

Bardet-Biedl Syndrome UK

Registered Charity No. 1027384 and SCO41839



BBS UK Spring Newsletter 2016



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NOTIFICATIONS

Josh Simon Edward McLean

4th June 2004 – 17th October 2015

It is with so much sadness that we announce the passing of Josh Simon Edward McLean on 17th October 2015.

Josh lit up the lives of all who knew him and our heartfelt condolences go to all his family. Josh's family would like to express their deepest thanks to all their family, friends and neighbours who have been so supportive during a very difficult and sad time.

*"You are always in my thoughts
Your love is still my guide
And though I cannot touch your hand
I know you are by my side
My Sunshine My Son"*



Congratulations

Our warmest congratulations to Craig Barrass and Susan Thomas on their New Year's Eve engagement. Craig and Susan met at Pearey House in North Shields. They had been friends for nearly four years and had their first date at their local Harvester. Craig said, 'We sat and talked for over three hours and things just clicked!' The wedding will take place at Whitley Bay Baptist Church on 19th August 2017.

On behalf of everyone at BBS UK, we send our love and best wishes for the future.



Ryan Jones Retires

BBS UK Patron, Ryan Jones, Wales and Bristol forward, retired from rugby in August 2015 on medical advice following surgery for a shoulder injury.

The former Ospreys captain won three Grand Slams in 2005, 2008 and 2012. In all, Ryan captained Wales on 33 occasions and played in three Tests for the British and Irish Lions on the 2005 tour to New Zealand.

Ryan said, "Looking back on my career, I can say that I have enjoyed some fantastic highs and, although there were some well documented lows along the way, the overriding feeling is one of immense pride and satisfaction... If someone had told me 20 years ago that I was going to achieve and experience a fraction of what I have, then I would have been over the moon."

On behalf of everyone at BBS UK, we wish Ryan all the very best for the future.

Foreword

Sitting here at the beginning of February 2016, I cannot believe where the time has gone; it seems only 10 seconds since last year's brilliant BBS Family Conference and yet Conference 2016 is again just around the corner.

Over the winter months, the new committee has been very busy developing the future of BBS UK to ensure that we are in a secure position to continue carrying out the valuable work that is needed. We are all very keen to develop new projects for the future that meet the needs of our families and adults affected by BBS.

Julie and Tonia continue to work tirelessly co-ordinating the smooth running of BBS clinics and have been invaluable mentors, helping build and strengthen the new committee as we go forward in our new roles. I am very proud to be working with such a dedicated team of people who all share the same goal of ensuring BBS UK continues to go from strength to strength.

Tonia, our Newsletter Editor, has been hard at work over the past year, developing and publishing the new BBS Medical Information booklet which will be launched at this year's family conference. This has been a mammoth task and our grateful thanks go to everyone involved. I am sure the new BBS Medical Information Booklet will be an invaluable resource for patients, parents and carers as well as those involved in the care of BBS patients. We are also delighted to have gained Information Standard Certification with NHS England.

Over the past six months, a new BBS UK Web Site has been under construction and our thanks go to Rob and Nicola Hueting for their dedication to this project. The new website should be going live in the near future.

The charity has a hardworking team of trustees who are dedicated to supporting our members and we look forward to meeting with old and new faces again at this year's conference. We always welcome your input and suggestions and look forward to hearing from you over the coming months.

Steve Burge, Chairman, BBS UK

BBS UK Out and About

Birmingham Children's Hospital Rare Disease Engagement Event

In September 2015, Tonia and Julie attended Birmingham Children's Hospital's Rare Disease Engagement Event. The purpose of the day was to find out what families and young patients want from the proposed new Rare Disease Centre. BBS UK attended a planning meeting in the early part of 2015, along with representatives from Wolfram Syndrome and Alstrom Syndrome, to put forward a 'wish list' of what we would like from the new centre.

Local families attending rare disease clinics at BCH were invited to attend the event and there was a great turnout. Various child friendly activities were set up around the room, designed to engage the young patients and find out their thoughts and ideas. In particular we liked the graffiti corridor; rolls of plain wall paper were hung and the young people were invited to doodle and graffiti their thoughts. We also liked the 'washing line'. Paper cut into t-shirt and trouser shapes represented 'tops' and 'pants'; good things were written on the 'tops' and pegged to the line and bad things were written on the 'pants'.

Separate workshops for parents and children allowed both to speak freely and there were some great contributions from both groups. All in all, an enjoyable and successful day.

