LMBBS Summer Newsletter 2014

Foreword

Welcome to the Summer edition of the LMBBS newsletter 2014.

Writing this, I am just chilling in my office, recovering from what was a very successful family conference and would like to thank all of the committee and our volunteers who make this annual event such a success for all of our members.

Shortly after the conference we received the very sad news of the death of one of our BBS family, Stephen Sherwood, who sadly passed away just a couple of days after the conference. I first met Stephen when he was nine years and old and he told me that one day, he wanted to design racing cars! His loss leaves a great hole in the BBS family and I know that he will be greatly missed. The sad death of this intelligent funny young man inspires me to keep doing the work that needs to be done to support adults with BBS. I think we can all learn from the example that Steve gave us in living our lives to the full.

During the time since the publication of our previous newsletter I have been very busy forging links with the Norwegian BBS Society and was privileged to be asked to speak at their annual conference in March; there is a full round up of my exploits in the Netherlands elsewhere in the newsletter!

January saw me taking delivery of my third guide dog, a rather large and handsome brute by the name of Rufus, who some of you will have met at the conference this year. He is doing well and continues to give me great confidence during all of my activities out and about, living life to the full as a musician and sound engineer in the heart of Londinium. You can read more about this later, in my training diary, which Tonia put together from my Facebook posts.

This summer will be a busy one for me, as I will be supporting the rest of the committee in our valuable work with the BBS clinics and I hope to see some of you during the lunch time period at Guys Hospital. Please talk to me, feel free to ask any questions or give me your feedback; I always love talking to and supporting new adult members with BBS.

I am off to California in the summer and am also looking forward to becoming an uncle, as my sister is pregnant with her first child, due in September.

I wish you all a great summer and hope you have fun, living life to the full.

Steve Burge
Vice Chairman.

Congratulations!

Some of you will remember Chris and Phil's granddaughter Lisa, from the many LMBBS Conferences she has attended as a member of the fabulous care team. On Thursday 5th June 2014, on a glorious sunny day, Lisa and her partner Dave were married in a wonderfully romantic setting, in front of close friends and family. The ceremony took place in a Victorian Conservatory, set in the grounds of Belle Vue Park, close to their home and it was a truly fantastic, memorable day for all who attended. Our congratulations to Lisa, Dave and their little boy, Rhys; we wish you much love and happiness from everyone at LMBBS.

Stephen Sherwood
24th December 1988 - 30th April 2014

There is so much that could be said and I can only say a fraction here; I'll just try to give you the 'big picture'. Stephen was conceived on April Fool's day 1988 and born on Christmas Eve that year. You might say that his legendary sense of humour and his sense of mission were both presaged in these dates! Jane and I lived together from 1979, married in 1987, and he was our only child.... planned to be a home-birth in our Herefordshire country hideaway, where for some years we'd lived a self-sufficient life with goats, chickens and veggies. We were young and healthy and everything looked good until two weeks before Stephen was due, when a sharp-eyed ultrasound operator saw something which caused her to send us to the big hospital in Birmingham, the first of many. After a tense few hours we were told something was wrong with his kidneys, and maybe more. Some quick rearranging led to Stephen being born instead at Queen Charlotte's Hospital in West London, as this maternity hospital was connected to Great Ormond Street Hospital (GOS), which would give us the best chance of expert diagnosis and care.

When Stephen was born we were so relieved he was alive, breathing and could urinate, that we really didn't pay too much mind to the intensive care, or to the extra toes and fingers... he wasn't robust but he had made it into the world and our journey together was just beginning. A few days and an ambulance ride later, we were setting up camp in the old Victorian renal wing at GOSH, quite unlike the wonderful new hospital that now exists! Due to the circumstances we were fraught, and so were the staff – amusing in hindsight but difficult to deal with at the time, they insisted I couldn't sleep over in the cubicle with Stephen and Jane, in case this caused the building to collapse! It was the first of many a roller-coaster ride, bringing both worries and relief, conflicts and better-understandings, as crises came and went.
I always feel grateful that within only a few weeks, Stephen was stable and we were allowed to go home, taking with us a name for 'what was wrong'. A nice GOS consultant (the first of many) explained that, on the basis of the renal condition, the extra digits, and test results showing retinal abnormalities, Stephen had either Prader-Willi Syndrome, or more likely Laurence-Moon-Bardet-Biedl Syndrome. It was made clear to us that Stephen would probably still enjoy a full and rewarding life - so I was able to say to myself, 'wow, we don't know quite what's in store but this will certainly be an interesting adventure and a challenge for us all'.

And so it has proved! At that time of course, there was very little known about LMBBS, no Society or self-help group, no Professor Beales, no conferences or get-togethers. All we knew was that it was an auto-recessive syndrome entailing blindness, obesity and renal impairment and that in Stephen's case he had an extra-bad dose of the latter and might not make it. Nevertheless, within months, Stephen's engaging personality was already shining and whenever we took the long train ride to GOS for clinic appointments he would charm everyone in sight!

Stephen, Jane and I have all come a long way since 1988, as has our 'extended family' in LMBBS. Stephen grew into a wonderful, joyous and strong-spirited child, teenager, young man and would-be politician. Along the way he acquired his first kidney transplant aged three and gradually got stronger and fitter – so for many years we attended the annual Transplant Games, where he competed well, and he also played football and rugby at school. Unfortunately, in his late teens he got carried away on a spiral of junk-food, weight-gain and diminishing exercise, which took its toll.

Stephen's eyesight held up well until age 14, but then declined in stages which got ever-quicker, so that in recent months he worried he was 'going blind'. Even though he'd been registered blind ten years earlier, he never really saw himself as blind and took on all kinds of journeys on his own by train, bus and plane, often to places he didn't know at all. Only occasionally did I get a call to say he was lost and never, thank goodness, to say he'd fallen down a hole!

The LMBB Society was formed and we came regularly to conferences, which enabled Stephen to share his experiences with others and so come to terms with his condition, and the whole family to learn more as knowledge about the syndrome grew. As things became more difficult for Stephen in mainstream schooling, he came to realise what lay ahead and agreed to try specialist VI education, going first to New College Worcester for his GCSEs, then to the RNC at Hereford (just a few miles from where he grew up) for his BTECs, where he met his first girlfriend, Lauren Wigglesworth. He then went back into mainstream education at Portsmouth University, where he studied Business and became best-friends with Stefan Crocker, who he already knew from LMBBS conferences.

In deciding to attend university a long way from home, Stephen bravely took on a considerable challenge through which he was able to mature his ambitions towards a career and independent-living, learning a great deal in the process – some of it the hard way! He developed good communications skills which earned respect from his tutors, and in order to maintain his romance with Lauren, take responsibility for his clinic appointments and visit home occasionally. Stephen developed an incredible ability to regularly travel independently, around Portsmouth and to places as far apart as Manchester, Hereford, London and Cardiff. Unfortunately things did not go according to plan - after 18 months at Portsmouth, he found himself in Guy's Hospital due to unexpected renal failure and had to return home.

For the next two years he was on dialysis thrice-weekly in Hereford. Nevertheless, during this time he took three A levels at the local Sixth Form College, got his own flat in Hereford, and actively involved himself in national politics, campaigning all over the region for the Liberal Democrats. He took up Nichiren Buddhist practice as a member of the Soka Gakkai International, and managed to lose enough weight to get a second kidney transplant, this time from his mum who bravely offered one of hers to help get him off dialysis and back on track. While recovering from the operation, Stephen decided he wanted to become a legally-qualified advocate for disability rights and last September he embarked on a foundation course in Paralegal Studies at Worcester Technical College, requiring an early rise and a demanding journey. Only a week before he died, Stephen travelled on his own to Cardiff Crown Court to experience legal processes first-hand; plus on the political side he had already filed papers to run for Hereford City Councillor next year on the Lib Dem ticket.

Unexpectedly, Stephen died on 30th April, aged 25, peacefully in his sleep and for 'no obvious cause' although we await final post-mortem findings. Although he'd been brought up to practice healthy-eating and fitness, in adulthood Stephen had not managed to control his diet or his weight. He also had a lung-function deficit, for which he was issued a CPAP machine by the Royal Brompton, though he never used it. Undoubtedly these were factors.

