throughout life's challenges – whether it's making you a cuppa, and chatting about options during a clinic visit, talking about everything and anything at our annual conference, or being there to work through classroom needs.

**RARE
NOT
ALONE**

Now, we want to cheer on all the ways that those in our community are there for each other, while raising funds to help BBS UK's work to continue. That's where YOU come in. You can join in with the campaign by completing a goal in the best way possible – with other wonderful people involved!

Grab a friend, carer, family member, colleague, or a whole crowd and raise awareness and fundraise for our BBS community. The idea is to spread awareness about BBS by involving someone else, anyone else, in your fundraising! Whether it be hosting a fancy dress party or an online gaming tournament; staging a flash dance or running a marathon; hopping on a tandem bicycle or learning a new dance routine; learning how to bake together or partnering up to become a karate master – we encourage you to get creative on how you bring together people in your life to contribute to Rare Not Alone.

Join us by participating in Rare Not Alone and celebrate that making connections helps to make any diagnosis feel more manageable. Remember, in this journey, nobody is alone. Let's make a difference – together!

Want to get involved? Contact us at fundraising@bbsuk.org.uk

Summer Fundraising Spectacular



In July 2023, a group of members living with BBS and family members of people living with BBS put on a Summer Fundraising Spectacular in the Middleton Archer pub in Manchester. The event raised funds for BBS UK as well as VI Bees. VI Bees are a voluntary community group based in Manchester supporting blind and partially sighted people. They aim to empower the people they support, to ensure no one is socially isolated or alone and encourage people to be able to socialise with others living with a sight loss.

The fundraising event raised awareness of Bardet-Biedl syndrome and was kindly organised by Rachael Foley (BBS UK Trustee), Dianne Hand (BBS UK Trustee) Richard Zimble (BBS UK Volunteer), Liam Dempsey, Catharine Auty, Sarah Leadbetter and Helen Stirland.

The event was a great success with over 50 people attending and £380 for each of the two charities. There was live music from the band Smudge, hot food, and a raffle with many amazing prizes.

Everyone that attended the fundraising spectacular had a great evening socialising, dancing, laughing, having fun, and helping to raise money and awareness for two amazing charities that are very dear to the hearts of the organisers.

Thank you to everyone who organised and attended the event!

BBS Afternoon Tea

By Ollie Sloan

It's that time of year where I start thinking about inviting friends and family to join us for our BBS afternoon teas!



In 2019, our BBS Afternoon Tea around Christmas time raised £376 for BBS UK. After a couple of years break because of COVID, we started organising them again in 2022. They were very successful and so we held three that year. One of my PA's opened up her home to host the afternoon tea and together we raised £628. This year we'll be holding 3 themed teas.

With help from Mum and my PAs, we bake everything ourselves. In the photo there are delicious scones, sausage rolls, cakes, and freshly prepared sandwiches. We even make our own jam!

As prices of ingredients have soared, we were told that the Tesco Community Officer could help with ingredients as we were fundraising for charity. So we gave them a shopping list of flour, eggs, butter, jam, chocolate. Their help made a big difference to us.

It's an enjoyable way to raise some cash for BBS UK. Most of us enjoy a drink and some cake after all...Fingers crossed for another sunny summer!



2024 Afternoon Tea fundraisers in Kent

(£12.50 per person including tea or coffee.
Prosecco or elderflower cordial £2.50 a glass)

Wednesday 26th June from 1pm
Wimbledon themed afternoon tea

Friday 23rd August from 2pm
Botanical afternoon tea.

Friday 29th November from 12pm
Christmas afternoon tea

If you live in Kent and would like to attend any of the Afternoon Teas, please contact admin@bbsuk.org.uk

Gareth's fundraising and awareness raising

By Gareth Mainwaring

Hi, my name is Gareth Mainwaring and I'm 17 years old. As I write this article, I am preparing to run the London Landmarks Half Marathon. That's something I never thought that I'd be saying!

It all started during lockdown. Having BBS means that I have a constant urge to eat and so I was gaining weight rapidly. I was very aware of the possibility of developing diabetes, so I changed my diet to a low-carb, no sugar diet, and started running.

To begin, I downloaded a free NHS Couch to 5K app, and the rest is history...

In September 2022 I ran the Swansea 10k to raise funds for Eye Believe Eye Can, a local group for sight impaired children and young people in Carmarthenshire, where I live. My mum runs with me as my sighted guide. I managed to raise £550 and I got the bug for running. We decided to carry on running 10k every weekend when possible. So much has happened since then. My next goal was to run a half-marathon. As soon as I turned 17 and was old enough to sign up, I applied and got a place at the London Landmarks half-marathon.

Whilst training, I heard about BBS UK's We Carry the Gene campaign and I immediately wanted to contribute. I wanted to raise money for BBS UK because I have had so much support through the BBS Clinic in Birmingham, the conferences which I love, and through the wealth of information that we've received about BBS. Mum and I ended up running 65 miles and raising £660! I was so happy that I could give something back to this amazing

charity that has helped me so much.

Last February I discovered an amazing sport called Goalball during a taster session at RNC Hereford. I immediately loved it, and it has now taken over my life! I've joined the South Wales Goalball Club and played at several tournaments, been invited to the Goalball UK Academy, and also been selected for the Under 19s Great Britain Goalball Squad that will be competing in the 2025 Para Youth Games in Rotterdam. All funds I raise by running the half-marathon will go to South Wales Goalball Club and Goalball UK. Goalball has really changed my life.

In March my school held an own-clothes day, a coffee morning and a rugby game between staff and pupils, to raise money for my half-marathon campaign. We raised a total of £1,000. As part of my Welsh Baccalaureate qualification, I prepared a presentation for Year 7 and 8 pupils to raise awareness about BBS at school. This gave me an opportunity to tell people about my condition as well as understand it better myself.

After creating my Enthuse fundraising page and sharing my story on social media, I immediately had a lot of interest which allowed me to share my story even further. I've been on the radio and television giving interviews about BBS and my fundraising. I was on the Welsh news on S4C, the Welsh and UK BBC news, national radio stations in Wales, in Welsh and in English, and my story has been on their websites and social media platforms.



Today, my local Cadet Unit, that I attend every Thursday evening, did a 13.1 mile sponsored walk (the length of a half-marathon) to support my fundraising efforts. We were also joined by a local television company, and they interviewed me, Mum and the Cadets and filmed the walk. They also came to our house to interview us and to learn more about living with BBS, playing Goalball and fundraising. So, I will be on the TV again next week. People keep on pulling my leg and saying that I am now a celebrity!

I feel that raising awareness of BBS is very important, because every time I tell people that I have BBS they have no idea what I'm talking about. But now, after raising awareness, more people in Wales know about BBS and that is a fantastic feeling.