5th Anniversary Ciliopathy Alliance Meeting

Tonia, Julie and Angela, members of the BBS UK Family Support Team, attended the 5th Anniversary Ciliopathy Alliance Meeting which was held at the Institute of Child Health in October 2015. The focus of the meeting was the development of a new, soon to be commissioned specialist service for rare ciliopathies, based on the BBS service. Once commissioned, the new service is expected to begin in April 2017 and will run alongside those already commissioned, including those for Bardet-Biedl Syndrome and Alstrom Syndrome. NHS England have specified that the new service should be based on the BBS model, which is extremely gratifying, however we will be watching closely to see what we can learn from the new service that might be of benefit to our patients.

Sight Village, London

John O'Donoghue and Steve Burge represented BBS UK at Sight Village, London, in November 2015. John and Steve said they had a good steady stream of people interested in BBS UK and lots of information was taken. Sight Village is an excellent exhibition for vision impaired people, providing information and demonstrations on accessible technology, Guide Dogs, Braille, banking, sporting activities and so on. BBS UK would like to exhibit at Sight Village, Birmingham this year across the 19th and 20th July. If anyone is interested in helping on our stand, please email info@bbsuk.org.uk.

BBS UK Family Support Team

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

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

If you would like help and support from a member of the team, contact Tonia Hymers (Children's Service) or Julie Sales (Adults Service), their contact details are below:



Tonia Hymers

BBS Clinics Children's Service Lead and Family Support Worker

07805 685342
tonia.hymers@bbsuk.org.uk.



Julie Sales

BBS Clinics Adults Service Lead and Family Support Worker

07917 252585
julie.sales@bbsuk.org.uk



www.bbsuk.org.uk

bbsclinics@bbsuk.org.uk

info@bbsuk.org.uk

Tonia and Julie are supported by Family Support Workers, Angela Scudder and Kate Zaczek.

We are delighted to introduce Kate, the team's newest recruit and the Family Support Worker for the BBS Clinics Adults Service. Kate is currently putting together an events programme for adults living with BBS, for more information see the events page. Kate introduces herself below:



Angela Scudder

Angela is a Family Support Worker for the BBS Clinics Children's Service. She has been particularly busy supporting families with accessing Education, Health and Care Plans over the past few months

and has developed a good understanding of the application process.

Angela has also developed an events calendar for the children's service, including last year's highlight, the Avon Tyrrell Activity Weekend.



Kate Zaczek

Hello I'm Kate and I am excited to be joining the team as a Family Support Worker. Having lived in several different areas around the country, I now

live in south Leicestershire.

My background is in Education Welfare where I spent a number of years working with families, schools and Health and Social Care professionals. This has given me a wealth of experience in supporting families to promote positive change. I am passionate about improving outcomes for all and I hope to bring my skills and experience to facilitate this in my new role.

I look forward to meeting you all soon, Kate



Information Standard

The Information Standard is a certification programme for all organisations producing evidence-based health and care information for the public. Any organisation achieving The Information Standard has undergone a rigorous assessment to check that the information they produce is clear, accurate, balanced, evidence-based and up-to-date. We are delighted to report that BBS UK has achieved the Information Standard and the recently released BBS UK Medical Information Booklet bears the logo.

Accessible Information Standard

The Information Standard certification scheme is voluntary and is for organisations to show they are following a robust information production process. The *Accessible* Information Standard, however is compulsory and aims to make sure that disabled people have access to information that they can understand and any communication support they might need. The standard, which was agreed on 24th June 2015, tells organisations how to make information accessible to patients, service users, parents and carers and includes making sure that people get information in different formats if they need it, such as large print, braille, easy read or via email.

The Accessible Information Standard also tells organisations how to support people's communication needs, for example by offering information in easy read, large print, email or braille, a deafblind manual interpreter or an advocate.

From 31st July 2016, all organisations that provide NHS or adult social care must follow the Accessible Information Standard by law; organisations that provide NHS or adult social care must do five things:

1. Ask people if they have any information or communication needs, and find out how to meet their needs.
2. Record those needs in a set way.
3. Highlight a person's file, so it is clear that they have information or communication needs, and clearly explain how those needs should be met.
4. Share information about a person's needs with other NHS and adult social care providers, when they have consent or permission to do so.
5. Make sure that people get information in an accessible way and communication support if they need it.

BBS Clinics patients will be asked about their information and communication needs in advance of their next clinic appointment. This information will be recorded and the relevant BBS Clinic Centre will be informed of any needs well in advance of the appointment. The BBS Clinics family support team will continue to advocate on behalf of patients to ensure they receive appointment letters and reports in the required format.



