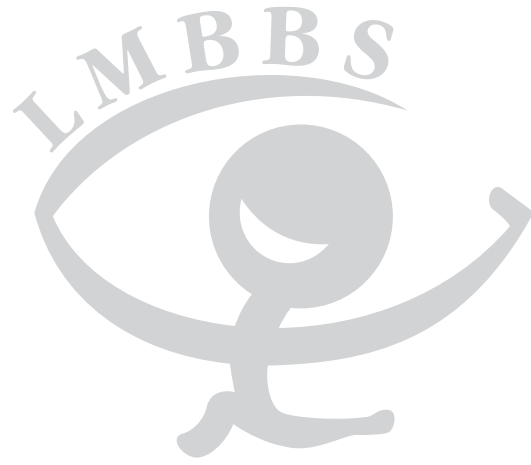


Laurence-Moon-Bardet-Biedl Society

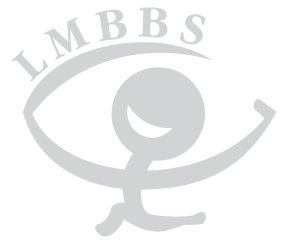
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LMBBS

Summer Newsletter

2015



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Foreword



I was delighted to be voted in as Chairman of the LMBBS Committee at this year's conference; it is a responsibility that I take very seriously and I look forward to taking the charity from strength to strength, alongside the rest of our valuable committee who work tirelessly all year to ensure its healthy future.

I would like to take this opportunity to thank both Phil and Chris Humphreys for their many years of dedication to LMBBS; I only hope that I am able to follow in their footsteps as successfully.

There are many exciting things happening within the charity at present; we have new additions to the committee and I know that all new trustees will bring the same passion and expertise to their roles over the coming months.

I have just returned from a walking holiday in Yorkshire with my brother Timmy; Rufus and I had a lovely time. I cannot believe that Rufus is three years old already; he is turning into a great guide dog and our partnership is now well on the way to the success that is possible, when you welcome a guide dog into your life.

I do hope you all enjoy the rest of the summer and whatever you are up to, live life to the full and enjoy every minute.

Notifications

Ali Bokhari

On 6th October 2014, we received the very sad news of the sudden passing of Ali Bokhari, son of Mr Ashiq and Mrs Hafeez Bokhari of Birmingham. The family have been members of the Society for many years and have attended several weekend family conferences. Our love and condolences go to all the family.

Terry Crotty

It was with sadness that we said goodbye to Terry Crotty, LMBBS Trustee and family member, on 8th June 2014. His wife, Anne, pays the following tribute:

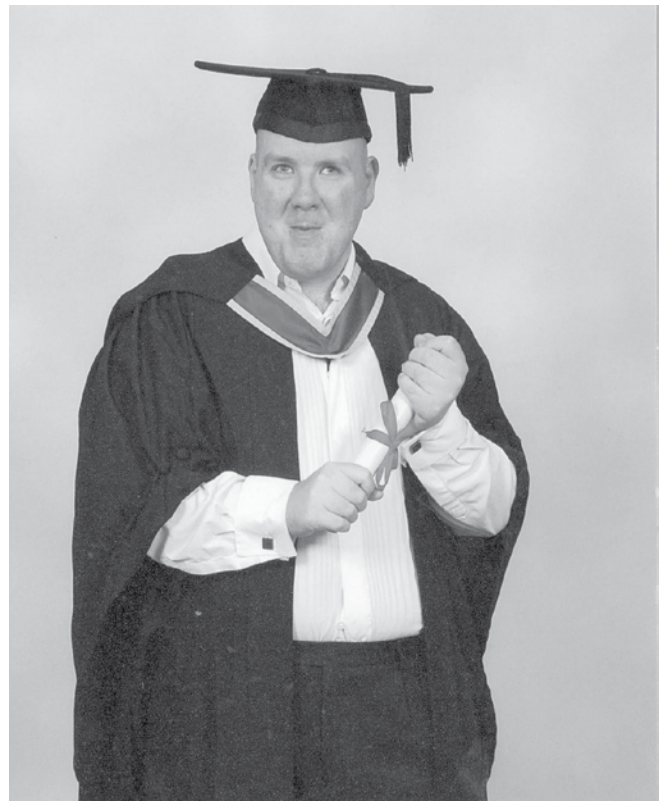
"Terry was loved and respected by people of all ages and from all walks of life. His motto when training fire service recruits was to be "Firm, Fair and Friendly" and the many tributes received since his sudden death at home on 8th June 2014 have shown that he continued to live with those guidelines."

Love and condolences to Anne and family, from everyone at the Society.