As I look forward to running the half marathon

on Sunday, I am already thinking about my next challenge. To my Mum's horror, I have said that I would like to run a full marathon next time. Her answer was that I would have to find another guide runner – but I'm sure that I will be able to convince her...

I have really loved raising awareness of BBS and telling people my story. I also love showing people that whatever condition you live with, it doesn't have to hold you back. I am determined to succeed and to be the best version of me that I can be. I want to push the limits of what is possible and that thought really drives me. I'm not sure where this is going to lead me. I want to push forward with Goalball to whatever level I can reach, and I hope that one day I will be telling my story to the whole world and not just the whole of Wales.

BBS UK Clinics Support Service

The NHS commissioned BBS clinics offer both face-to-face and virtual appointments to those living with Bardet-Biedl Syndrome. At each clinic, patients are seen by an ophthalmologist (eyes), nephrologist (kidneys), dietician (food and nutrition), clinical psychologist, geneticist (genes), speech and language therapist and endocrinologist (hormones). BBS UK are contracted to provide support and facilitation services and this year, our team will be supporting 19 virtual clinics and 15 face-to-face clinics in Birmingham, and 9 virtual clinics and 16 face-to-face clinics in London.

Both the Birmingham and London clinics have had a great start to the year! We have seen an increase in new referrals, with higher numbers of new families coming to the clinics. This means more people with BBS are getting the support they need.

After each clinic appointment, we ask patients to complete a feedback form so that we can continually improve; the feedback about the entire clinic service has been very positive:

“Very knowledgeable and well explained.”

“Staff very welcoming.”

“Looked after all our needs and we were in

Ophthalmology for ages but they never left us!”

“It's been great to get the assessment done in one day. Everyone has been very caring and helpful.”

“I liked that accommodation has been given to us so we did not need to travel back and forth.”

“They were able to review my eyes properly and make me feel confident.”

Thank you to all the BBS clinicians for making this possible!



News Updates

The BBS Clinic at GOSH (Great Ormond Street Hospital) has moved. You will now find it on the 4th Floor rather than the 2nd floor. Everything else remains the same!

Unfortunately, the GOSH service is still unable to provide lunch to patients due to the hospital Trust policy. We really hope this will change soon, but in the meantime, please bring food with you, as it's a rather long day. We will still provide tea and coffee on Friday morning, so if you have your own travel cups, please bring them for us to fill, as we like to be as green as possible!

In October last year, GSTT (Guys' and St Thomas' Hospital) started using a new computer system with a patient portal called MyChart. This allows GSTT patients to access their clinic information and medical test results. If you do not have an account yet, please contact Angela Scudder at angela.scudder@bbsuk.org.uk for a setup code, or we can help you during your clinic appointment.

Dr Denise Williams, genetics consultant at Birmingham Children's Hospital and Queen Elizabeth Hospital is retiring this year and will be leaving the service from the end of May 2024. We would like to wish Denise a wonderful retirement and send our heartfelt thanks for the outstanding support and service she has provided to our families over the years; she will be sorely missed.

In January, the London service welcomed Clinical Nurse Specialist (CNS), Katie White to the team; Katie will work alongside CNS, Kath Sparks.

We were over the moon to hear that one of our GSTT patients has become a Mum to a beautiful baby. Congratulations! We've also heard of many engagements and weddings within our community and offer our best wishes to all those celebrating!

Transition Events

The thought of moving from children's clinics to adults' clinics can be a daunting experience for the young person and their family. New doctors, new schedule, at a new hospital - what will the day look like?

To support our young people with their transfer from child to adult services, we have started a new transition event. Young people and their parents/carers will be able to discover everything they need to know about the adult clinic with the familiarity of the BBS UK team at their side. The

day will include an orientation visit to the hospital to familiarise them with the surroundings and enable introductions to key members of staff.

Last November, we held our first Transition event in Birmingham for twelve young adult patients. They familiarised themselves with the Rare Disease centre in the Heritage building at Queen Elizabeth Hospital and met the CNS, Sarah Borrows, who introduced the service. Transition Coordinator Marie McGee guided the visit, providing insights into managing changes and key milestones in young adults' lives, preparing them for the transition to adult healthcare.

After the hospital visit, we checked into the hotel and then went out for a social event, enjoying a meal and a game of bowling. This gave the young adults a chance to mingle, while parents/caregivers had the opportunity to chat with other families and the BBS UK staff team.

One attendee said that the Transition Event made them feel less worried because they now know and understand how the adult clinic is run, and another said that their first appointment in the adult clinic was far easier than expected.

Our next Birmingham transition event will take place on 14th-15th November with another twelve young adults transferring over to the Queen Elizabeth Hospital. This time we have the pleasure of collaborating with Anne Cheesborough and the Sense team at Touchbase Pears in Birmingham. After the orientation visit and meeting with the hospital team, we will go to Touchbase Pears to participate in a workshop, covering topics including employment, college opportunities and future planning. Once again in the evening, we will enjoy a fun, social activity providing the opportunity to make friends and share experiences.

Most patients will already be familiar with many staff members attending, including Sarah Flack, dietitian from GOSH who will be doing the joint consultation with Ken, dietitian at GSTT. Rebecca Perfect from the BBS UK Advice service will be attending, and, together with Angela and Shirin, will give a tour of the hospital and patient hotel. Patients and their families will also be introduced to the Eye Care Liaison Officer (ECLO) who will share lots of useful information to help with the transition into adult services.

These fantastic events are open, and free of charge, to all young people attending their first transition clinic, and we hope that all those invited will make the most of this wonderful opportunity.

BBS UK have a Transition Handbook for young people living with BBS called 'My Life My Future'. This invaluable booklet has proven to be a useful toolkit of information to support older children with their independence and self-advocacy. It is also a useful resource for supporting conversations about transition and future opportunities and choices with younger children. You can find this on our website.

Cancellations and Did Not Attend

We have noticed an increase in the number of cancellations, and instances where patients miss appointments without giving notice. We understand that this is sometimes unavoidable, but with limited appointments and growing patient numbers, BBS clinic appointments are a truly precious resource for the ongoing care of everyone living with BBS. Appointments can also take a lot of time and resources to organise, and sometimes it just isn't possible to fill a late cancellation; by letting us know as soon as possible if you need to cancel, you will be helping someone else with BBS get the appointment they need and helping to keep waiting times down for everyone.

We urge all patients to attend their scheduled appointment, however if you do need to cancel or rearrange, please contact your Patient Liaison



Officer as soon as possible, so we can offer the appointment to others. If you're open to last-minute cancellations, please let us know.