On the plus side, in many ways Stephen went out on a 'high', having had a great weekend at the LMBBS conference with his closest friends and also his beloved girlfriend Laura Wilson whom he met last year through the LMBBS. Many people said he was on top form that weekend, and the very last time I spoke with Stephen, on his return to his flat that Sunday night, he sounded fine, despite the very late nights, the copious top-notch vodka and having an unfinished college assessment due the next day! His tutor at Worcester College has confirmed he was doing well and to my pleasure it's emerged he had also made many friends and won much respect in his eight months there, unlike his preceding years at the 6th Form College where he struggled academically and socially. He was now making notable progress in both areas. Also he was taking ever-more responsibility for managing his social care and in recent weeks had successfully pressed the council for a full review, earning respect from the department head for his determined, articulate emails, demanding reinstatement of his social worker!

Stephen's funeral on 17th May was joyous and sunny, attended by well over 100 people from all sorts of connections he had made, including Lib Dems, Buddhists, tutors and friends from every college he'd attended, good friends from the LMBBS, his girlfriend Laura and her family, and family from UK and overseas. Along with tributes from myself and others, Stephen would undoubtedly have been especially proud to have heard read the two-page handwritten letter from Nick Clegg praising his efforts and his spirit! Through email, Facebook and post there have been so many wonderful, moving tributes, not just for his legendary belly-laugh and quick-fire wit, but also to an extraordinary, unexpected extent for the way his courage and commitment had profoundly inspired many people. Some of these tributes and photos of Stephen and of the funeral can be found on the Stephen Sherwood Memorial Group set up on Facebook by his step- brother Guy (whom some of you may have met at the LMBB conference) - you're all invited to join and contribute if you like. The funeral was fantastic, with songs, laughter and tears; numerous people said it was 'uplifting', 'enjoyable' and 'the funeral I'd want for myself'. It all brought home to me just how special Stephen was, how much he had developed himself and his relationships in recent years, and how much he had quietly, steadily achieved, in his very own way, being true to himself, with humour and kindness, with keen perception and desire to make a positive impact. I will miss him much, and it helps to know there are others who feel the same.

There are many, many people to thank for their love, their support, their professional expertise, and their humanity towards Stephen, Jane, myself and others who shared the journey of his life. Many of those are in the LMBBS or closely associated with it, and to them I say a heartfelt thank you. Without the LMBBS, this would have been a lonely and difficult journey, with much less light and hope. Let's all take courage and inspiration from what Stephen was able to achieve, let's learn from the way he lived, and from his death. Let's do all we can to strengthen each other, and the organisation.

Myoho-renge-kyo, as Nichiren Buddhists say, and Viva Steve!

Professor Beales: Super Hero!

18th May 2014, Professor Phil Beales and the University College London Superhero team ran 5K in Regent's Park dressed as their favorite superhero!

The team raised just over £1,000 for Rare Disease UK (RDUK), the national alliance for people with rare diseases and all who support them. They believe that everyone living with a rare disease should be able to receive high quality services, treatment and support.

We are not sure whether donations will still be accepted at time of going to print, however if you would like to have a look at the team's fundraising page and try to donate, the address is : **www.doitforcharity.com/www.UCLSuperheroes.com.**

Duxford Christmas Party

"We would like to thank the LMBB Society for giving us the opportunity to take Suvannah back to the American Air Force Christmas Party at the Imperial War Museum in Duxford for the second year running. The party was hosted by American Air Force personnel, their spouses and partners and they have all fallen in love with Suvannah and have become friends. We met up with the Air Force personnel and their families who were there last year; they were very delighted to see her again and they all knew her name.

The children enjoyed arts and crafts, various game stalls, face painting, balloon modelling and also saw Santa arrive on a fire engine. We were informed that the American Air Force imported all the kid's presents from America; Suvannah was given a Barbie Doll as her Christmas gift. Lunch and refreshments were also provided for every person there. "

Suvannah and her family met up with another BBS family at the party, Zac and Zara and their mum, Angela. If you would like the chance to attend this special event, contact Chris Humphreys for more information: chris.humphreys4@ntlworld.com.

Keep in Touch!

LMBBS has two FaceBook pages, 'Laurence-Moon-Bardet-Biedl Society', our 'international' page, and 'LMBBS UK' for UK based members only. This is proving to be an excellent way for the Society to keep in touch with its members, more importantly, though, it is there for YOU to keep in touch with each other, so, if you haven't done so already, become a 'LMBBS FaceBook Friend' and keep up to date with the Society and its supporters. LMBBS has also recently joined Twitter, so look us up and get 'tweeting' @LMBBS1.

It's Good to Talk!

New Families Contact

Claire Anstee, is our New Families Contact. Claire is married to Jason and they have three children. Claire's daughter has LMBBS and so she knows too well how difficult the early days of diagnosis can be. If you feel you would benefit from talking to another parent about the syndrome and diagnosis, Claire is more than happy to listen and help in any way she can. She can be contacted by telephone after 4.30pm, Monday to Friday, on 01604 454477 or via email at ansteeclaire@gmail.com

Adults Contact

Steve Burge is our contact for affected adults, their families or carers. Steve was diagnosed with LMBBS at eleven years old, lost his vision at the age of 21 and has been involved with the Society since 1997. Music has always played a big part in Steve's life and he credits his love of music, especially his drumming, with helping him cope with having the syndrome. Steve can be contacted on 07833 228463, at steveburge@live.co.uk, via Skype at budge-2005 or by post at 38 Pocklington Court, 74 Alton Road, Roehampton, London, SW15 4NN

SEN Contact

Dianne Hand is a Special Educational Needs Co-ordinator and has a son with BBS, so has a great deal of knowledge about the education system with regards to Special Educational Needs. If you have any questions about getting support for your child at school, or would just like to chat to someone with knowledge of how the system works, Dianne is more than happy to help. She can be contacted via email at diannehand@live.co.uk or by telephone on 0161 442 0989.

Don't forget you can also contact us via the LMBBS helpline: 01633 718415, further contact details are on the back page of the newsletter.

Training Diary: A month in the life of Steve Burge and Rufus Bear

20th Dec
Very, very pleased to be meeting my new guide dog, Rufus, on 30th December (2013). If he likes me, we will start training on Monday 3rd, what a great early Christmas present.

3rd January
Ok, so first day of dog training went well. Rufus was a bit coughy still, so he is staying with the trainer until Monday, just to make sure he is not contagious for the other dogs living at the lodge. We did a blinder of a route all around Euston station and he worked well, but he is a greedy boy and tried to eat a few things on route. He did work well though, so it is early days, but very promising and great to be with a dog again.

9th January
Well Rufus is now fit and well and is coming to live with me very soon. I have also now been given a one bedroom flat at the lodge so am very pleased and looking forward to moving in as soon as the new carpets are laid and the painting completed. There will be plenty of room for Rufus as well as my drums. I am looking forward to getting started properly with our training so I can get out on my own in the near future.

10th January
Well that's the tactical assault on Sainbury's, Hammersmith, finished and it was mad. Lots of goodies bought for the weekend and some good low fat stuff found as well, so making little changes instead of big ones, which is where I always go wrong with diets. I think that Rufus will keep me fit and help me lose a bit of weight over the coming months as he is young and very fit. I got him a bone today, but not sure if it is big enough for this huge dog.

11th January
Rufus is in the building and he is doing ok. So far, a good morning of getting him properly settled. Now starting his musical education and thought we would start with 'Asia' from Steely Dan. He has already shown an interest in a set of 5a vf drumsticks - good choice my man. We are now in a bonding period and will then continue with training full time from Monday morning. It feels really weird now, being responsible for another life form again. The size of him makes Faith seem like a puppy.

12th January
Waiting for food. Rufus enjoyed me playing drums for him and he did not bark or cry, so he obviously loves music and has enjoyed going through several CDs this weekend, chilling with daddy! An early night, tonight, before miles of walking tomorrow as we carry on with training - only two more weeks to go.

14th January
What a day of walking in the rain - route walks all over west London with Rufus - he was brilliant. We smiled and laughed in the face of adversity and waged war on the urbanites of Shepherds Bush with sniper like precision.

Rufus and daddy are listening to Pink Floyd, 'Dark Side of the Moon'. This little big boy has some taste tonight - he lay under the drums whilst I played and was next to the kick drum feeling some good vibrations! I never tire of listening to Dark Side of the Moon, the whole way through, from start to finish, no pauses for coffee, no stopping for emails, just kicking back and enjoying.

15th January
Found out this morning that Rufus is a sponsored puppy and he has his own dedicated blog! He has better promotion than me - maybe he can become my new manager! We are waiting for David to turn up for more walks and more urban warfare - I am really starting to enjoy the training after a very successful day yesterday out in the Bush.

Another great day with Rufus he is doing well and went for a walk in the park this afternoon to do obedience training with other dogs. He did very well - good boy Rufus, keep it up for daddy!