Mrs Anuradha Kochar

In January 2015, we were deeply saddened to hear that Mrs Anuradha Kochhar, a lovely gentle lady who regularly attended conferences with her son Abhimanyu, passed away in hospital after a short illness. Our love and condolences to Abi and all the family.

Terry Begley BSc



Congratulations to Terry Begley who graduated with a BSc in Computer Science on the 18th July 2014. Terry's mum, Margaret, writes, 'we are so proud of him, he has been through a lot this past two years...' Congratulations Terry, what a fantastic achievement!

Welcome Baby Luke



Our congratulations go to Helen (May-Simera) and Chris on the birth of beautiful baby Luke, who arrived in April, weighing 6lb 8oz. Helen writes:

"I was so sorry that I had to miss the conference this year, but as many of you may know I had a good reason. A few days after the conference my baby boy Luke was born. He made me wait a good few days past his due date and not being a very patient person it was driving me crazy. Now that he is here I can't imagine a life without him. I can't wait to bring him and my husband Chris to the conference next year, so that they can get to meet the LMBBS 'family'. Maybe Luke will manage to do something that I have never done and that's go to Drayton Manor one year.

The other news is that I have now moved to Germany and am starting to set up my own research group working on BBS. Things are going slow and steady, but I have two people recruited

already and I am really excited to get the ball rolling when I return to work in a few weeks. If anyone wants to visit in the future you are always welcome. With love to all and see you in April 2016."

We send much love and very best wishes on behalf of everyone at LMBBS.

LMBBS Annual Family conference and AGM

The LMBBS Annual Family Conference 2015 was again a resounding success, thanks to the dedication and attention to detail of our Conference Organiser, Chris Humphreys. It was also a very emotional weekend as it was Chris' last as a Trustee and as Conference Organiser. A full report of the weekend will be out late summer, however we just wanted to take the opportunity to say a heartfelt thank you to Chris on behalf of everyone she has supported over the years. There were many other changes to the Board, and we also said 'good bye' to our Chairman, Phil Humphreys; Treasurer, Kevin Sales; Julie Sales and Tonia Hymers who all retired as Trustees. Our love and thanks go to them all. Kevin, Julie and Tonia will continue in their BBS Clinics roles and will support the new Board of Trustees over the coming year. We therefore have a new board in place and would like to say 'welcome' to:



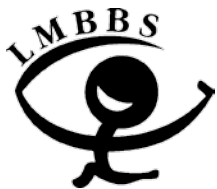
Steve Burge: Chairman
Richard Zimble: Vice Chair
Laura Dowswell: Treasurer
Emma Oates: Fund. Co-ord.
Allan Clark: Trustee
Stefan Crocker: Trustee
Dianne Hand: Trustee
Rob Hymers: Trustee
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07833 228463
07791 428302
07966 574461
07861 770164
07795 265991
07766 316266
07980 404879
07905 056666
07774 208008

steveburge@live.co.uk
richard.r.zimble@btinternet.com
laura_dowswell@yahoo.co.uk
ejoates@btinternet.com
Allan.Clark@west-dunbarton.gov.uk
rincewind101@hotmail.co.uk
diannehand@live.co.uk
roberthymers@btinternet.com
gplongly@gmail.com

There are two vacancies on the LMBBS Board of Trustees. If you feel you have the skills and experience to offer the charity, please contact Tonia Hymers who will send you the LMBBS Trustees Information Book for further information (toniahymers@btinternet.com or 07805 685342).

LMBBS: Change of Name



It has become apparent over the past few years that the name of our charity, 'Laurence-Moon-Bardet-Biedl Society' is out of date. The name was chosen by the founders of the charity

because it incorporated all variations of the name given to the Syndrome at the time. The medical establishment now consider the condition to be Bardet-Biedl Syndrome and all referrals are made in this name, which means many patients, families, medical and educational professionals who are trying to find support and information often overlook the Society.



At the 2015 AGM, the Board of Trustees proposed that the charity change its name from the Laurence-Moon-Bardet-Biedl Society to Bardet-Biedl Syndrome UK. The delegates voted unanimously in favour of

the change, which will take place over the coming months. The Charities Commission has been notified and other changes will include an updated website, which will be under: www.bbsuk.org.uk, and a new logo.

Success for Maria



Maria Dowswell has always loved horses and has loved riding since the age of 10. From a young age, Maria has been determined to pursue a career in the equestrian world, which is quite remarkable considering she was diagnosed with retinal dystrophy at 13 years old and later with Bardet-Biedl Syndrome.

Maria said: "I studied at Bicton College for four years, and I was really nervous when I started, like everyone is, but I settled in instantly and really enjoyed it. My riding came along really well and the teachers really helped my confidence. I chose Bicton College because it offered me the course that I wanted to study with horses and the support that I needed because of my visual impairment.