Advice Service Report

It has been a productive couple of months for the Advice Service, with lots of new referrals received. Shirin and Rebecca have enjoyed meeting lots of new adults and families and supporting them with their needs. The areas in which our support has been required have been wide ranging, but we are seeing a lot of Personal Independence Payment (PIP) benefit reviews, as well as social care package reviews. As always, if you are having any social care issues, the sooner you are referred to our team, the easier it is for us to support you.

The Advice team were delighted to welcome their second Social Work student, Tinashe, who joined BBS UK on a 70-day placement in February. Tinashe's placement will be a chance for him to learn all about BBS, whilst also gaining understanding and insight into the complex

and often challenging health, education, and social care systems that our families navigate on a daily basis. We are sure you will all make Tinashe welcome. He has written an article for the newsletter about his first visit to clinic, which we hope you enjoy reading.

In the next few months, we'll be starting some other projects, including a new weekly virtual 'meet and play' session for our youngest child members (ages 0-4) in partnership with the RNIB and their 'My Time to Play' project. We also hope to restart our virtual Zoom Social Meet ups for our most isolated adults. These sessions will be advertised via social media, but if you aren't on social media and want to join our monthly virtual socials, please contact Rebecca via email on rebecca.perfect@bbsuk.org.uk.

Social Care Student Visit to Great Ormond Street Hospital

By Tinashe Shumbambiri

Tinashe is BBS UK's second student to undertake a placement within our Advice Service as part of his university degree in Social Care. He is shadowing Rebecca and Shirin as they work, assisting with case work, learning all about BBS and the complexities of navigating Local Authorities and other support services, as well as visiting our clinics to see firsthand how vital the clinics are for our members. He describes his first clinic visit in the article below:

In February I had the pleasure of attending my first BBS clinic, which was the children's clinic at Great Ormond Street Hospital (GOSH). Shirin is one of the BBS UK Social Workers and Patient Liaison Officers and she was there to greet me at reception.

I'm not someone who usually expresses many emotions, but even I felt a rush of emotions when I walked onto the clinic floor. It brought back memories of my early years, when I had spent a lot of time in a similar setting with a loved one.

I was introduced to the GOSH team of clinicians and was a little overwhelmed at first because I'd never been in a room with so many different health professionals before. But after the friendly introductions, I felt completely embraced by them. I met the nephrologist, clinical psychologist, geneticist, speech and language therapist, ophthalmologist, endocrinologist, and dietitian.

I was given the chance to sit in with one family for several of their meetings with the clinicians. At GOSH, the family are allocated a room, and each clinician in turn spends approximately 20-30 minutes with them. It was great to experience in person how each clinician treats the family in a similar, non-judgmental manner. I was able to pick

up some important life lessons from each clinician, which was fantastic because it felt like a big, exciting day of learning.

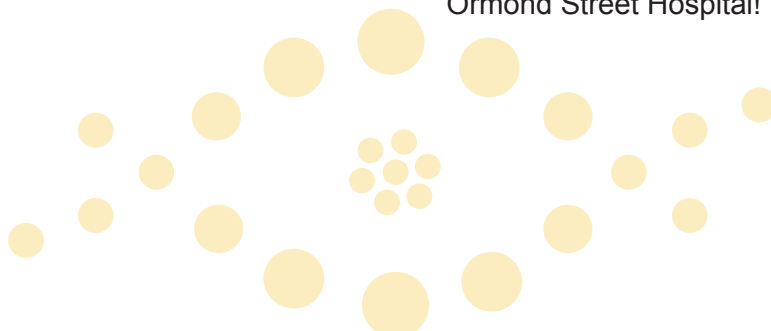
When the clinician left to take care of another family, I took the chance to establish a connection with the family by asking some questions, sharing my cultural background which they could relate to, and generally getting to know each other.

After having the opportunity to introduce myself to another family with my supervisor Shirin, I was comfortable enough to use our database to confirm the accuracy of that family's information. Since it was my first day, I appreciated the clinicians' and families' patience with me as I grasped how to use the database

I took away several things from my visit at GOSH; the importance of good communication from the health clinicians to the families, the value in being non-judgmental as each family comes from different cultures which include different values and religions, as well as the power of building a rapport/relationship with families. I observed how families feel free to elaborate on their current issues or concerns for the children, when a rapport is built rather going straight into asking lots of questions, without a warm greeting, or asking how they are doing.

Attending the clinic in person gave me a better understanding of some of the key features of BBS, such as visual impairment and decreased mobility, as well as the impact that BBS has on children. I was also able to observe how the different health professionals work together to give the family and child the best possible outcome.

I look forward to my next clinic visit at Great Ormond Street Hospital!



Online Conference 2024

We have reviewed the feedback from Conference 2023 and although overwhelmingly positive, it is clear that you want us to look for an alternative venue, one that is easier to get to with accessible rooms. We hear you and we agree! We also wish to bring the event back to Spring.

This means that whilst our BBS UK team is working hard to improve our conference experience for 2025, Conference 2024 will be an online event.

When:

Saturday 8th June 2024
10:00am - 3:00pm

Programme:

At the time of writing, we are still developing our programme, but can confirm that it will include updates on the research and management of BBS, invaluable personal perspectives from our members and an update on the work of BBS UK.

Confirmed presentations include:

- Professor Phil Beales: Update on Research and Study of BBS
- Dr Elizabeth Forsythe: Update on Setmelanotide
- Philip Warford, Renaissance Legal: Future Planning
- Dr Kym Winter, RareMinds: Mental Health Support for the Rare Disease Community
- Dr Arlene Drack, University of Iowa: Gene therapy research for eyes
- Clare Kassa, SIBS, a charity supporting siblings: Title to be confirmed

How to join the conference:

We will use Zoom, the same platform we used to livestream our conference in September 2023.

You can register to join our online conference by

BBS UK Virtual Conference 8 June 2024



scanning the QR code which will take you to our website. There you will find the link to register.

Upon registration, you will be sent a link that will give you access to the event. On the day of the event, you will simply need to click on the link from your chosen device and enjoy the presentations from the comfort of your home.

If you have any questions about the conference or would like to submit a question to one of the speakers in advance, please get in touch via admin@bbsuk.org.uk



FAQ

Is there a cost?

No! The online conference is free to watch and listen to.

I'm not available on 8th June. Can I watch and listen to the conference another way?

Yes! A recording of the conference will be available on our YouTube channel and website.

How do I use Zoom?

You can either download the Zoom app on our device, or you can access the conference through your web browser (Google Chrome, Safari,

Internet Explorer etc.) If you're new to using Zoom, we recommend visiting our website for links to guides on how to use Zoom.

Please test your internet connection and speakers before the conference. Our staff will be running the conference and might not be able to help on the day.

We hope you can join us!

Are you a Member of BBS UK?

Please take a moment to ensure you have joined our BBS UK membership.