17th January
A great afternoon of walking in Hammersmith with Mr Rufus. He is starting to work well… today was the busiest walk we have done yet and he worked very well. He now knows where Starbucks is for a caffeine fix. We got the bus back and then did the route to Sainsbury's and then back home. He has just had his tea and is chilling until he gets a well deserved free run tomorrow. I am off to the pub later for a well earned beer or two.

21st January
We are up, dressed and ready for battle - more routes today in the Bush and then Hammersmith via Goldhawk Road Tube Station, so that Rufus can do his first Tube journey - a short one to start and then on to the big stuff.

I have lost half a stone on my diet so far and am feeling better for it. My target is to lose a stone in weight first and then I am going to go for the long haul after that. I am finding that if I change little things, I do not feel like I am missing out – I haven't had a pizza at all in 2014 yet, so Dominos must be going out of business in the Bush! Enjoying my new lifestyle.

22nd January
Ok, so hopefully it won't rain today and will not be as cold as yesterday - we are off to Hammersmith again to do some more shop location exercises. Rufus has got his maps out and is doing his homework before class!

Feeling tired - a great day of dog training with Rufus around Hammersmith. We did the Tube, Marks and Spencer , Boots and TK Max and then a coffee - proper little window shopper. Rufus is really working well and he is turning into a great friend already. Today we were out, walking through the masses and it was good fun, he did some great decision making and kept me safe which is all I can ask for. Keep it up you lovely little big boy.

I am so hungry I could eat a horse, all of this walking is doing wonders for my appetite but I am still eating quite well, so am not worried just yet. Still no pizza, so a miracle is being witnessed. I have had a text message from Dominos offering me all kinds of free things since New Year but I am still not biting. I have now found a takeaway in London that does diet food - marvellous. Tomorrow stew is going in the slow cooker, I've got steak, potatoes and loads of vegetables for dinner when I return with the Rufus bear.

23rd January
Ok - Rufus is in the debrief room and we are discussing his behaviour this afternoon - seriously good work and window shopping at River Island. A great walk and he is doing well, mastering all of the necessary routes around where we live. This afternoon we walked smoothly down the street finding what we need to find and walking at the same speed as all of the sighted people in the street - to sighted people, I cannot tell you how good that felt for the first time in seven months. Onwards and upwards.

Next up is trains and big stuff, starting next week with a dry run to Clapham Junction and then expansion onwards to wherever we need to go. Rufus is chilling and I am awaiting food - just about to crack open a few Budweisers.

24th January
Feeling rubbish as spent the whole evening finding and picking up dog puke from Rufus. The poor little boy is a bit sick but he is ok now and we got it all up so no problems. He is now sleeping so hopefully tomorrow he will be a bit better. Could really do without this - Rufus is now a priority over anything else in my life for the foreseeable future.

25th January
Well my little boy is poorly and he is not up to working today. The vet says that he has a virus that is going around and he may have picked it up in the park. I have never found so much puke from one dog in one small flat! Oh well, it's all a part of the job of being daddy to the Rufus - hopefully he will look after me when I am ill. Life is stressful today.

27th January
So we moved up several gears today with the Rufus and made it to Croydon and to The Edge pub for live music and to see my good friend Matt Saunders. Rufus was great on the trains in Clapham and also on the train to Croydon so we will expand on this, later this week.

I feel shattered - it has been a long day but very worthwhile. I have just finished an hour of drum practice for a recording project with Matt. Right now, the sun is well and truly over the yard arm, so a gin and tonic is in order.

28th January
What a day! Rufus made it to the mighty Redstone fm Studios and then back home via Victoria and the District Line, what a clever boy! He is doing well and we are both making good progress. Just finished drum practice for the day and am now awaiting the stew which I threw together this morning and popped in the slow cooker. A couple of beers then bed.

Ciliopathy Alliance

Michael and Drina Parker continue to represent LMBBS in the Ciliopathy Alliance, with Michael on the Board of Trustees. The Ciliopathy Alliance (CA) aims to promote research into rare diseases with defective cilia and to provide support for patients with ciliopathies, their families and carers. LMBBS is so well established now that it has NHS-funded BBS clinics which provide medical support for those with the Syndrome, and of course LMBBS itself which supports the clinics and all other aspects of the Syndrome. The smaller, rarer syndromes such as Jeune Syndrome and Joubert Syndrome do not have these advantages and CA, as an umbrella group for all ciliopathies, aims to cover this shortfall.

Cilia 2012, the medical conference, attracted researchers and clinicians from all over the world and was a huge success. Several families from LMBBS and other members of the Ciliopathy Alliance attended the reception at the British Medical Association prior to the start of the scientific conference. These doctors were interested to meet those people in the real world, outside the laboratory!

CA decided to hold a conference in 2013 for people with ciliopathies, their families and carers to cooperate in producing a route map for future support. The Cilia 2013 Conference was successful thanks to the hard work of Tess Harris, General Secretary of the Ciliopathy Alliance. Tess drew on the template of LMBBS Conferences: it was held in the same hotel, the Northampton Hilton, and the expertise of Chris Humphreys, Julie Sales and Tonia Hymers was drawn upon. No wonder it was such a success!

This year, Cilia 2014, a second medical conference, is to be held at the Pasteur Institute in Paris, 18 - 21 November. As with Cilia 2012, those with ciliopathies, families and carers are going to be encouraged to attend the reception on the evening of Tuesday 18th November. There is a special reduced delegate fee of €105, for people affected by ciliopathies, who wish to attend the medical conference.

Michael and Drina attended Rare Disease Day at the House of Commons on 26 February. They were wearing two hats (or two badges, at least), representing LMBBS as well as the Ciliopathy Alliance. The theme for Rare Disease Day 2014 was care, with the slogan, 'joining together for better care'. Alistair Kent, Director of Genetic Alliance UK, said that 'experience shows that bringing together scattered knowledge and resources for people living with rare diseases is the most efficient and effective way to mobilise the care patients and families need and deserve'. This mirrors the aspirations of the Ciliopathy Alliance.

It was encouraging to hear Alistair launching the implementation strategies for better care for those affected by rare diseases in England, Northern Ireland, Scotland and Wales as well as assuring us of the European Union's commitment to 'developing a plan to address the needs of patients living with rare diseases as well as facilitating much needed research into these conditions' . It was also heart-warming to think that a lot of the aims of the smaller groups supporting rare diseases have already

been achieved by LMBBS. This doesn't mean that LMBBS should be complacent: we may be ahead of the game but there is still much to strive for.

Silent Heroes

This edition's Silent Heroes nomination goes to Amanda Wilbraham, pictured here at our recent Blindfold Bowling Challenge.

In 2004, Amanda, a close friend of Chris and Phil Humphreys, was coerced into joining our Conference Childcare Team, along with her husband Jason and daughter Rebecca, a role they happily embraced, returning year after year. Since that time, Amanda has supported the Society in many ways, including fundraising, with the specific aim to raise funds towards the Conference weekend.

In addition to the Conference Childcare role and fundraising, Amanda has been a great practical support to Chris, overseeing thousands upon thousands of sheets of photocopying over the years at High Cross Primary School. The School has always been supportive of LMBBS since James spent his school years there, and our thanks go to them also. Amanda has given up her lunch hours and stayed behind after school, ensuring all sheets are photocopied and put in order before being returned to Chris for mailing.

Amanda is currently working on a November project of an evening's entertainment with the Big Mac Wholly Soul Band, having successfully negotiated a large discount for the charity. A couple of years ago, Amanda organised a hugely successful 60s themed party. We have no doubt the next party will be equally successful.

Amanda you deserve this accolade, 'Thank You' from everyone at LMBBS.

Jeans for Genes 2014

We are very excited to report that the LMBBS has been successful with their application for a grant from Genetic Disorders UK, as part of their Jeans for Genes programme 2014. We have been awarded just under £17,000 to employ a Child Development Worker for a one year placement.

Young people with Bardet Biedl Syndrome face many challenges including visual impairment, emotional immaturity, mobility difficulties, obesity and lack of social awareness, all of which impact on their confidence and self-esteem. Depending on where they live, some of our families are well supported by their schools, local disabilities team or social services, however many are severely lacking and are unaware of the benefits they should be receiving or the support they should be getting from their local authority. Furthermore, many children are struggling in schools that are failing to provide adequate support or ensure a Statement is in place.

The contact we have had with our families and young people has shown us that from mid primary school age onwards, an awareness of being different and isolation sets in. Unchecked, this has long

term implications for confidence and self-esteem and we would like to be able to bring our young people together for activity breaks to enable them to build on friendships and break down the sense of isolation. This sense of community could be extended through our newsletter and webpage.