After I completed the level 2 BTEC diploma in horse care I wasn't too sure what to do, as it's quite a leap from level 2 to level 3 and my sight was getting worse, so I decided to do a subsidiary diploma, and then went on to do my level 3 extended Diploma in Horse Management."

Maria understood that to pursue a career with horses, she would need work experience, which is how she ended up at Otterdene Equestrian Centre. Polly Edwards, owner of Otterdene Equestrian Centre, said: "Maria contacted me offering to do a voluntary week's trial. I thought I would give her a chance and I haven't looked back! She's one of the best working pupils we've ever had, I have no worries with her; she just gets on with everything and does a fantastic job."

Alex Robinson-Barr, Head of equine at Bicton College, added, "Maria is such an inspiration to all of us; I can't express how proud I am of her to be working in industry while also continuing with her British Horse Society Stage 1 training course."

For more information on the range of courses available at Bicton College visit the website: www.bicton.ac.uk

While Maria was studying with Bicton College, she was living at WESC Foundation, a specialist centre for visual impairment in Exeter. Below, Maria tells us about a radio show fundraiser she did last year with her partner, Harry Roberts.

Maria Dowswell and Harry Roberts: Radio Fundraiser



Some of you will know me from the LMBBS Family Conferences – I am Maria Dowswell and I have BBS; I am often talking to families at the conference about how it feels to grow up with BBS and live an independent life (I am now 21 and have recently left home).

Myself and Harry were both students at WESC foundation, a specialist college for visual impairment in Exeter, and regularly hosted a Sunday afternoon radio show. We are both severely visually impaired but manage to navigate our way round all the hi-tech equipment needed to host a live radio show.

We decided that we would like to raise money for the LMBBS charity and, with the permission of the college, we decided to do a marathon live 12 hour radio show in the summer of 2014. So on a very hot 12th July, we started broadcasting live from 9am right through until 9pm without stopping. Listeners could tune in at www.viradio.org and could phone or email the studio to request a special song to be played in return for a donation

or they could go live on air to dedicate their song to someone. There were requests for 60s music right up to current songs and we even had a request for a Des O'Connor song, which we only played because they made a large donation!

There were also quizzes during the show where listeners could phone in to guess the answer for a small donation. We had 'guess the song', 'guess the age of the pop star' and 'guess the year the song was in the charts', it was good fun.

Lots of people we know phoned in, including staff from the college, our families and friends from the LMBBS society. We had lots of phone calls and emails and just about managed to play all the dedications. Lots of people also followed our twitter feed and sent in silly photos which made us laugh. We also had live interviews with Steve Burge (LMBB Society) and Laura Dowswell (LMBBS Clinic Support and my Mum). They both spoke about the importance of the LMBB Society in supporting families, explained how the multi-

disciplinary clinics were run, and stressed the importance of raising funds for the Society. Steve did brilliantly as he has his own radio show so was used to being live on air, but my Mum was very nervous – she did really well though.

The show was streamed live from WESC Foundation's two charity shops in Heavitree and Exmouth and we gave a shout out to all the shoppers; they must have been surprised as they were browsing around the shops!

We realised that lots of people were listening across the UK and my Aunty who lives in Greece also listened in and made a request so we were international at one point. It was a very hot day, especially so in the studio, but we managed to last the 12 hours and really enjoyed doing the show.

We raised about £200 for LMBBS.

For more information about WESC: www.wescfoundation.ac.uk

1st GENETIC DISORDERS Leadership SYMPOSIUM



Genetic Disorders UK invited the LMBBS to attend their first Genetic Disorders Leadership Symposium, which was held in London across the 6th and 7th March 2015. Tonia Hymers and Angela Scudder attended the event which included a gala dinner and a full one-day conference. The dinner involved table jumping between courses, which allowed delegates to network and get to know other individuals and groups. Actor, Warwick Davis was keynote speaker and talked about his experiences of living with a rare disease. In 2012 Warwick co-founded 'Little People', a registered charity and an essential resource for the social, medical and financial needs of the little people

community in the UK. Warwick spoke with warmth and wit about his childhood and the challenges he faced and about his film and television career. He also talked about the



pain of losing his first child, who sadly inherited both parent's form of dwarfism. It was a privilege to meet Warwick and listen to his story, and to meet so many other inspirational individuals, all focused on improving the lives of those living with a rare disease.

The following day, there was an intense, packed programme, running from 8.30am until 4.30pm including over 25 speakers. Caroline Harding of Genetic Disorders UK said, 'In the UK there is great flux in all aspects of the lives of families affected by a genetic disorder. The NHS is undergoing major changes in its core structure, the benefits system is becoming more difficult to access and the new Children and Families Act 2014 will completely overhaul the way children with special educational needs access support at school. All of this change is taking place alongside advances in the science of diagnosis and the availability of treatments for genetic disorders, making it essential for those affected to better understand how the world is changing so that they can be more knowledgeable

and better empowered'.