How will I know if I am already a member?

To become a member of BBS UK, you will have either completed an application form or consented to becoming a member when asked by one of our team. If you have been sent AGM voting information in the past, you are already a member. If you are not sure, contact us and we will check for you: admin@bbsuk.org.uk

Benefits of Membership:

BBS UK's members are at the heart of our work. Become a member and you will join a growing group of people who play a part in everything we do. For BBS UK, having dedicated members enables us to meet our aims and objectives more fully. Engaged and involved members ensures transparency, credibility, and expands our impact through increased volunteering and community engagement. The collective strength of our membership not only benefits individual members, but the BBS community as a whole.

Members also have:

- The opportunity to participate in decision-making and shape the direction of the Charity

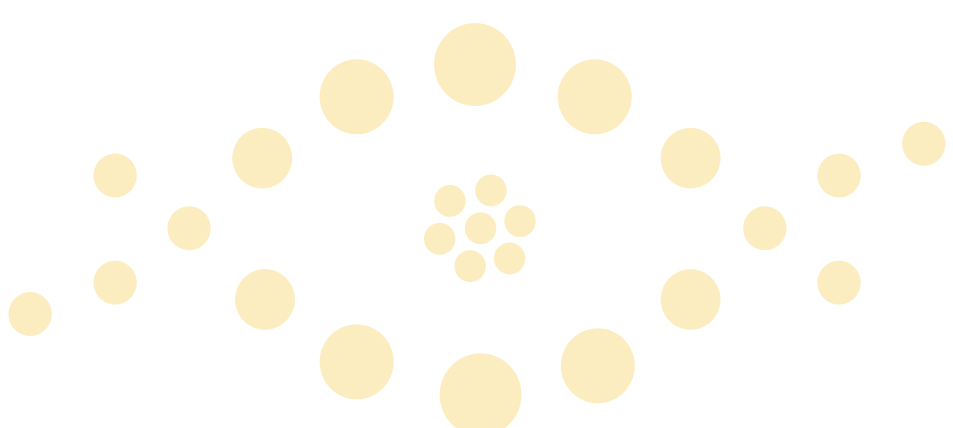
- The chance to vote to elect BBS UK trustees and to become a trustee
- Access to BBS UK projects including the IT Equipment Fund and Chris Humphreys Memorial Fund

In addition to becoming a member, you can support BBS UK's work in all sorts of ways. There is no pressure to do anything, but if you are keen to take action, we will support you every step of the way.

Options include:

- Taking part in surveys, focus groups and government consultations
- Sharing personal experiences
- Fundraising to support BBS UK's work

Membership is entirely **free** to ensure that everyone who needs our support can access it. To become a member, visit our website www.bbsuk.org.uk and click 'Become a Member' at the top of the home page, or you can scan the QR code.



Service User Advisory Group

BBS UK are pleased to have the support of the newly established Service User Advisory Group (SUAG), which has been formed to help BBS UK hear from the most important people: our service users.

What is the Service User Advisory Group?

The BBS UK Service User Advisory Group is a sub-group of BBS UK, established to provide service user perspective, experience and knowledge, to promote the needs of the wider BBS community and advocate for strategy and service improvements.

We reached out to the BBS community and asked those who regularly use our services to apply. Throughout the process we have ensured that membership of the group is representative of our community, including people with BBS, parents and carers of those with BBS, from England, Scotland, Wales, and Ireland, whilst also ensuring cultural representation.

The group is chaired by BBS UK Trustee and service-user, Rachael Foley, with support from Trustee, Dianne Hand and BBS UK Operations Assistant, Natalie Braunton.

What will they do?

SUAG will review BBS UK's services and provide their feedback and suggestions on how to improve them and make them even better.

BBS UK services include:

- Advice Service
- BBS Clinics Support Service
- Annual conference and social events
- Website and social media
- Information booklets
- Newsletter

We are sometimes asked by external organisations, for example, researchers, sight loss charities, or pharmaceutical companies, to review documents or processes, which SUAG will also support. The work of SUAG will inform BBS UK decision making and support improvements and strategy development.

Meetings

Since January, SUAG have had two online meetings where they introduced themselves and their connection to BBS, learnt about what the SUAG's aims are, and gave feedback about the

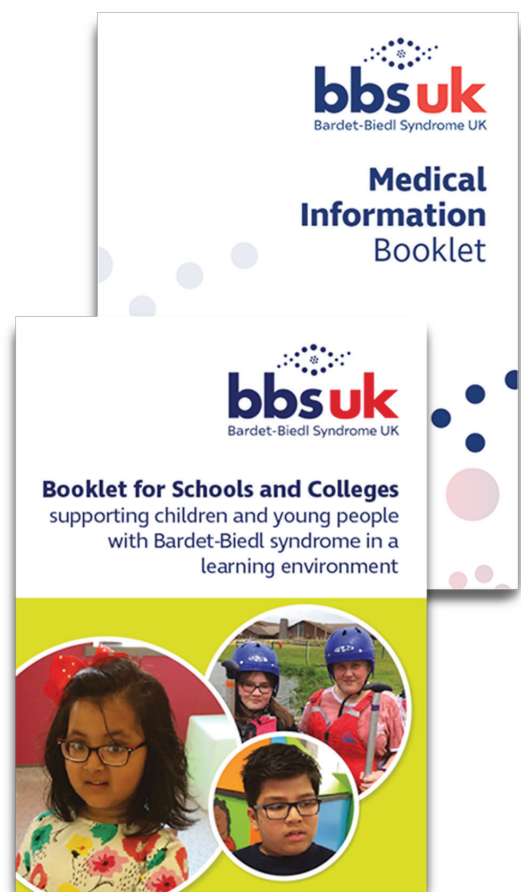


Winter 2023 newsletter and Medical Information Handbook.

Who can join?

We currently have four spaces in the group and, to ensure a diverse range of service users and views, we are currently looking for male applicants, including those living with BBS, and fathers of children (under 18) with BBS.

If you are interested, or want to find out more, please contact Natalie Braunton at admin@bbsuk.org.uk.



Medical Information Booklet Review

We need your help to review our publications! We're asking the whole of the BBS UK community to give us feedback on how they use the Medical Information Handbook. We are also asking for you to contact the key medical professionals involved in your care to give their feedback.

BBS UK is a Trusted Information Creator accredited by Patient Information Forum (PIF). This means that our health information is trustworthy, evidence-based, accessible and reviewed regularly. The feedback from the BBS UK community will help us to ensure that our publications are fit for purpose, give enough information about BBS, and are easy to understand.

To provide us with your feedback, please visit our website and complete the online form by scanning the QR code on the right or visiting www.bbsuk.org.uk/medical-information-handbook-review.