We have liaised with some schools and local authorities and subsequently managed to improve the situation for some and our contribution has been well received by the various authorities. We would very much like to be able to do more for our families and now, thanks to the support of Jeans for Genes, we will be able to do so.

Our 'Child Development Worker' will support our young people and their families. The position will be for approximately 15 hours per week and activities will include:

- Family support and Advocacy: through attendance at BBS Clinics, telephone contact and home visits, the Child Support Worker will ensure families are receiving the support they need, financially, educationally and socially. This would involve advocating on the family's behalf with Social Services and the young person's school, to ensure the complexities of the condition and the additional support that will be required are understood.

- Organisation of activity breaks: we aim to give young people and their families the chance to get away from the day-to-day challenges they face and build friendships with others in the same situation.

- Raising awareness and the provision of information: this could be achieved through a monthly e-newsletter, website development, attendance at BBS Clinics, contribution to LMBBS Newsletters and events such as Sight Village etc.

- Promoting exercise: exercise is very important for our young people and the promotion of activity is paramount.

We are currently putting together a job description for this role. If you feel you may have the required skills, please email Tonia for more information: toniahymers@btinternet.com.

To say 'thank you' to Genetic Disorders UK, we are getting fully behind their Jeans for Genes Campaign 2014, which this year falls on Friday 19th September 2014 – pop it in your diary and calendar now!

Five of our families have generously agreed to be contacted by the media to raise awareness of the syndrome, the Society and Jeans for Genes. We will post further information regarding this on our web page, Facebook page and Twitter.

We have put together two letters, one for schools and one for workplaces asking for everyone to join in with Jeans for Genes 2014. It really is a very simple idea, wear jeans for the day and make a donation! If you would like to ask your school or workplace to get involved, the letters can be downloaded from our webpage and Facebook. For those of you who are not at school or work that day, we are having a National Coffee Morning and Bake Sale! Invite your friends round, stick the kettle on and put a pot out for donations – what could be simpler! Fundraising ideas and materials are available from the Jeans for Genes website: www.jeansforgenes.org .

Don't forget to send us your photos so we can have a Jeans for Genes gallery in our next newsletter!

Fundraising Round-Up

The Laurence-Moon-Bardet-Biedl Society has continued to raise funds in various ways, despite the continually difficult economic environment and the committee are grateful to all members, friends and family for their continued support. Every penny counts and goes directly where it is needed, providing support and information to our members, the production of newsletters and towards our annual family conference which offers huge support and friendship to many.

During the last financial year, we secured a grant from the BBC Children in Need Appeal and recently have been successful in securing a grant from Jeans For Genes.

We have also had people taking on personal challenges, in the form of running half marathons and 10k races or undertaking challenging walks. One such member, Tania Ansell ran the Pontypool 10k in February, raising more than £200 for the Society. This is what she had to say;

“It was a cold Sunday morning at 9am in misty Pontypool Park on the 23rd February 2014, I lined up with the other 600 runners and asked myself "will I make it round?" I had completed a small amount of training beforehand, but was slightly apprehensive as it was the furthest I had run before. I watched the elite runners warming up on the spot for their sprint. I decided I was going to just get round before sun down and not worry about a ‘personal best! The doubts of completing the run without stopping, soon started to fade as my sister Kelly's voice rang out in my head "You can do anything if you put your mind to it". She has always been good at not letting life get her down or hold her back from anything, even as a BBS patient; if she's not line dancing, she's belly dancing! There's no end. My brother James also has BBS and is also an absolute inspiration and a real ‘pick me up’ on any grey day! He has more ambition and determination and lust for life than anyone I know. A fearless nature of "you can't knock it till you've tried it".

With this in mind, the race started and I was off! It was a tough gradient at times but very much like life, you have to climb the mountains to see the great view on the other side. I kept climbing and pushing on as I knew my 1 hour 22 minutes of pain was a small sacrifice in comparison to what Kelly and James go through on a daily basis. A constant struggle wearing a constant smile! At last, I had done it! Thank you James and Kelly! Thank you for all the support on ‘Just Giving’ in helping me beat my target. It is a small step in raising funds for such a worthy cause. The LMBBS Society do a fantastic job of supporting families of those affected by BBS, the diagnosis can be such a frightening time of uncertainty. But how great to know there is a network of people who have first hand experience and advice ready and available. I realise how important it is that the money continues to fund this service and I hope through fundraising to raise the awareness of this rare genetic life limiting illness and help more families. “

Another family which we would like to offer a big vote of thanks to is The Eccles family. They have undertaken a range of fundraising events over the year, well done and thank you.

Going forward we have a number of people with up and coming fundraising events. Rachel Wade is running a 10 mile race in July, Aneeba Ahmed is selling LMBBS wristbands in her local college and Maria Dowswell has exciting plans to stage a radio show at her college, talking all about LMBBS and featuring songs from Tom Oates' CD, 'The Climb', which he recorded as part of his GCSE work. Tom has sold 150 copies, making £130 for the society. For ways to sponsor these and other events, please keep an eye on our Facebook page or email me at ejoates@btinternet.com

Our main fundraiser for the forthcoming year is a bike ride from London to Paris which has been organised by two of our members who are parents of children who have the syndrome. This ambitious event will be a 250 mile ride over four days; the last day is planned to coincide with the final day of Le Tour de France and we have nine friends and family cycling, together with a two man support crew. All those participating have funded themselves for accommodation and travel, and sponsorship for this event is already well in excess of £1000.

You can donate by texting 'LMBB01 £5' to 70070, by visiting www.justgiving.com/Nigel-Hills1, or by posting a cheque to Emma Oates (Address on back page) There will be a full report of this and our other future fundraisers in the next newsletter.

We are always keen to hear your ideas for fundraising, so please get in touch and let me know what you are doing or have done to help raise money for this very special charity.

The committee and trustees are very grateful to all those who volunteer and freely give up time to support the charity in its vital work and without this support, much of our work would not be possible.

Emma Oates.

Family Fund

Family Fund is a registered UK charity which has provided grants for low-income families, raising children aged 17 and under, for over 40 years. It can help with essential items such as washing machines, fridges and clothing but can also consider grants for sensory toys, computers and much needed family breaks together.

The Family Fund website (www.familyfund.org.uk) is very informative and apart from telling you where you might be able to make savings you hadn't thought of before, it also makes you aware of other agencies that could help your family.

They may not be able to help you with everything you ask for, but they are certainly worth a look.

If any of you have benefitted from the Family Fund and would like to share your experience, or if you know of other groups that can help, especially ones that support all age groups, we would love to hear from you.

Transition Skills

All young people, with or without long term health needs, go through a variety of transition periods. The most well known is the transition from primary to secondary school. In healthcare, the word transition is used to describe the development of a young person's knowledge and skills to manage their own healthcare; this will include their eventual *transfer* to adult services. Transition continues after *transfer* into adult services and hence involves child, adolescent and adult centred services.

It is a gradual process that gives young people, their family and anyone involved in the young person's care, time to get them ready to transfer to adult services and discuss what healthcare needs are required. This will include deciding which services are best for the young person and where they will receive that care.

Throughout the transition process, young people should have the opportunity and be encouraged to actively participate and make decisions. As they gain competence in strategies of self-advocacy and self determination, their level of participation increases. One of main goals of transition planning is to enable young people to become more responsible so they can participate and contribute in the adult community as independently as possible. It is very important that during adolescence, they are encouraged and supported to develop their self-advocacy skills and speak up for themselves.

Many young people can be anxious or shy with medical staff; however it is very important that they feel able to communicate effectively with their health care team. It is a common occurrence that some doctors or nurses direct the consultation and conversation at the parent, rather than at their young patient. This can lead to them taking a passive role with the parent taking the lead. Over time the young patient carries out the passive role without developing the skill to speak up for themselves. This can happen for a number of reasons and is quite natural for parents to be protective especially if they have had to be the voice of their child for their earlier years. Given support, parents can begin to learn to 'let go' and give their youngster the opportunity to speak up for themselves.

All young people with or without additional needs will all have their own communication style, including sign language, Makaton, writing, drawing or speaking through an interpreter. Once the healthcare staff have been advised of their patient's communication needs they will advise the team and endeavour to find the best way possible to interact with them.