BBS UK Activity Weekend

In September 2015, BBS UK hosted a family activity weekend at Avon Tyrrell Activity Centre in the beautiful New Forest. Avon Tyrrell House is Grade 1 listed and is the last known 'calendar house' to be built in the UK; it has 365 windows (days), 7 outer doors (days per week), 52 rooms (weeks), 12 Chimneys (months) and 4 wings (seasons). This historical house stands as the focal point within a beautiful 65 acre estate and is home to the registered charity UK Youth.



Avon Tyrrell Activity Centre offers young people of all abilities the chance to experience new challenges within a safe and inclusive environment. During our weekend there, our families enjoyed den building, archery, low-ropes, an assault course and a bonfire. The weekend began on the Friday evening with a meal and the chance to get to know each other. There were crafts, pool table and table football for the children and young people, which were all put to good use. We also used the opportunity to have a second meeting of our Young People's Group, 'Have Your Say!'



Following a hearty breakfast, the weekend's activities began with Den building, with the group split into two teams; of course rivalry between the dads was high, with both dens becoming increasingly more elaborate. The children had a lot of fun with their parents in the beautiful woodland setting. At the end of the session, the children presented their dens, explaining why theirs was the best. Tonia was nominated



at Avon Tyrell



to decide on the winning den and after much deliberation, it was declared a draw – both dens were fantastic and it was impossible to choose between them.

The group very quickly became good friends and thoroughly enjoyed having the space and time to get to know each other. The children revelled in the freedom and experience; it really was a wonderful experience for everyone. On the Saturday night we built a bonfire and toasted marshmallows, before heading back into the warmth of the big house.



The weekend's activities culminated in an obstacle course, with the focus on inclusion. Everyone got stuck in, supporting each other over and under the many obstacles, some of which were a real challenge, but they all did it and they cheered each other on all the way; a fantastic end to a wonderful weekend.

We have provisionally booked the centre for the weekend of the 23rd to the 25th September 2016, with the cost per person expected to be around £80, inclusive of activities and meals. (Under 4s are free of charge). If you would like to reserve a place for your family, contact Angela by phone on 07958 204414 or by email angela.scudder@bbsuk.org.uk. We can't wait to see you there.



For more information about Avon Tyrell Activity Centre, go to www.avontyrell.org.uk.



Fundraising Round-Up

Bardet-Biedl Syndrome UK has seen an active and diverse year of fundraising and the committee and members continue to be very grateful to everyone who has contributed. The charity relies heavily on these stoic efforts and the money is used in so many ways, from providing support and advocacy services and producing information to subsidising our annual family conference; a weekend valued by so many people, especially our members who have BBS.



donated by our colleagues. We know from one of our employees that you do very valuable work in supporting the families of those with BBS and we wish you all great strength going forward”.



One of our members, Tom Oates, turned 18 in March 2015. He enjoyed a great party with family and friends and chose a 'no presents' policy. Instead he asked for donations to BBS UK and collected a fantastic £933.00. Well done Tom and many happy returns.

Vera Scudder, grandmother to Zac, one of our young people who has BBS, sent us a cheque for £903.70. She is a member of RBS Bowls Club and they had chosen BBS UK as their nominated charity for fundraising this year. Vera said "Everyone has been very generous and I'm delighted to send you this amount... I'm so pleased to help such a deserving charity".

We received a cheque for £230.93 from Norton Webb Ltd who held a 'bring and buy' sale. They said, "we had great fun with a 'bring and buy' for our staff where, not only did we raise funds for you, we got to recycle our pre-loved clothing, bags and shoes and buy second hand bargains



In November Danielle Sales, who has BBS completed 80 lengths of her local swimming pool in Tonbridge, Kent, raising a fantastic £800. Well done Danielle you are a star.

Peter and Jane Taplin of Bishop Monkton, North Yorkshire, once again generously offered to open up their garden and model railway on Spring Bank Holiday Monday, this raised £280 for us. The Taplins have now raised around £2000 in total for the charity, amazing!

In addition to these fantastic efforts we have had donations from the Community Trade Union (£250), Recycle For Charity (£10.35) and from Carol-Anne Howes (£200) among many others, we are so very grateful to you all.

The committee would like to thank everyone who has made a difference to the Charity by raising money over the course of the year – you are all heroes!

Please keep me posted of anything you are doing to help us along!

Emma Oates

Oliver Sloane: Fundraising Hero

Over the past few years, Ollie Sloane has been actively fundraising to support BBS UK. In 2015, Ollie, with the help of his family, hosted two family quizzes, an afternoon tea and a craft stall at a local garden centre. Ollie enjoys all different types of crafts and is lucky enough to have a craft studio at the bottom of his garden where he enjoys making and selling cards all year round; they can be viewed and bought via his Facebook page, www.facebook.com/ollie.sloane.