If you cannot access the online form or find it difficult to use, please contact us at admin@bbsuk.org.uk and we can arrange for you to give feedback in the way that's easiest for you.



The Medical Information Handbook and all our other publications can be found on the 'Publications' page of our website. Scan the QR code on the right or visit www.bbsuk.org.uk/bbs-uk-publications. If you would like a physical copy of a publication sent to you, please contact us.



Thank you for your support!



Ireland Regional Group's Meetup in Dublin

On Saturday 23rd March at the Radisson Blue Hotel at Dublin airport we held another successful all Ireland family get together with the support of BBS UK. It was great to meet up with some new families and familiar faces from the successful family information day held last May in Antrim, Northern Ireland. In total twenty-four adults and seven children travelled to attend. It was a very informal event where people shared difficulties they've faced as well as some fantastic achievements. The hotel was bright, spacious and proved to be a very safe environment for the children to sit, play together or have a bit of 'me' time. The children were given beautiful cloth bags to colour in while the adults mingled. Lunch was served at 1pm and the informal get together ended at 3pm.

After the get together, the core Ireland Regional Group held a meeting which was the very first face to face meeting since the group first formed back in 2021. A lot has been achieved by the core group from its formation but we all believe it will be a long and arduous journey to achieve our ultimate aim of establishing a Multi-Disciplinary

clinic here in Ireland. The biggest issue for families in Southern Ireland is getting access to the BBS clinics in England. We are very fortunate that a member of our group is a patient member of the steering group with the Health Service Executive which was set up to develop a new strategy for Rare Diseases Ireland. In addition two members have volunteered to take part in the Rare Diseases Forum to ensure families with BBS will have a voice. A number of action points are being taken forward and another online meeting is scheduled for May.

Do you think you could help us in achieving our ultimate aim of getting a BBS clinic in Ireland that will benefit all of our families? All the progress made to date would not be possible without the help of the core group. We meet up on Zoom about five times a year and meetings last about an hour. We would love for you to join the group!

If you are interested, please contact:
lindsay.mcknight@bbsuk.org.uk



Healthy Eating Workshops

Clinical Psychologists: Emma McGibbon, Jane Waite and Gemma Wilson

Dietitians: Kenneth Michie and Sarah Flack.

During the BBS UK Conference in September, we had the opportunity to meet together as professionals, parents of children and young people with BBS, and people with BBS to talk together about healthy eating. We know that everyone has times in their lives when they have been able to eat more healthily and when it hasn't felt possible. We recognised that we often know what we should be eating, but it can be tricky to do this.

Below are some of the tips and strategies that were shared with each other.

TOP TIPS

Managing portion sizes:

- Making batches of meals and freezing them in separate containers.
- Buying one treat at a time (i.e. one single sized chocolate bar) rather than multipacks or large sized chocolate bars.
- Weighing and measuring food before eating.
- When the weather is cold and dark, be aware that you might crave more comfort food. If you don't buy it, you won't be tempted to eat it!

Motivation:

- Notice how when you eat less healthily, you can feel more tired and inactive. When you eat more healthily, you can often feel more energetic and happier.
- Sometimes, motivation can come from a health scare, such as a doctor telling you that you may become unwell if you don't change your eating habits. Take action before this happens!
- When trying to lose weight, it helps to focus on a goal.
- Attend a slimming club to help you maintain your motivation.
- Ask friends or family to help you with encouraging comments.
- Make healthy choices. Each small step can build into a success.

Snacking tips:

- Keep healthier treats close by.
- Eat something healthy before eating

something unhealthy. This way you can work out if you are actually hungry, or just wanting the treat.

- Avoid sugary drinks and make simple changes, for example, swap higher calorie or alcoholic drinks for soft drinks.
- Eat before you go shopping, so that you are less hungry, and more likely to buy what you know is healthy.
- Plan ahead what you will eat each day and plan meals for the week. Think about the support that you might need with preparing or cooking meals. Ask personal assistants/ carers, friends or family to help you with this.

We also heard about how challenging it can be to eat healthily. Sometimes you might have limited help from carers or personal assistants, or healthy food is more expensive than highly processed foods. This is where planning ahead and asking for advice from professionals will be especially important.

Socially, it can be difficult to say no to meals out. However, having occasional treats is not going to be as big of a deal if you aim to eat healthily for the majority of the time.

We thought about how different things work at different ages and stages for our children. When they are younger, we have more control over what happens day to day and more contact with teachers at primary school. As children get older there are new challenges, perhaps because they are physically bigger, they want more independence and can make their own choices, particularly if they are at mainstream secondary school. Busy home lives can make healthy eating a challenge. There are barriers to physical activity, and we reflected on the opportunities for exercise again, as children get older and become teenagers.

Patient Experience and Involvement Project

This project was supported by Assistant Psychologist Emilia Roselli, Gemma Wilson and Sarah Flack.

The Psychology and Dietetics team in the BBS

clinic at Great Ormond Street Hospital recently carried out a project to explore parental views on the ways they support healthy eating and activities in children with BBS and their families. This involved holding telephone interviews with parents of children who were seen in the BBS clinic over the past year. Ten families with children of a range of ages, abilities and cultural backgrounds were offered the opportunity to take part, out of which seven families completed telephone interviews.

The interview prompted parents to reflect on the conversations they had in their most recent appointments with the dietitian and clinical psychologist and the advice they were given. Three out of seven families reported that their conversations with the clinical psychologists also covered their concerns about diet or food related behaviours and/or challenging behaviour around encouraging activity.

Parents were encouraged to reflect on whether they had been able to use the advice given to them to make changes to their children's diet and activity levels, and if so, how difficult this had been to achieve. Some parents reported that changes had been difficult to make because they had been too busy, and we also learnt that families have been having trouble finding accessible exercise clubs for their children and young people. Other

families reported that they were able to make positive changes, using personalised strategies that worked well for their child.

The interview asked parents for their thoughts about the clinic offering a joint appointment with the clinical psychologist and dietitian to discuss diet or food related behaviours and/or challenging behaviour around encouraging activity. All seven families felt this would be helpful, and different age-points when this might be most beneficial were discussed. Four families felt this would have been most helpful when their child was younger, whereas two families felt this would be more helpful when their child approached teenage years.

This project highlighted some of the barriers parents face in supporting their children to make positive changes to their diet and activity levels and emphasised the fact that children will respond differently to strategies for supporting these changes. It emerged that parents would find it helpful to be offered a joint appointment with the clinical psychologist and dietitian to discuss diet or food related behaviours and/or challenging behaviour around encouraging activity. We learnt that the age-points at which this would be most beneficial also differs for each family.