Top Tips for Parents/Carer

- Encourage your child to develop their confidence when speaking to the healthcare team
- Support your young person to know about their medical needs - name their condition and describe the impact it has on them
- Help your young person to know their strengths and what areas they need support with

Top Tips for Young People

- Tell healthcare staff a little about your life and what you like doing
- Know about your medical condition and how it affects you
- Know how to ask your healthcare team for help
- During a chat don't be afraid to ask if you don't understand what a health professional has said. For example 'I didn't understand what you said, can you say that again?'

Marie McGee, Transition Care Co-ordinator, Rare Diabetes Team Birmingham Children's Hospital

Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. They support siblings of all ages who are growing up with, or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition. The issues they provide support with may be emotional, such as coping with isolation or guilt, or practical, such as how to make plans for future care. They have an online forum for adult siblings, a buddying service, and run workshops on adult sibling issues.

Sibs also provides email information and support to young siblings (children and young people) on any sibling issue. They run workshops for siblings on understanding their brother or sister's disability and on coping strategies for dealing with difficult sibling issues. These workshops can be bought in by statutory and voluntary agencies.

The 'parenting siblings' phone service for parents, helps them support siblings with sibling issues such as giving attention, explaining disability, and dealing with siblings' feelings. They also run workshops for parents on supporting siblings, which again, can be bought in by statutory and voluntary agencies.

Sibs provides training and consultancy for professionals on supporting siblings, how to develop local services for siblings, and how to run sibling groups. Their long term vision is that every local authority in the UK will have a dedicated sibling service for young siblings and a support network for adult siblings.

For more information, go to: www.sibs.org.uk

Think Right Feel Good: Promoting Young People's Well-being

Think Right Feel Good is a short course, developed by Guide Dogs, aimed at promoting well-being in young people with vision impairment. The program is offered as a resource for education and mobility professionals, experienced in working with young people with vision impairment.

After carrying out an extensive survey, Guide Dogs found that there was a particular need to promote well-being in young people with vision impairment. The research showed that, overall, young people with vision impairment do not perform as well as other young people in terms of confidence, independence, initiative, self-esteem, social skills, mobility and social networks. Encouraging well-being is important because young people who feel good about themselves and are confident are more likely to achieve higher grades in school and have the skills to make friends more easily.

The course is intended to contribute to the development of emotional, social and personal competencies and to complement the support that schools provide, for example through the Social and Emotional Aspects of Learning (SEAL) programmes. Materials are available to download from Guide Dogs web site: www.guidedogs.org.uk.

If you feel your child or young person would benefit from this course, speak with your child's SENCo (Special Educational Needs Co-ordinator); they may be able to link up with other local schools, bringing together visually impaired students to benefit from this excellent resource.

Guidelines for Teaching Staff
Dianne Hand
SENCo

My son is partially sighted and is lucky to be supported by Stockport's Sensory Support Service. The Service has produced a list of guidelines for staff at the school to help him access his learning more effectively. Although these guidelines have been put together for my son, I feel they will be useful for many parents when talking to their child's school about how their child can be supported further.

GUIDELINES TO STAFF

- Avoid glare. Diffuse light is more helpful than strong light.
- Lights may need to be on when they would usually be off.
- The child or young person should ideally sit in the middle, near the front of the class close to and facing the action.
- If you wish to address a child or young person individually, say their name first to attract their attention.
- You need to check the recommended print size for the child. Text should be clear, well spaced and on a contrasting background – see below for further information. (Ask if the Local Education Authority has an adaptation Service which can produce materials in the appropriate format).
- Ensure all verbal instructions are precise. For example: 'do this' or 'don't do this' can all be explained with more verbal detail.
- Avoid sharing learning materials such as books and computer screens.
- Use a black pen for recording.
- Ensure that comments written on a child's work are legible and written in a clear, dark pen.

Thank you to Stockport's Sensory Support Service for letting me share this information.

Sources of Large Print, Audio books and eBooks

A visually impaired child or student may need help by modifying materials to make them clear and accessible.

Difficulties may include:

- size, style and format of print
- seeing detail in pictures or print on a coloured or 'cluttered' background
- understanding information in diagrams and graphs
- recognising 2D line drawings of 3D objects
- glare from standard white photocopying paper
- no sighted access, therefore differentiation of materials into a braille and tactile format is needed

There is a range of websites that can help to provide accessible materials:

Clear Vision:	www.clearvisionproject.org
Gutenberg Project:	www.gutenberg.org
Books should be free:	www.booksshouldbefree.com
Calibre:	www.youngcalibre.org.uk
Audio Books for Free:	www.audiobooksforfree.com/home
BBC:	www.bbc.co.uk/podcasts/genre/childrens
Load2learn:	www.load2learn.org.uk
RNIB:	www.booksite.rnib.org.uk/eDelivery
Listening Books:	www.listening-books.org.uk/library.aspx
Seeing Ear:	www.seeingear.org/our-library
StoryNory:	www.storynory.com
Tactile Library:	www.tactilelibrary.com

Many thanks to Stockport's Sensory Support Service for suggesting these websites.

If parents and young people in education can let me know further strategies that have helped their child in school, I will add to the resource of 'Guidelines for Staff' and pass on these suggestions in a future Newsletter.

Dianne Hand, parent and SENCo

BBS Clinics Update

Julie Sales

As many of you may be aware and for those who are not, I have been part of the LMBBS Management committee for 16 years, a year after both our daughters Danielle and Hollie were diagnosed by Professor Phil Beales. Kevin, my husband, has also been our treasurer for many years too.

Danielle was diagnosed at six years old and Hollie at age three. As you know, it is a tough ride in the beginning, coming to terms with a diagnosis, feeling both relief and dread. The girls have been through many different challenges over the years and we wouldn't have coped without the support of our LMBBS family and of course our own family.

For the past four years, I have been a part of the BBS clinics team, working closely with Tonia Hymers and the four centres. Both Tonia and I are Family Support Workers/Clinic Coordinators; I look after the adult services at Guy's Hospital, London and Queen Elizabeth Hospital, Birmingham and Tonia looks after the Children's services at Great Ormond Street Hospital, London and Birmingham Children's Hospital. If at any time you require any further information regarding the clinics, feel you need to be seen, or are anxious about BBS please do not hesitate to contact one of us. Our contact details are on the back of this newsletter.

Across the four hospitals and over the past four years, we have worked with some great teams and together, we are now building up more expertise and understanding of BBS. At times we have had challenges, but on the whole, these become less as the years go by. It is great to see our clinician's expertise and experience with BBS grow, and we have seen many of the more obscure aspects of BBS, previously unrecognised, now being acknowledged, which is very promising for the future treatment of BBS.

We had our first transitional clinic in March 2014 at Guys Hospital, London, where nine of our patients from Great Ormond Street Hospital moved across to the adult service. We informed our patients and their parents well in advance of the clinic with transitional information and communicated with the families to ensure they felt comfortable with the move; it was a great success. We aim to have the same service in place for patients moving from Birmingham Children's Hospital to Queen Elizabeth Hospital this October, with seven patients transferring across from the children's service.

We have seen a steady increase in patients over the years, starting in 2010 with around 200 patients across the four centres, to around 468 today. We still have regular referrals to both our adult and children's services; Professor Beales feels that there will be around 20 babies born every year with BBS. On the clinics database we have 295 patients for the adult service and approximately 173 on the children's service. We have increased the capacity and number of clinics to try and accommodate the increase in patients. Guy's now have 8 clinics per year accommodating 11 patients per clinic, with appointments running at around 18 monthly. QEH now have 7 clinics per year accommodating 9-10 patients per clinic, with appointments running at around 15-18 monthly. Both GOSH and BCH have 8 clinics per year, seeing 6-7 patients per clinic with appointments running at around 18-19 monthly. As you can see we have grown quite significantly over the past four years, so please bear with us. If, however, at anytime you are anxious about your appointment, please do not hesitate to contact one of us.

We are very pleased to have a rolling contract with NHS England, which means we will not have to put in a new bid, however, the downside to this is that there will be no increase in our funding for the foreseeable future. This can sometimes hinder the amount of time we would like to put into our roles, and at the moment no extra staff can be employed to assist. On a positive note, we do have a great team of volunteer helpers available for each clinic date; if you are interested in joining this team, contact either myself or Tonia. We of course pay expenses for the day, and hope to continue to build up a good team to support us and our patients.

Also very positively, the LMBBS have succeeded in obtaining a grant from Genetic Disorders UK as part of their Jeans for Genes campaign for 2014. This will help us to continue to support families outside of the clinic setting. The grant is to enable us to employ a Child Development Worker to provide specific support and activity opportunities for our families and young people. Details of this grant will be covered elsewhere in this newsletter.