The quiz nights, which are held at a local cricket club, are great fun. A family friend compiles the questions and Ollie sources prizes for a raffle from local businesses. A fantastic £831 was raised from the last two quiz nights and Ollie is already planning more!

Last summer, at the family home, Ollie's family hosted an afternoon tea. It was a lovely sunny day and the drinks and sandwiches were delicious. A raffle was held, and each person paid £10 to attend. The garden was beautifully decorated with colourful wicker chairs and bunting and everyone had a fabulous time, raising £465 in the process.

In December, Ollie, together with his family and friends, made all the products for a stall at a local Christmas Fayre. The stall looked fantastic and was full of Christmas decorations, cards, candles, cushions and more. It was a magical atmosphere with lots of festive stalls and carols being sung.

We would just like to say a huge thank you to Ollie, his family and friends for their continued fundraising efforts, you are all wonderful.

BBS UK Events



London Zoo
7th May 2016

Whipsnade Zoo
18th June 2016

Your BBS UK Family Support Team will be attending the Special Children's Day at London Zoo on **Saturday 7th May** and at Whipsnade Zoo on **Saturday 18th June**. It is a unique annual event, welcoming children with special needs and their families and friends. We will meet up at 10.30am before heading off to enjoy the many wonderful exhibits and will meet up again for lunch. With increased specialist facilities and number of staff, as well as special interactive events and discounted entry, the London Zoo and Whipsnade Zoo Special Children's Day is a great day out, not to be missed. We will be providing discounted tickets so pop the date on the calendar and get in touch, it would be lovely to see you there.



Family Activity Weekend

Avon Tyrrell 23rd-25th September 2016

We are very excited to be holding a second BBS UK Family Activity Weekend at Avon Tyrrell Outdoor Activity Centre, in the beautiful New Forest, across the 23rd-25th September. You will have read from the report and photos in this newsletter that we had a fantastic time last year and can't wait to go back. Booking forms and subsidised places are now available, we hope to see you there.

For further information about the Zoo Days and the Activity Weekend, contact Angela: angela.scudder@bbsuk.org.uk or Tonia: tonia.hymers@bbsuk.org.uk.

Your **BBS UK Adults Support Team** are currently working hard at putting some events together for adults living with BBS. We hope to include a social weekend event in the summer and an activity weekend in the autumn, if you would like to receive information about these and other events, please contact Julie: julie.sales@bbsuk.org.uk.



BBS UK Young People's Group: Have Your Say!

Welcome to the new Young Members Page!

The BBS UK Young People's Group met up in September 2015 during the Avon Tyrrell Activity Weekend. We asked them to put together some ideas for the new Young Member's Page for our younger readers – we hope you enjoy it!

Ben's Favourite Day Out



Ben with his dad at Legoland

Ben likes going to Legoland and his favourite ride is 'The Dragon'. Ben also loves going to Centre Parks, lodge breaks with a hot tub and going to B&Q to buy 'fiddle bits'. Ben had a great time at the BBS UK Activity Weekend and especially enjoyed the zip-wire.

Favourite Activities

Some of our young members like doing arts and crafts, riding accessible bikes, visiting the zoo and going to Drayton Manor – why don't you tell us about what you like to do? A big 'shout out' and 'high five' goes to **Hamza**. Hamza likes practical jokes and made us all laugh a lot at clinic. Hamza likes to play Candy Crush Saga, 8 Ball Pool and Four in a Row. His fun way of keeping fit is to play Tig and Tag and Stuck in the Mud with his friends – his favourite game is Tig and Tag.

Emmy's Top Tips

No one likes homework and there is nothing worse than leaving it all till the last minute and then feeling panicked. Emmy's top tips are:

- Get your homework done on the day you get it
- Sort out and tidy your books during the holidays
- If you use a piece of electrical equipment (ipad, laptop etc) organise it the night before

Emmy finds that being more organised means that school is not as stressful... maybe you have some useful tips for our readers? We would love to hear them!



Emmy with a friend at the family conference



Have Your Say!

This is where you can 'Have Your Say'! Maybe there is something that bugs you or something you want to ask others about; send it in and 'Have Your Say' in the next newsletter.

"We are all special and if we can't do something, we find another way. We should not be judged because in life there is more than meets the eye!"

"No child with BBS should be treated differently. I think that it is wrong that we are judged on what we look like and not on what our personalities are."

"We are the same as you, we just need people to support us and give extra assistance."

"Stop Bullying."

"Rewarding people for 100% attendance is unfair – we never get 100% attendance because of BBS."