VI Cricket and Representing England at the IBSA World Games

The 2023 IBSA (International Blind Sport Association) World Games were held in August at Birmingham University, thanks to a combined bid between British Blind Sport, UK Sport, Birmingham City Council, the University of Birmingham, and Sport Birmingham.

Hannah Young, a member of BBS UK with Bardet-Biedl syndrome, participated in the IBSA World Games as part of the England Women's cricket team. Hannah is 38 years old and lives in Suffolk with her husband Sean, her guide dog Archie, and her retired guide dog Diane. She was diagnosed with BBS in her late 20s and is visually impaired, struggles with managing her weight, and is affected mentally and emotionally by her diagnosis.

Before Hannah was diagnosed with BBS, she recalls that she used to stay at home a lot, watch soaps, and was not very active. She had always loved sports but had never really participated in them before.

This all changed in her 20s, when Hannah and her husband were at their local cricket club, and they came across a poster advertising VI cricket. The poster invited people with visual impairments to attend a development day, where they could learn about VI cricket, have a go playing it, and socialise with cricket team players and other attendees.

Hannah attended the development day as a complete beginner to VI cricket and had a great time playing the sport. She loved that she could take part in the game while being visually impaired and enjoyed meeting lots of people with different eye conditions, including other people with BBS. She was quickly welcomed onto the Berkshire

Stags VI Cricket Club as a team member and started playing every month. During the winter training period, the team would train indoors, and during the summer training period, they played matches outside.

Hannah says that playing sports has significantly improved her health and overall wellbeing, both mentally and physically. She has lost weight, found that regular exercise has improved ongoing back issues, and being part of a team and making lots of friends has helped to improve her depression.

IBSA World Games 2023

Hannah has been part of the England Women's VI cricket team for around 8 years and secured her place in the team by trying out and attending development sessions. The team of 30-40 players from across England were asked to participate in the IBSA Games 2023, and Hannah happily accepted. Alongside the England Men's VI cricket team, they played against teams from many different countries including Australia, India, Bangladesh, and Pakistan.

Hannah recalls how much she enjoyed interacting with the players from abroad, and how everyone was competitive, but still very supportive of each other. Players would cheer and congratulate each other, regardless of what team they were on. The support of the audience really helped to make the games exciting and special.

During the IBSA games, they supported players

from other sports and had the opportunity to try out different sports, including show dance, blind air hockey, tennis, goalball and more.

Hannah is passionate about VI sports and would like for there to be more sporting opportunities for VI adults. She encourages people to try it for themselves with this message:

"If you're feeling unsure about trying an accessible sport, thinking you might be judged, come along to an open day and just listen and watch to see if you want to try it in the future."

If anyone would like to contact Hannah Young and find out more about VI cricket, you can email admin@bbsuk.org.uk and she'll happily get back to you!

Are you ready to try VI sports?

British Blind Sports have a handy activity finder on their website so you can discover VI sports activities in your area:

www.britishblindsport.org.uk/activity-finder



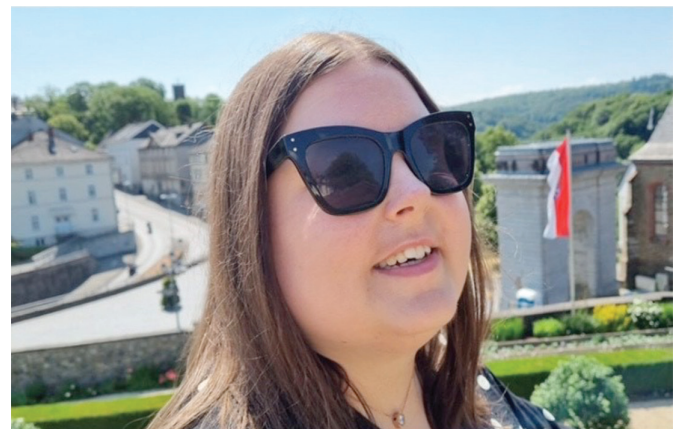
VI Mentoring with LOOK

By Maria Dowswell

A LOOK Mentor is a visually impaired young person aged 18-29 years who can relate to the concerns of their blind and partially sighted mentees as an older peer, and in a different way to a parent, teacher, doctor or health worker.

Hello. My name is Maria Dowswell and I am 30 years old. I live on the South Coast with my partner, and my hobbies are mostly sports and being outdoors. I have BBS, am registered blind and have a little bit of sight.

I first heard about LOOK through another VI charity who were looking for VI mentors. I thought



"I could do this! I need a new challenge!", so I applied to be a volunteer mentor. Next thing I knew, I was at the training weekend. I was nervous

but knew that after the weekend I would feel a lot more confident, which I did. LOOK staff taught us everything we needed to know about mentoring, from the online secure platform, to how to actively listen to our mentee. I came away feeling positive about mentoring.

Later on that year I got partnered with my first mentee which was very exciting. We mostly used the online platform to communicate with each other. This partnership lasted 12 months. After being a mentor, it really gave me a taste of wanting to work with VI people.

At this time, I was working in retail and I enjoyed it but didn't want to do retail for the rest of my life. So at the beginning of this year, I started looking for jobs in the disability sector, as I have my own lived experience and felt I could bring a lot to a disability job role.

I couldn't really find anything that suited me and began to lose hope, until I saw LOOK was recruiting for a mentor project officer. I applied and was invited for an interview. For anyone who knows me, they know I love to talk, but even I was nervous about the interview! After waiting

anxiously, I got the phone call to say I had the job. Believe it or not I was speechless.

I started my role as Mentor Project Officer in May last year. My day-to-day tasks are checking in with mentors/mentees, talking on the phone with young people who want a mentor, recruiting new mentors, writing resources and a lot of admin.

At LOOK we don't just offer peer mentoring, we have a lovely online parent support group who meet every two weeks, and there is a holiday flat in Scarborough which we offer to VI families at a discounted rate. Our two big events of the year are LOOKfest, which is our amazing family festival, and Jamies Farm, where mentors run the week and mentees get to go and help out on a working farm.

The thing I love most about my job is networking at conferences and events and telling people about LOOK. A lot of people don't know about LOOK, so I love talking and spreading the word.

If you want to find out about becoming a mentor or being matched with a mentor, visit www.look-uk.org.

Sicilian Adventure

by Richard Zimblar

There are a number of organisations in the UK who can help you find and book a holiday which is especially tailored for people with sight loss, such as Traveleyes and Seable. Bodies such as Tourism for All UK, Visit Britain and the Association of British Travel Agents (ABTA) can also provide information about booking a holiday from mainstream tour operators who have made efforts to make their information and holidays more accessible.

While we mention a specific company in this article, please note that it does not imply any form of advertising or endorsement by BBS UK.

My fiancée Rachael Foley and I went on our first guided holiday in June 2023. We chose to go to Sicily for 7-nights. We both have BBS, and I have no vision while Rachael has some useful vision.