Both Tonia and I are very passionate about our roles within the clinics and the Society. Like many of you, we are very aware of the need for support with the many aspects of this

medical condition. The clinics have made us both aware of the lack of support many individuals and families experience with regards to local authorities and benefits agencies, and understand that this can cause as much stress as BBS itself. This was one of the reasons we put together our BBS Benefit and Social Care Assessment, which we send out to patients before clinic to complete. If you feel you would benefit from this support, complete and return the assessment and we will do our best to help, be it regarding benefits, school referrals, social services, leisure activities and so on. If any extra support is needed from our BBS Clinicians, such as a supporting letter or phone call, we are happy to contact them on your behalf. They can often help in areas such as housing, benefits, eye classifications, social services, schools, blue badge applications and so on.

We have certainly found over the past year that there are many areas that we have been able to help, and we are both very happy to support you where needed. It has certainly broadened our knowledge in many areas and we have extended our learning further by attending a benefit training course. We will continue to attend such courses, especially in connection with the many changes ahead that we will all have to bear. We continue also to attend conferences, seminars and other training courses to further our knowledge. I am speaking at the Rare Disease Information Day on the 21st June 2014 at QEH, Birmingham, to clinicians from QEH plus patients and families living with a rare disease. I hope to promote LMBBS, the clinics and tell the story of our journey with Danielle and Hollie.

Change of Address

If you move house, please remember to pass on your new address to everyone involved in your or your child's health care. Many people don't realise that the computer system at their GP surgery is not linked to the hospital where they receive specialist care. Likewise, if a patient notifies their hospital, this information will not necessarily be passed on to other health care bodies. So, if you move, let your GP know, let your hospital(s) know and let us at the LMBBS know.

Congratulations Helen

We are thrilled to report that Dr Helen May-Simera has been chosen to receive the Sofja Kovalevskaja Award. This prestigious award allows the successful applicant to spend five years building up a working group and working on a high-profile, innovative research project of their own choice at a research institution of their own choice in Germany.

Helen was first introduced into the world of LMBBS when she did her PhD with Professor Beales at the Institute of Child Health, London; during that time she was investigating the molecular and functional basis of the syndrome. In 2008 she moved to Washington DC to continue her research at the National Institute of Health. She moved to the National Eye Institute (still in Washington DC) at the start of 2012 because she wanted to focus on aspects of the disease that more directly affect BBS patients.

Applicants for The Sofja Kovalevskaja Award must be successful top-rank junior researchers from abroad, have completed a doctorate with distinction in the last six years, and have published work in

prestigious international journals or publishing houses. Helen will be starting her own research group looking specifically at cilia in the eye and possible treatment options.

Helen attended her first Weekend Family Conference in 2004 and despite being based overseas for the past six years, has only missed one conference in that time. She would like to thank all of her friends in the BBS family for their continued support which allows her to stay motivated in the lab.

Many congratulations, Helen, we are all right behind you.

The first ever UK Strategy for Rare Diseases

In June 2009, the UK adopted the Council of the European Union's Recommendation on an action in the field of rare diseases. This document recommends that member states 'establish and implement plans or strategies for rare diseases' and that these should be adopted 'as soon as possible, preferably by the end of 2013 at the latest'.

Since this Recommendation was adopted, Rare Disease UK (RDUK) has been working to ensure that the UK develops a strategy that is comprehensive and effective, and accurately reflects the needs of the rare disease community. In November 2013, RDUK was pleased to welcome the UK Strategy for Rare Diseases.

Key features of the UK Strategy include:

- ✓ a clear personal care plan for every patient that brings together health and care services, with more support for them and their families;
- ✓ patient centred, coordinated approach to treatment services, specialist healthcare and social care support;
- ✓ evidence-based diagnosis and treatment of rare diseases;
- ✓ help for specialised clinical centres to offer the best care and support;
- ✓ better education and training for health and social care professionals to help ensure earlier diagnosis and access to treatment;
- ✓ promoting the UK as a world leader in research and development to improve the understanding and treatment of rare diseases.

To achieve the UK-wide vision for rare diseases, there are 51 recommendations which all four countries of the UK have committed themselves to deliver by 2020. These recommendations can be accessed via: **www.gov.uk/government/publications/rare-diseases-strategy**.

RDUK, in conjunction with the Department of Health in England and Great Ormond Street Hospital (GOSH), held an event to mark the publication of the UK Strategy. The event was an excellent opportunity to find out more on the UK Strategy and network with those interested in the field of rare disease. A number of high-level speakers presented, including Earl Howe, Minister in charge of rare diseases, Dr Mike Berwick, Deputy Director of NHS England and Alastair Kent OBE, Chair of Rare Disease UK.

Earl Howe announced key themes in the UK Strategy, stating that a priority of the Strategy is to empower patients; ensuring that patients are listened to, informed and consulted every step of the

way. The Minister confirmed the Government was committed to working closely with patient groups and others to improve services for those affected by rare conditions. Dr Mike Berwick, Deputy Director of NHS England, presented on the action NHS England will take in order to achieve the 51 commitments in the UK Strategy. He noted that the NHS would work with a number of partners, including RDUK to hold scoping and engagement events throughout the next three months, inviting all stakeholders (including patient groups, industry, clinicians and commissioners) to attend.

Patients, clinicians and members of the public will be asked for their views on the top priorities before NHS England sets out its plan. A statement of intent will be published on February 28th 2014 and the final plan is due to be released in July 2014. Alastair Kent OBE, Chair of Rare Disease UK, welcomed the UK Strategy for Rare Diseases, stating that patients can now have a clear expectation of what the NHS aspires to provide for them, wherever they live in the UK. He stressed that that the UK Strategy is just the beginning of the process and we must now focus on the implementation.

Before the presentations Earl Howe had the opportunity to meet with a number of experts based at UCL Institute of Child Health (ICH), including Professor Phil Beales, who then accompanied Earl Howe on a tour of the research laboratories at the ICH.

Rare Disease Day 2014: Join Together for Better Care

Rare Disease UK held receptions in England, Scotland and Wales to mark Rare Disease Day 2014. They also worked with colleagues in the Northern Ireland Rare Disease Partnership (NIRDP) to hold an all-Ireland event in Belfast. Rare Disease Day provides the rare disease community across the world with the opportunity to increase awareness of rare diseases and highlight this public health priority to governments and health departments. Rare Disease Day focuses on care and encourages everyone in the rare disease community to join together for better care. Caring for people living with a rare disease has many facets. Some patients have access to medicines while others have no treatment available. Some patients are fairly independent while others require intensive physical assistance and equipment. Care can consist of special equipment, expert medical consultation, physical therapy, social services, medicines, respite for family members and much more. For most children and adults living with a rare disease, primary care is provided by family members. For more information on Rare Disease Day please visit: **www.rarediseaseday.org**.

This article has been adapted from one first appearing in the Genetic Alliance Winter Newsletter. Our thanks go to Farhana Ali, Public Affairs Officer and Rare Disease UK Secretariat, for allowing us to reprint.

farhana@raredisease.org.uk

Remploy

Remploy's mission is to transform the lives of disabled people and those experiencing complex barriers to work by providing sustainable employment opportunities.

They achieve this by:

- ✓ Creating equality in employment
- ✓ Facilitating access to sustainable employment and careers

- ✓ Enabling people to achieve their ambitions and maximise their potential

Since 1946, Remploy has been providing employment and support for disabled people and a large network of factories was developed in the 1950s and 60s employing disabled people.

But as the economic climate became more difficult for manufacturing and society began questioning whether it was right for disabled people to be employed in segregated workplaces, Remploy started developing employment services which supported disabled people into mainstream jobs working alongside non-disabled colleagues.

They understand that work is a key element of an independent and fulfilling life, and that everyone has skills and abilities to offer. They work extensively with people to help them to identify, develop and make the most of those abilities. To achieve this goal, Remploy has invested significant resources into supporting disabled people and those experiencing complex barriers to work into mainstream employment. They have a network of more than 64 town and city centre branches and offices and a comprehensive range of tailored support services provided through them.

Remploy recognise the fundamental role that employers play in delivering sustainable employment. They also recognise that employing disabled people delivers real social and economic value for business. So, by helping employers to better understand and act upon the benefits of employing disabled people through their range of Business Services, in effect transforming business, they can help to transform the lives of individuals.

Through Remploy, individuals can access careers advice, personal training and development, support from advisors and other organisations which can help people overcome the barriers they may face, a friendly community where individuals can chat with those going through the same experiences and lots of other useful tools aimed at helping people achieve their goals.