Jokes

What do you call a man with a seagull on his head?

....Cliff!



Patient: Doctor, Doctor, I can't stop stealing things!

Doctor: Take these pills and if they don't work, get me a plasma TV and a bag of gold bullion!



Patient: Doctor, Doctor, I think I'm a bell!

Doctor: Take these pills and if they don't work, give me a ring!



Patient: Doctor, Doctor, have you got anything for wind?

Doctor: Certainly – here's a kite!



Thanks Emmy for sending us these jokes, we can't wait to see what you all send in for our next newsletter!

BBS UK Get Active Challenge 2016!

We would love to hear from those of you who took part in the Get Active Challenge last summer and all of you who love being active and having fun with sports. We think our young members should lead the way with a new challenge this year so if you have any ideas, send them in. We would also love to hear about what you like to do – maybe you can inspire other young people to take up a new sport or activity!

Young members, we need your help to keep this page going- send your suggestions, stories, recipes, jokes, artwork and comments to Tonia at tonia.hymers@bbsuk.org.uk. We can't wait to hear from you.

Shore Water Sports Weekend Fundraiser

Laura Dowswell

Many of you will know us and our family, I am a Trustee of the charity and we attend conference every year.

This year we were very fortunate that Shore, a local water sports company where our son Greg works, had a paddle sports demo weekend on 11th and 12th July, 2015 and kindly agreed that donations from the event would be donated to BBS UK.

On the Saturday the sun shone and there were around 350 people trying out the water sports on offer in return for a donation, collected in our distinctive yellow BBS UK buckets.

Some enjoyed the kayaking, paddleboarding and just being in the sea, while others enjoyed live music, ice creams and generally soaking up the atmosphere.

We worked alongside the staff team of Shore and manned the registration desk which was a great opportunity for us to chat about BBS and collect the donations.

In the evening there was a guitarist on top of the O'Neill tour bus playing live music; a few people danced while others lounged around on cushions and deckchairs and as darkness fell, the tour bus was transformed into an outdoor cinema and a film was shown; it was such a great atmosphere.

A 'bar' (kayak filled with ice) provided drinks and another great opportunity to collect more donations – the more people seemed to drink and dance the more they seemed to donate, with a few crisp notes being placed in the jars towards the end of the night!



On the Sunday it rained (first rain we'd had in almost a month) which was really disappointing and the sea state was so poor, no-one was allowed on the water and the event had to be cancelled.

We still managed to raise a fantastic £906 which was way more than we had hoped for!

The whole team at Shore were really supportive of us and must have spent a small fortune on the drinks which they provided in exchange for donations; we would like to extend a huge thank you to the whole team, we really are so very grateful.

Shore's team are as passionate about all things surf as they are about customer service and are not satisfied with less than 100% achievement; they will do their utmost to get customers the right product at the right time - at the right price. For all your water sport needs go to: www.shore.co.uk



Could you be a Friend of BBS UK?

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

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

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

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

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

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

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

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



Friends of BBS UK

Name:

Address:

Post Code:

Tel No:

I would like to become a Friend of BBS UK:

I have completed the Standing Order form overleaf Tick

Please send me a collection box

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

Gift Aid Declaration

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

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

Thank You



Friends of
BBS UK

Standing Order Form

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

Please pay the sum of £

Amount in words:

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

With effect from: (Date)

And **monthly** thereafter.

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

Name:

Address:

Postcode:

Name of Bank:

Address of Bank:

Postcode:

Account No:

Sort Code:

Reference:

Signed:

Date:

Please complete and return to:

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

Let's Shine!

Aneeba Ahmed

My name is Aneeba Ahmed, I am 24 years old.

Some of you guys will remember me from the conference, some of you will remember me from my previous newsletter articles and some of you won't remember me if you are new to the syndrome.

On the 12th September 2015 I took part in this year's Big Birmingham 5K Fun Run, which was in Cannon Hill Park, Edgbaston, to raise money for the BBS UK charity as they have helped people like myself who are affected with the syndrome.

On the day I felt a bit nervous as I didn't know if I could do it, but when I started the race I thought to myself that I could.

When I got to middle-way I felt very tired and that my legs were getting weak, but I didn't want to stop as I wanted to carry on, which I did and when I got to the finish line, I knew that I had achieved something that I didn't think I could achieve.

I completed the race in one hour and twenty minutes.

So you can see that having LMBBS has not stopped me from achieving my goals in life and I would like to say:

'Don't let LMBBS stop you from achieving your goals and don't let it get you down!'