Seable Holidays were incredibly helpful, providing



us with all the necessary details to choose our destination. They specialise in accessible holidays for the visually impaired, complete with local assistance. Our booking process was smooth, done over the phone, and they even organised our flights from Manchester for a small fee, along with assistance throughout our trip.

From the moment we arrived at Manchester

airport, we received assistance every step of the way - from check-in to boarding the plane. The cabin crew were exceptional, ensuring our comfort throughout the flight. Upon landing in Catania Sicily, the assistance continued, guiding us through passport control and helping with our luggage.

At the airport, our local chaperone greeted us and escorted us to our hotel in Aci Trezza. Over drinks and dinner, they briefed us on our holiday itinerary and provided their contact details for any assistance needed during our stay.

Upon arrival at the hotel, we were given a thorough tour of our room, with detailed descriptions of its layout.

During our holiday we:

- Relaxed by the swimming pool and lounged on sunbeds.
- Explored various attractions, including a Tactile Museum featuring model replicas of historic buildings from Sicily and around the world.
- Experienced the vibrant local markets of Sicily and savoured traditional street food.
- Embarked on a tour of Aci Castello village, ascending a volcanic rock to explore the Norman Castle.
- Indulged in Sicilian desserts and participated in an ice-cream tasting session.
- Enjoyed a memorable boat trip with a local fisherman.
- Spent a delightful day on the beach, basking in the sun.
- Visited a local organic farm, learning about its animals and history, and sampled Donkey milk.

- Toured a winery, followed by a traditional Italian 5-course lunch paired with different wines.
- Went shopping in Catania city centre for souvenirs to cherish our wonderful holiday memories.

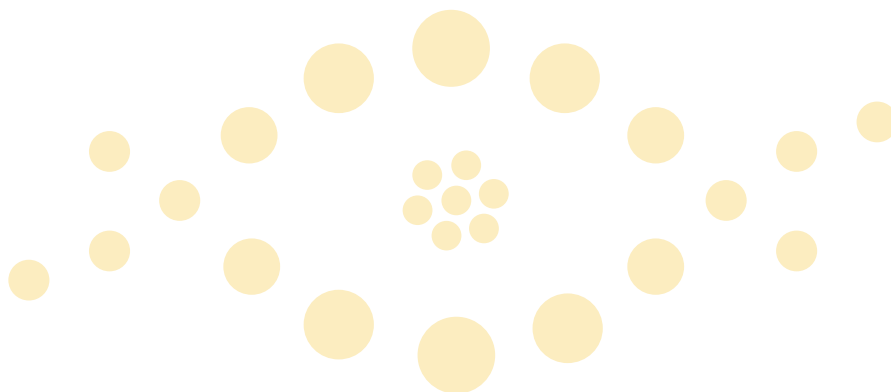
The chaperone made our sightseeing and excursions truly remarkable. Fully trained in sight guiding and fluent in Italian, they assisted us with menus and ordering food, making us feel like we were vacationing with a friend who went above and beyond. There was plenty of time to enjoy the holiday just the two of us though, as our chaperone would arrange a time to come back for us.

It was just so great to have the details of attractions described to us, and the knowledge that the chaperone had, as they were from the country we were visiting, was just amazing. This is the first accessible holiday that we have both been on and it will certainly not be the last!

For anyone hesitant about going on an accessible holiday, I highly recommend taking the leap! Whether joining a group, traveling solo, or with loved ones, it's worth giving it a try!

Message to Rachael and Richard from BBS UK

On behalf of everyone at BBS UK, we'd like to congratulate Rachael and Richard on their upcoming wedding in June! They truly are an inspirational couple, and we wish them a long and happy marriage.



Research Round Up Spring 2024

By Professor Helen May-Simera, University of Mainz

Since the start of 2024 there have been over 28 new research publications that mention BBS on PubMed. PubMed is like a huge library of scientific articles about health and medicine that you can access online for free. It's where doctors and scientists share important information about diseases, treatments, and how the body works. Many of these publications are case studies, that describe the condition in new patients and often mention new gene variants. Several of these are also review articles that describe the syndrome and the cause of the syndrome known to date. There were a few articles that highlight some new findings, three of which are described below.

Early development and adaptive functioning in children with Bardet-Biedl syndrome

Keifer E, Berg RL, Richardson JG, Haws RM; 2024 Jan

In this study they wanted to learn how children with BBS reach different milestones and learn new skills when they're young. First, they looked at information from a big research group called the Clinical Registry Investigating Bardet-Biedl syndrome (CRIBBS). Then, they applied a special test called the Adaptive Behaviour Assessment System (ABAS-II 0-5) to see how well these children are doing in learning new things. They got details on the milestones of 652 children, but they didn't always have information on every single milestone for every child. They tested 101 children and could show that children with BBS often take longer to learn everyday skills, especially things like taking care of themselves. They also tend to have trouble with speaking, compared to other children their age. They also noticed that children with different types of BBS genes do differently in these tests, with those with BBS1 usually doing better than those with BBS10. Plus, as children with BBS get older, they might struggle more with learning new skills than other children their age do.

BBS genes are involved in accelerated proliferation and early differentiation of BBS-related tissues

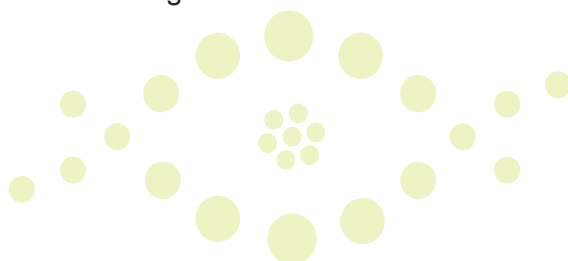
Horwitz et al; 2024 Jan-Feb

In this study researchers have found that certain genes related to BBS are involved in the early growth of fat cells and insulin-producing cells in the pancreas. But they don't know much about how these genes affect other parts of the body linked to BBS. To learn more, scientists studied how these genes are involved in the growth and early development of different types of cells related to BBS. They looked at cells from skin, nerve, fat, and immune systems in the lab. They found that when certain genes related to BBS were turned off, some cells grew faster and behaved differently. Overall, this research shows that one specific gene related to BBS plays a big role in how different cells grow and develop. Understanding this can help us learn more about how BBS develops and find new ways to treat it.

POMC Neuron BBSome Regulation of Body Weight is Independent of its Ciliary Function

Guo DF, Williams PA, Laule C, Seaby C, Zhang Q, Sheffield VC, Rahmouni K; 2023 Dec 23

In this study the researchers saw that deleting the BBS1 gene in a specific brain cell type, made mice gain weight and accumulate more fat. But removing the BBS3 gene in the same cells, didn't have much effect on weight or fat levels. These findings suggest that BBS1 and BBS3, although part of the same group of proteins, have different effects on energy and glucose regulation in the body.