In the last four years Remploy Employment Services has found more than 50,000 jobs in mainstream employment for people with a range of physical, sensory and mental disabilities and other disadvantages. Remploy Employment Services is partners with more than 2,500 of the country's biggest employers including BT, ASDA, Royal Mail, Sainsbury's, the NHS and Marks & Spencer.

Remploy may be able to provide a number of options tailored for individual needs, including access to work, vocational assessments, job coaching, mental health support, employer liaison, courses and so on. They also continue to support individuals after they have gained employment though their 'In Work Support Program'. Remploy currently undertake referrals from the Job Centre through a Disability Employment Advisor.

For more information, go to: www.remploy.co.uk

Sugar and Diet

Diets have been a hot topic in the media again this year, with lots of debate about whether it is reducing the amount of sugar in our diet or reducing the amount of fat that is the key to help us lose weight and maintain a healthy body weight in the long term. For this article I thought I'd focus on sugar and then in the next newsletter look at fat.

What is sugar?

We all probably have a bag of sugar in our cupboard for baking and we know exactly what to look for at our local supermarket when buying sugar. However, did you know that sugars are found naturally in most foods? Lactose is the sugar found in milk and milk products and fructose is the sugar found in fruit. These naturally occurring sugars in foods are ok to include in our diets, as we get other important nutritional benefits from the food that contain them. Milk is an important source of calcium for us which helps keep our bones strong. Fruit is a rich source of vitamins which are needed in so many ways to keep our bodies healthy.

We know when and how much sugar we use at home when we are cooking, but we don't always appreciate how much is added to foods that we buy. Sugar is added to many manufactured foods, for example sweets, chocolate, cakes and drinks. Sometimes it can be added to foods that you would not expect, or in larger amounts than you would imagine. Certain flavoured waters have a large amount of added sugar making them not so different to a fizzy drink! Food manufacturers sometimes 'hide' sugar in foods by using names that we are less familiar with.

Sugar in one form or another has been added to a product if you spot any of the following in the ingredients list:

- ✓ **Fructose**
- ✓ **High Fructose Corn Syrup**
- ✓ **Golden Syrup**
- ✓ **Molasses**
- ✓ **Treacle**
- ✓ **Glucose**
- ✓ **Sucrose**
- ✓ **Maltose**
- ✓ **Corn Syrup**
- ✓ **Honey**
- ✓ **Hydrolysed Starch**
- ✓ **Invert Sugar**
- ✓ **Raw/Brown Sugar**

When you read a food label to see what ingredients a food contains, the ingredient found in the largest amount will be listed first. Sometimes manufacturers are even sneakier at hiding

added sugar in their foods by using several different types of 'sugar' in one product. Looking through my cupboards I found the following foods as examples:

Flapjacks: oats, golden syrup, vegetable oil, sugar, butter, dried apple pieces, natural flavouring, salt

Marshmallow Chicks: sugar, corn syrup, gelatine, potassium sorbate, natural flavours, blue colouring and carnabua wax

The Marshmallow Chicks have remained hidden in my cupboard since a friend brought them back from America. I just can't feed my children anything that blue! Reading the ingredient list you can see that they are basically just sugar - the gelatine and additives will only be used in very small amounts.

Has 'added' sugar always been part of the British diet?

Sugar is mentioned in historical documents much earlier than you would think, however, initially sugar was very expensive and so not part of the diet for the majority of the population. By the 1800s the average Briton was eating 8kg of sugar a year but this increased to 40kg by the 1900s. It wasn't until after the Second World War that our intake of sugar increased more rapidly. From this time, our dietary habits changed significantly as we had access to mass produced convenience foods.

Today our lifestyles and shopping habits have changed enormously which impacts on how and when we eat. Food manufacturers are constantly developing new products based on the latest food trends and the market for 'healthier foods' is huge. Manufactured healthy options aren't always as good as you may think. Did you know that 'low fat' foods often have extra sugar added to keep them tasting as good as the higher fat version?

Is sugar a problem for our health?

There is evidence in the literature that too many sugary drinks (cola and lemonade) is linked with obesity - and just changing this aspect of a diet has been shown to achieve weight loss. Sugary foods and drinks are also linked with tooth decay.

There has been lots of research about different types of diet and ill health risks, for example, looking at risks of heart disease or diabetes. However, it is very difficult to look at one element of a diet or lifestyle in isolation. Certainly it is true that if you are overweight this increases your risk of type 2 diabetes and heart disease. We do know that if we eat more energy (calories) than our bodies burn off through activity we will gain weight and this increases our chance of getting certain diseases.

Are all the low sugar or low carbohydrate diets that have been in the news the same?

No! Sugar is a carbohydrate food but so are starchy foods like potato, pasta, rice and chapatti. Please discuss any 'wonder' diet cutting back on carbohydrates you have heard about with your clinic dietitian before trying it. Some diets which dramatically reduce carbohydrate intake can result in other health problems because you eat more fat and protein rich foods. This type of diet may not be medically suitable for you; especially if you have kidney problems. There are also unpleasant common side effects with low carbohydrate diets including bad breath, headaches and constipation.

We can all change our diets safely by honestly reassessing our portion sizes and the proportions of different food groups on our plates. If your lunch and evening meal plate is covered by an equal amount of protein (meat, fish, eggs or pulses), starchy carbohydrates (pasta, rice or potato) and vegetables - try swapping to have half of your plate covered with vegetables instead. This will reduce your calorie (energy) intake without making you hungry so allowing you to lose weight slowly over time. If we lose weight slowly and steadily, it is much more likely that this weight loss can be maintained in the long term.

There is no need to cut down on most 'natural' sugars in food. These foods ensure we get adequate essential nutrients to keep us well. It is well worth cutting back on added sugar in our diet to help control our weight. High 'added' sugar foods include sweets, chocolate, sweet biscuits, cakes, puddings and sugary drinks.

How can I cut down the amount of 'added' sugar in my family's diet?

Drink choices

If you regularly drink sugary fizzy drinks or squashes - try a simple swap to diet, sugar free or no added sugar drinks. Remember water is sugar and calorie free which makes it the perfect drink for between meals.

How much fruit juice or smoothie do you drink each day? One serving is actually only a small glass full (125ml) - this amount can also count towards your 5-a-day. If you drink more, it won't count as another portion of fruit and vegetables as you're not getting the fibre or other health benefits from the real thing! Fruit juice contains more natural sugar than you may think. Try squeezing oranges at home to see how many you need to get a glassful of juice - it will be far more than you could eat in one go! Fruit juices and smoothies actually have a very similar calorie content to fizzy drinks - understanding this may help you stick to just the one glass a day! Try water or sugar free squash as an alternative cold drink instead. For small children always remember to dilute juice with an equal amount of water

Do you take sugar in your tea or coffee? Why not try cutting back by a very small amount each week, even a quarter of a teaspoon less is a good start! Try to cut back further every couple of weeks. If you can't drink tea or coffee without any sugar, try a low calorie sweetener instead.

Breakfast choices

Do you have a cupboard full of chocolate flavoured or sweetened cereals, for example, Crunchy Nut Cornflakes, Sugar Puffs, Chocolate Weetos, Cinnamon Grahams or your supermarket's own varieties? If you look at the nutritional information on the label you may be surprised about how much sugar they actually contain.

It is worth thinking about the wholegrain unsweetened cereals that you and your family like - try swapping to these, for example, Cheerios, Shreddies, Porridge oats. You could initially have the unsweetened cereal alternate days, then try eating these an extra day each week until you only buy these types!

If you don't really like any unsweetened cereals - and, for example, you only love sugar coated cornflakes - try buying plain cornflakes as well and mixing an equal amount of each cereal in your bowl. Over time try cutting down the amount with added sugar - this will gradually cut your calorie intake and may also save you some money!

Do you add sugar to your breakfast cereal? Try gradually reducing the amount added until you can stop it altogether. If you can't stop, try an artificial sweetener or adding dried fruit to sweeten the cereal instead. A handful of dried fruit will also count as one of your 5-a-day and the added fibre may help you feel fuller for longer too which is a great bonus.

Do you have jam, marmalade, syrup or honey thickly spread on your toast? Trying cutting back a little. A sliced banana on toast spread with a little low fat spread is a great breakfast idea and also counts as one of your 5-a-day too.

Snack choices

If you are baking your own cakes or biscuits - cut back a little on the amount of sugar in the recipe and you will be amazed about how good it still tastes. You could also add some sweetness using dried fruit pieces to replace some of the sugar. Before you try though, meringues will not work with less sugar!