Spring into a Healthier 2016

Sarah Flack, Principal Dietician, Great Ormond Street Hospital

I have just got drenched walking home from dropping my children at school, stupidly having believed the weather app on my phone and being ill-equipped for the wintry weather - roll on summer please! Now is the time to think about making dietary changes or increasing activity levels to help us get in shape and ready for our summer clothes.



Sugar was the big story last summer when the Scientific Advisory Committee on Nutrition published their recommendations for the UK population to cut down on their sugar intake

to help make us a healthier nation. There is evidence that links excess sugar intake with obesity, diabetes and the risk of tooth decay. So this article will look at the surprising sugar content of some foods and how we can make small changes in our diets to cut down our sugar intake.

These new recommendations focus on reducing our intakes of 'free sugars'. Free sugars are those added to food or drinks by manufacturers or when preparing food at home e.g. sugar added to a cup of tea or on your bowl of cereal. However it can be harder to guess where sugar has been added by manufacturers as this can be added to savoury foods too e.g. tomato ketchup or tomato based pasta sauces. Free sugars also include the sugar found naturally in honey, syrups and fruit juice.

Does this mean all foods containing sugar are 'bad' for us?

No! It is important to consider what other nutrients an individual food provides in our diet and not just the sugar content e.g. a fruit flavoured yoghurt will contain some sugar but

also it is an important source of calcium and protein.

Some foods naturally contain different types of sugars e.g. fruits, vegetables and milk products. These are not classified as 'free sugars' and are important to include in a balanced diet. We still need to eat our 5-a-day and have adequate amounts of milk or calcium enriched milk substitutes to ensure our diets are balanced.

However some foods and drinks have a high 'free sugar' content and these are the ones to focus on cutting back e.g. fizzy drinks and sweets. In our diets these just provide a source of energy (calories) and so cutting back will have health benefits. As we know, if we eat more energy (calories) than our bodies need, the extra energy will be stored as fat.

Research has linked sugary fizzy drink intake with weight gain because the amount of food eaten is not affected by having the extra energy (calories) from the drink; so total energy (calorie) intake increases. Most sugary fizzy drinks contain 30 to 50 kcals per 100mls which doesn't sound very much, but quickly adds up when you look at typical portion sizes. One can (330ml) of sugary fizzy drink contains on average 130 calories. One 'small' individual bottle from a shop contains 500ml and so this provides 200 calories in one hit. Did you know in food terms you would get 200 calories from six slices of melon or two bananas or two slices of bread or one large pitta bread with three tablespoons of salsa? Take a minute to think which would be most satisfying. Need further convincing, then why don't you have a look on the internet at 'what does 200 calories look like' to see how much food this equates too?

Try changing from full sugar fizzy drinks to diet

or sugar free versions. An even better change would be swapping to water or sparkling mineral water if you miss the bubbles! Did you know that research has shown that drinking diet drinks can make us want sweet food - that may explain why you often see people with a bottle of diet cola in one hand and a chocolate bar in the other! Remember, making dietary changes that last takes time so set yourself realistic goals - if you are drinking a can of sugary fizzy drink each day stopping altogether may be really hard. A more realistic goal may be to allow yourself a sugary fizzy drink on alternate days so Monday and then Wednesday etc. Once you've achieved this for a week or two, try cutting down your intake again: you could try reducing to two fizzy drinks a week. If you'd like help setting goals why don't you give your clinic team a call?

Is fruit okay to eat as it contains sugar?



It is true that fruit does naturally contain some sugar, however the fruit also provides our diets with many vitamins and minerals and is an important source of dietary fibre. Most fruits have a low to medium glycaemic index, meaning unlike a sugary drink, they do not lead to a sharp rise in your blood glucose levels as the sugar is absorbed more slowly from this complex food. Fruit is a great alternative to foods high in free sugars and fat. If you have diabetes or kidney issues please chat to your own dietitian, specialist nurse or clinic team before changing your diet.

It is important to limit your intake of fruit juice or smoothies - even if they are unsweetened the sugar from the fruit is classed as 'free sugar' once the fruit is juice or pulped. Also it is easy to consume a large amount of fruit without the important fibre that helps you to feel full once it is in this liquid form. Why don't you try squeezing your own oranges at home to see how many it takes to fill a small glass with juice? You may need to squeeze six to eight oranges. Could you actually eat this number in one go? This helps to explain why the maximum recommended intake of fruit juice is to stick to one small glass (150ml) daily. Remember to dilute fruit juice for young

children with water.