Cilia Conference 2024

Every two years, there is a big scientific conference held in Europe, entirely devoted to all things Cilia. Mutations in BBS genes cause changes in the proteins that are needed for the part of the cell called the primary cilium and for this reason, BBS is medically categorised as a ciliopathy. The cilia conference is very important for BBS researchers and interested specialists, where the latest research is shared and discussed.

The very first Cilia Conference was held in London in 2012, organised by Professor Beales and colleagues, supported by the Ciliopathy Alliance. This was followed by a meeting in Paris (2014), Amsterdam (2016), Copenhagen (2018) and then Cologne in 2022. Bardet-Biedl syndrome was very well represented across the event in 2022 with key-note presentations from Professor Beales and presentations from Dr Elizabeth Forsythe and James Williams who spoke at the BBS UK conference in 2022. Maria Dowswell, an adult with BBS dialled into the conference from the UK

and gave her inspiring personal perspective to an audience of 400 which was mirrored by Nick Dowswell's perspective as a father, the following morning.

This year, the Cilia 2024 conference will be held in person in Dublin, Ireland, and streamed online across 10th-13th September and will bring together cilia researchers, clinicians, patients and patient representatives from across the globe, with a wide-ranging programme including 11 scientific sessions, 4 keynote lectures, 35+ oral presentations, 22 flash talks and 3 poster sessions! BBS UK's Operations Manager, Tonia Hymers, has been asked to give a presentation at the patient day and will be attending along with Chair, Laura Dowswell, to connect with other BBS groups and researchers, and to represent our community.

To find out more about the Cilia Conference, you can visit www.cilia2024.ie.

BBS UK Out and About

Team BBS UK have been out and about educating people about Bardet-Biedl syndrome, making important professional connections, and learning about technology and support services that might benefit our community.

Rare Disease Day February 2024

Rare Disease Day is an international awareness raising event, held on 28th or 29th February by over 1000 patient organisations. The campaign aims to spread awareness, share stories, and show support for those who have a rare disease.



We were honoured to be the first charity invited by University Hospital Birmingham and Queen Elizabeth Hospital and the Rare Disease Day staff team to join them in raising awareness of rare diseases on 29th February 2024. BBS UK's Amy

Clapp and Laura Davis attended with volunteer Aneeba Ahmed and spent the day speaking to medical students, professionals and the public about Bardet-Biedl syndrome, the specialised clinics, and how vital they are in the management of BBS. BBS UK looks forward to being part of this growing event in Birmingham.

Aneeba Ahmed said, "it was lovely to see people who wanted to know about BBS. I can't wait to do it again next year!"



At Guys' and St Thomas' Hospital in London, BBS UK staff, Tonia Hymers, Angela Scudder, social care student Tinashe and trustees, Shehla Mohammed and Stefan Crocker spent the day speaking with clinicians, networking with other charities, and talking to the public about Bardet-Biedl Syndrome, BBS UK and our specialised clinics service. The COO of the hospital and the Director of Clinical Services came along and chatted and learned more about our unique service.

We hope next year some of you will be able to drop in for a chat. If anyone would like to volunteer at these events, then please do let us know. We understand the importance of having a representative who lives with the condition to share their experience.

BBS UK Chair, Laura Dowswell and Fundraising and Communications Officer, Samantha Serido were fortunate to be invited to a Rare Disease Reception at the Houses of Parliament in Westminster, where they heard from excellent speakers including MP, Liz Twist, who is the Chair of the Rare Diseases All Party Parliamentary Group, and Louise Fish, CEO of Genetic Alliance, who launched the rare disease strategy. It was a terrific opportunity to connect with other organisations and government leaders who are committed to making a difference for families impacted by rare diseases.

This year, Parliament promised to focus on helping young people transition into adult care; increase awareness of rare diseases amongst medical professionals; and accelerate rare disease research through a £14 million fund. We are greatly looking forward to these promises turning into positive outcomes for our BBS community.



Upcoming Events

Scan the QR codes to visit the official website for each of the events.

Sight Village Central

Monday 8th July 2024
10:00am – 4:00pm

Tuesday 9th July 2024
9:30am – 3:30pm

Eastside Rooms
2 Woodcock Street
Birmingham B7 4BL



Sight Village South-East

Tuesday 5th November 2024
10:30am - 5:30pm

Kensington Town Hall
Hornton Street
London W8 7NX



Retina UK Professional's Conference

Friday 27th September 2024
10:00am – 3:30pm

The Pendulum Hotel
Sackville Street
Manchester M1 3BB



Retina UK Annual Conference & AGM

Saturday 28th September 2024
10:00am – 4:30pm

The Pendulum Hotel
Sackville Street
Manchester M1 3BB



Would you like to volunteer at an event?

We welcome you to contact us to discuss how you might volunteer with us. Our volunteers help us by answering questions people might have about BBS and sharing their own personal experiences. Our volunteers need to be local to the event. We will pay for travel and lunch for you.

Please contact your Patient Liaison Officer or admin@bbsuk.org.uk if you're interested.



Contact Details

General Information

admin@bbsuk.org.uk

General Contact/Enquiry:

Natalie Braunton

07784 922654

natalie.braunton@bbsuk.org.uk

Mon, Tues, Thurs, Fri 9:30am – 3:30pm

Fundraising & Communications Officer

Samantha Serido

07510 384242

samantha.serido@bbsuk.org.uk

fundraising@bbsuk.org.uk

Tues / Thurs: 8:00am - 4:00pm

Wed / Fri: 8:00am - 11:00am

Operations Manager

Tonia Hymers

07591 206680

tonia.hymers@bbsuk.org.uk

Mon - Thurs: 9:00am - 5:30pm

Advice Service

Rebecca Perfect

07421 455649

rebecca.perfect@bbsuk.org.uk

Mon - Thurs: 10:00am - 2:45pm

Patient Liaison Officer:

Birmingham BBS Clinic Service

Amy Clapp

07591 206787

amy.clapp@bbsuk.org.uk

Mon - Thurs: 9:00am - 3:30pm

Patient Liaison Officer:

Birmingham BBS Clinic Service

Laura Davis

07512 198484

laura.davis@bbsuk.org.uk

Tues - Thurs: 9:30am - 2:30pm

Patient Liaison Officer:

London BBS Clinic Service

Angela Scudder

07591 206788

angela.scudder@bbsuk.org.uk

Mon - Fri: 9:00am - 3:00pm



bbsuk
Bardet-Biedl Syndrome UK
www.bbsuk.org.uk
admin@bbsuk.org.uk