If you usually have two biscuits - cut back to one and try choosing plainer types without added chocolate, jam or a cream filling.

A slice of malt loaf, a small scone with low fat spread or a currant bun are lower calorie choices for occasions when you need something sweeter.

Don’t forget savoury snacks. A small pot of hummus with carrot or celery sticks, a handful of plain popcorn or a few breadsticks are all great options.

Fruit or fruit based snacks (there are lots in our supermarkets designed for children) are always great choices.

It can be sensible to set a ‘treat allowance’ to help keep your snack food intake in check. If you want more snack ideas ask your dietitian in clinic for more ideas.

Dessert choices

Tinned fruit in natural juice is a better buy than syrup or ‘light’ syrup.

Make a fruit salad with lots of different fruits - the more exotic the better.

Rather than making a syrup - use sugar free lemonade or a small amount of fruit juice.

Don’t ever offer second helpings of puddings at home. If you have made a large dessert like a fruit crumble, freeze leftovers as soon as it cools so you are not tempted to eat it later in the evening.

If you are eating a meal out for a special occasion - consider sharing a dessert. Order one pudding with two spoons.

Watch your portion sizes - kids’ portions should reflect their size and not be the same as the adult’s.

Look at ‘low sugar’ products carefully!

Sometimes these products can be more expensive than the regular choice. At my local supermarket their own brand of reduced sugar jam was twice the price of their ‘ordinary’ jam if you calculated the cost of each per 100 gram!

Some products aren’t that much of a sugar saving and watching your portion sizes of the food would work equally well.

Are artificial sweeteners safe?

All the low-calorie sweeteners used in the UK have been tested and approved as safe. Artificial sweeteners include aspartame, sucralose, sorbitol and acesulfame K. These are used commonly in sugar free drinks, sweets and low calorie desserts including yoghurts.

Consuming too much of certain sweeteners like sorbitol may lead to unpleasant side effects. You may have noticed that some sugar free chewing gum or sweets are labelled with 'excessive consumption may produce laxative effects.' It is certainly worth following this advice rather than ending up spending too much time on the toilet!

The European Food Safety Authority has recently announced that aspartame poses no health risks at 'approved consumption levels'. The current European Union 'acceptable daily intake' level for aspartame is 40 milligrams per kilogram of body weight. One can of diet fizzy drink contains approximately 180 milligrams of aspartame. So a 12 stone (approximately 76kg) adult would need to drink more than 16 cans to exceed this amount.

Before going wild with diet soft drinks, remember they may make you crave other sweet or sugary drinks so are best kept as one of your drink options. Try to drink some water too. For young children it is worth keeping diet fizzy drinks only for special occasions - especially drinks containing caffeine, if you want them to go to sleep at bedtime!

If you have any queries, please contact your clinic dietitian who will be happy to help.

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From Northampton to Norway
Steve Burge

In 2012, at our annual Family Conference, we were privileged to have Richard Ødegaard and his colleague visit our conference from the BBS Norway group and spend time with us over the weekend. For me this was a meeting of minds, as Richard is of around the same age, we both have BBS and are both the Vice-Chairman of our respective groups. Meeting Richard was a very special occasion for me, as for those who know me always assume that I am a very strong person who copes with life very well - I am, but sometimes I need someone to talk to as well and Richard and I hit it off straightaway and have become very strong friends.

During one of our relaxing periods in the bar at the conference in 2013, Richard asked if I would travel to Norway and speak at their annual conference and of course, the chance to go to Norway and sample fine Norwegian beer and meet new people with BBS was not a chance to be ignored. It was also a chance for me to have some much needed time away from all the madness of my busy life for a couple of days.

So on the weekend of the 5th March, I left Rufus with my mum and Gordon, and together with my trusty white cane, trundled off to Heathrow to catch the afternoon flight to Oslo. The usual stuff of checking in and getting around the airport was easy due to the kind help of British Airways staff. As someone who is used to flying a lot on their own, I never really get nervous of flying but sometimes I do get a little nervous trying to find my luggage at the other end. This time, I had planned for it by getting the BA staff to put priority stickers on my bags; sometimes being blind has its benefits when getting a little extra assistance than you would normally be entitled to!

A glass or two of wine and a two hour flight landed me in the cold, but very friendly city of Oslo. I had not been before, so this was a first and I wondered what was going to be in store over the course of my trip. I found my bags easily, the staff were very helpful and I managed to clear customs quickly - then the fun really began. I could not find Kjell who was meeting me and eventually, after much confusion, I managed to find him via a trip to the nearest bar. I always find that when you are disabled and travelling on your own, the word for beer is always generally a common understandable necessity.

Once I had hooked up with Kjell and his other colleagues, we proceeded to our taxi and travelled out of the city toward our destination, a trip of around 45 minutes to the Hurdal Vision and Activity Centre where the conference was to be held. The building is amazing and is a great hub of people all either blind or partially sighted in supported training and living. They have all sorts of projects running, including a music centre and an amazing sports centre with pool and fitness suite.

After checking in to my room, a basic but very warm room and my home for the weekend, I unpacked before meeting a lovely person called Maria who helped me out a lot over the weekend as a sighted guide. She had a lovely guide dog, so it was interesting to see how assistance dogs work in Norway. We went for dinner and I was introduced to the delegates and made to feel very welcome.

We moved to the conference room for the first session on the Friday evening. All sorts of thing were discussed and I did not understand most of it, as it was all in Norwegian, but a great guy called Ove who helped me over the weekend with translation, translated for us and we got told off for making too much noise, now does that sound like me? - honestly!

After a couple of hours, we exited to the bar and I was introduced to the great Norwegian delicacy called Aas beer along with several Jagermeisters, it was a flowing evening. I eventually got to bed in the small hours and awoke to the sound of people bustling around the centre, so decided to get up. At 8am, I was picked up by Kjell and Richard for breakfast, which was not what I am normally used to. There was lots of cheese and meat and some interesting goat's cheese which was nice, with loads of apple juice and hot coffee.

Between 9.00am and 10.30am I decided to take a well earned break and relax in my room with some coffee until I had to give my speech at 10.45am. I was nervous as I do not speak the language and I was worried that I would not be able to convey to the delegates, my experience of BBS and the work of the charity in the UK. Both Kjell and Richard made me feel at ease and we had two other people translating, so in the end it turned out really well.

I started by telling the audience about my life and my experience, both good and bad, growing up with BBS in the UK. There are good points and also very low points but not so many low points these days.
I spoke for around 40 minutes, pausing every few minutes to allow for translation. After a while, I got into a routine of talking and then waiting for the guys to translate and then moving onwards with the talk. Next, I moved on to my role in the Society and explained the work of the clinics and also the role of our family conferences and the privilege of becoming Vice-Chairman in 2013 at our annual AGM. I finished my talk by speaking about some of the challenges of having BBS and being blind and living in the UK and after a lot of talking and questions, it was evident that there were a lot of similarities.

During the evening, there was a much more formal dinner than what we are used to at our UK conference. We were all dressed up and it was great – there is a photo on my Facebook page, and reprinted here, of myself, Richard and Kjell after the dinner, all three a little worse for wear after a

lot of red wine. We spent the evening talking and laughing and everyone tried out their English, as they do not get that much chance to practice, so it was great fun; we were all exchanging funny stories and a great night was had by all.

Sunday morning I awoke to the sound of vacuuming, so I decided to get up and have breakfast. By now I was familiar with the layout of the hotel so was getting around ok with my trusty old white cane; it felt comfortable but I was missing Rufus like mad. I spent Sunday morning relaxing with the delegates, laughing about the antics from the night before and then found out we had two more hours of talks! I was in shock as at our conference we chill out on the Sunday and go home. The AGM took two hours so I decided to go and find more coffee and some more lovely goat's cheese. The language barrier was now proving to be a bit too much, so I decided that a sleep before my flight would be a good idea.

The journey home was interesting: I had a taxi ride to the airport and Kjell left me with airport assistance who then abandoned me in the middle of customs! I had to kidnap a British Airways girl which was great fun, as she was off duty and heading to the bar! She helped me to my flight and got me a seat at the back of the plane with her colleagues who were working the flight; they gave me a cup of tea before we took off and wine on the way home.

Rufus was very pleased to see me and so were my parents who were glad to have me home safe.

I had a cracking weekend - if you get the chance to go and visit the gang in Oslo, go, and enjoy their kindness.

Steve Burge
Vice Chairman.

We hope you have enjoyed this newsletter, if you would like to contact us about any of the articles, or to submit an article of your own, the addresses can be found at the end.

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