Some useful sugar swaps or hints to reduce your intake of 'free sugar':

- Change sugary fizzy drinks for diet fizzy drinks, sugar free squash or water
- If you buy high street coffee shop super duper flavoured fancy coffee or hot chocolate swap to unsweetened tea or filter coffee with skimmed milk
- Change flavoured milkshakes to plain skimmed, 1% fat or semi-skimmed milk
- Watch flavoured mineral waters as these can be loaded with sugar; stick to still or sparkling mineral water to be sure of avoiding this added sugar
- Try cutting back the amount of sugar you add to hot drinks - if you have two teaspoons reduce to one. Then gradually cut back further as your taste adjusts. Alternatively swap the sugar for any of the artificial sweeteners on the market instead
- Swap a small bottle of fruit juice for a piece of fruit and a drink of water - you still get the same sweet taste but without the 'free sugar' intake
- Stuck for snack ideas? Why don't you try vegetable sticks with a low fat dip, small bag of salted popcorn, savoury flavoured rice cakes, crackers and a portion of reduced fat cheese, plain breadsticks or fresh fruit?

In summary, a limited amount of sugar in our diet is not harmful. However we need to remember we get this from eating foods that naturally contain sugar like fruit, vegetables and milk products. So we should only consume a very small amount of foods with added sugar like cakes or biscuits. Surveys of dietary intakes show many of us consume too many foods with a high 'free sugar' content e.g. sugary drinks (sugar sweetened drinks or fruit juice) account for 30% of the sugar intake of 4 to 10 year olds, 40% of sugar intake for 11 to 18 year olds and 25% of sugar intake for adults. Cutting back on foods with a high 'free sugar' content would be beneficial for us all and looking at our drink choices is a great place to start.

Stefan Runs the Great South Run 2015

Location: Southsea, Portsmouth

Distance: 10 Miles

Date: 25th October 2015

At the 2015 family conference I decided to enter the Great South Run. This was an easy decision at the time because of my desire to raise funds for BBS UK and the fact that I was at university in Portsmouth. So on the Monday I paid up and arranged a free entry for my guide runner, my old university mate, Tom Dryland.

At that point (24th April) I had been attempting to lose weight since I graduated in July 2014. I had managed to get up to running between 4 and 5 miles in a sensible, but not overly speedy time. At this point, I thought a sub 2 hour time for the run was literally miles away.

I made sure that I had three square meals a day. For breakfast I regularly had rolled porridge oats with raisins and apricots soaked in soya milk, very sweet but also healthy and a good energy provider for running/walking. Lunch would be no more than one sandwich. Dinner was usually healthy, freshly cooked dishes, but not just chicken and fish, it was interjected with pork, lamb and steak. Here I must advocate that it is important to have either the one day a week or a weekend away now and again, to indulge a little and enjoy, otherwise training will drive you insane.

So, tales from the gym time. My main approach was to slowly increase the distance I did until I got to 7 miles. I then decided to work on getting a quicker time for the 7 miles. I went to the gym every other day when I could, and in between I would go for long walks. On the walks front it is handy to have an iPod to listen to audio books or music. I did do a little weight training in the gym but did not go over the top. One thing I would note is that integrating some cycling at the gym will improve times for the final run and I am doing this for this year's run. Once I had managed the 7 miles as quick as I thought was sensible, I started adding miles until I hit the 10 mile mark.

Amidst all this hardcore dedication it is important to keep one's sanity by playing games with your treadmill sessions. Try speeding up your average mile speed by just a few seconds, increase the calories burnt or add a few metres to the distance. This gives you a sense of achievement.

So the morning of the run came. I had my energy

giving breakfast and magic banana. I had my number attached to my t-shirt and we left the hotel for the short walk to the start line. We discovered that we were starting just after the elite women runners, but what we did not know was that we were going to get a proper announcement



in front of hundreds of people. I should mention here that my guide runner Tom had a heart transplant when he was younger, yes this was a proper all round disabled running team. The big announcement panicked him and we smashed the first mile. Thereafter Tom wore himself out and we opted to walk the next 2 and half miles with a bit of jogging. He had not trained quite as hard as he thought and had recently had a bad chest infection.

So at the three mile point, and as the crowd was thinning out, I asked Tom if he minded me jogging on. After a bit of concern he agreed and I opened the legs and ran. This was the point that had made all the training worth it as I ran past people fully sighted but slower. This was all great until about the 8 mile point where tiredness started to set in and the bizarre toe problem I was having started to niggle. As I got nearer the end, the crowds got bigger and their cheering kept me going. Eventually I finished and was super happy with myself for completing it. I grabbed my finish pack, destroyed my bottle of Lucozade and energy bar and found a spot to sit and wait for Tom to finish. At the time I did not know it but I had completed the run in 1 hour 58 minutes. 50 minutes later Tom came in and then we took almost as long to walk the mile and a half back to the hotel we were staying in.


Overall I would say to anyone considering doing one of the Great Runs to raise cash for BBS UK that it is a great thing to get involved in. It gives you a goal and helps to focus on getting fit - you know the thing you keep telling yourself you need to do, whilst having that third beer or attacking a bag of Kettle chips! Plus of course you raise funds for a great cause.

Stefan Crocker

Fundraising Opportunities & Events

We hope Stefan's article has inspired some of you into thinking about taking on a challenge to raise funds for BBS UK. To make it a bit easier, Stefan has pulled together a selection of events to choose from, ranging from a 1 mile swim to a 13 mile run.

Guide runners qualify for free entry in all events. For fundraising support, contact our Fundraising Co-ordinator, Emma Oates at: fundraising@bbsuk.org.uk. Good luck and don't forget to let us know how you get on!



BBS UK
Change of Name

In 2015, members of the Laurence-Moon-Bardet-Biedl Society voted to change the name of the charity to BBS UK. It has been a challenging undertaking and there are still one or two tasks outstanding, including Gift Aid, but we are happy to report that most of the changes, administration and paperwork are complete. Cheques and correspondence can now be made out to Bardet-Biedl Syndrome UK or BBS UK.

Great Manchester Swim

Distance: 1 mile
Date: 2nd July 2016
Location: Salford Quay, Manchester
Entry: £35
www.greatrun.org/great-swim/great-manchester-swim

Great Scottish Swim

Distance: ½ mile, 1 mile, 2 miles, 5k and 10k swims
Date: 26th-27th August 2016
Location: Loch Lomond, Scotland
Entry: £24-£58
www.greatrun.org/great-swim/great-scottish-swim

Great Women's Run

Distance: 10km
Date: 5th June 2016
Location: Glasgow, Scotland
Entry: £26
www.greatrun.org/great-womens-10k

Great North 10km

Distance: 10km
Location: Gateshead
Date: 3rd July 2016
Entry: £25
www.greatrun.org/great-north-10k

Great Newnham Run

Distance: 10K
Date: 17th July 2016
Location: Newnham, London
Entry: £32
www.greatrun.org/great-newham-london-run

Great Yorkshire Run

Distance: 10km
Location: Harrogate, Yorkshire
Date: 24th July 2016
Entry: £19
www.greatrun.org/great-yorkshire-run

Great Bristol Half Marathon

Distance: 13 miles
Location: Bristol
Date: 25th September 2016
Entry: £38
www.greatrun.org/great-bristol-half-marathon

Great Birmingham Half Marathon

Distance: 13 miles
Location: Birmingham City Centre
Date: 16th October 2016
Entry: £35
www.greatrun.org/great-birmingham-run

Great South Run

Distance: 10 miles
Location: Southsea, Portsmouth
Date: 23rd October 2016
Entry: £41
www.greatrun.org/great-south-run



Caravan to let on 5 star Haven site, Pagham, Nr. Chichester.

Wolfram Syndrome UK has purchased a brand new static caravan on a 5 star Haven Holiday Park and would like to offer Bardet-Biedl Syndrome members the chance to stay at a reduced rate. Guests will have full use of all the complex, with entertainment passes included. The site is close to Pagham Lagoon and Pagham Beach.

The caravan has 3 bedrooms, 1 double and 2 twins, all with electric heaters, a shower room with toilet and heated towel rail, a separate toilet, fully equipped kitchen and a living area with a 32"combi TV/DVD and selection of games and books. One of the sofas has a pull out double bed, allowing the caravan to sleep 8 people. The caravan is fully double glazed and has a gas fire in the lounge area. Guests will need to take their own towels for the pool and beach, dishcloths and bed linen.

Bed linen and tea towels can be provided for an additional cost of £20 to cover the cost of laundering. Broom, mop and hoover are provided but other cleaning essentials and toilet paper will be required. These can be purchased from the park shop or from the shops locally in Pagham. More details about the park can be found here: www.haven.com/parks/sussex/church-farm. The park is



disabled person friendly with dropped kerbs, slopes, hoists in the pool etc. however it should be noted that the **caravan isn't adapted for wheelchairs**. Check in is from 2.00 pm and checkout is at 10.30 am.

Wolfram have further discounted the Haven discounted prices, so please book early to avoid disappointment. Prices range from £150 to £300 for a weekend and from £200 to £800 for a week. To make a booking or for further information, please contact Tracy on 01903 211358 or tracy@wolframsyndrome.co.uk. Our grateful thanks go to Tracy and Wolfram Syndrome UK.



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