The goal of the 1st Annual Genetic Disorders Leadership Symposium was to bring together the leaders of UK-based genetic disorder charities and support groups to create an environment in which they could learn from experts, share best practice and network. The individual talks and presentations are available for all to download on the Genetic Disorders UK website: www.geneticdisordersuk.org.

Our thanks go to Caroline Harding and Genetic Disorders UK for inviting us to attend this exceptional event, we very much hope to attend again in the future.

New Diet Crazes: are they the answer to achieving weight loss that lasts?

Every year new diets, health crazes and exercise workouts hit the headlines especially in January. New Year is typically when we make resolutions to be healthier by altering our diets or pledging to increase our activity levels. To be honest, January is not the best month for most of us to try to make big changes to our lifestyles and even small changes can prove extra challenging! It is cold and dark, both in the morning and early evening so we can be tempted to eat more and stay inside as much as possible. As the weather improves in spring and early summer we have longer hours of daylight and warmth and it is a great time to re-evaluate our lifestyles to see if little changes can be made to help us feel better in the longer term. This article will focus on some fad diets that appear to work wonders, but should be avoided at all costs, and some ideas to help us feel more motivated to move!

Fad diets are dietary plans where you are allowed to eat a very restricted diet or an unusual combination of foods for a short time with the intention of losing weight quickly. This weight loss happens as you have drastically reduced your daily calorie intake - there is nothing magic about the foods you are eating. However, as you haven't changed your regular eating and lifestyle habits, the weight piles back on as soon as you stop. This weight gain can make people feel miserable and causes some people to eat

more and gain even more weight; some end up heavier than before they started.

Fad diets are never suitable for children as compromising nutritional intake during this time of rapid growth is dangerous.

Sometimes fad diets hit the headlines as being the answer to 'easy' weight loss. Celebrities may appear to endorse a diet craze but remember this reporting may be inaccurate and they probably have a personal trainer, chef and cleaner so nothing is quite as it seems.

Warning bells should ring if a diet promises a magic weight loss solution without you having to change your lifestyle, if it is based on a 'secret' yet to be discovered, if it promises rapid weight (fat) loss or suggests that a food has a magical fat-burning effect. If a diet recommends avoiding or severely limiting the intake of a whole food group e.g. dairy products, avoids foods in certain combinations, avoids cooked foods or needs expensive branded vitamin and mineral supplements, then this diet carries a high risk that it will not be nutritionally adequate and may be potentially unsafe in the longer term. It is important with any 'diet' that you actually get to eat and enjoy food, not just drink meal replacements throughout the day. No diet recommending eating non-food items should

ever be followed!

Each year the British Dietetic Association flags their five worst celebrity diet crazes to avoid; for 2015 they recommended avoiding urine therapy, the Paleo diet, the sugar free diet, VB6 diet and the Clay Cleanse diet. Let's look at these in a little more detail:

1. Urine therapy - involves drinking your own urine for supposed cosmetic, health or well-being benefits. There is no scientific evidence for any such claims and this may not be safe. I would recommend avoiding this at all costs as it isn't going to help with weight loss!
2. The Paleo diet (also known as the caveman diet) is based on foods that can be hunted, fished or gathered presuming these are the foods that our hunter-gatherer ancestors ate in the Stone Age. This means processed foods, wheat, dairy, refined sugar, potatoes, salt and alcohol are all off the menu. Obviously it is a good thing to eat less processed foods and eat more fruits and vegetables. However there are no accurate records of our diets in the Stone Age so this isn't based on any scientific evidence. There is a really high risk of nutritional deficiencies with this diet as so many foods are avoided and it may be tricky socially too - so this is one to be avoided too.
3. The sugar free diet hit the headlines in 2014 and there are many different versions. Some recommend cutting out all sugar which is almost impossible as this means avoiding fruits, dairy products, nuts and vegetables too; others recommend sugar substitutes which are actually sugar in a different form e.g. honey, palm sugar and agave. This is another diet to stay clear of, however reducing our intake of sugary foods and drinks would be a good idea for us all. Look for sugar free, no added sugar or diet fizzy drinks and squashes. Try having a piece of fruit as a snack instead of a couple of biscuits.
4. VB6 is the vegan before 6pm diet - before 6pm on this diet plan your intake is based on beans, pulses, whole grains, nuts, fruits and vegetables and avoids all animal products e.g. dairy products, meat, fish and eggs. Being vegan doesn't necessarily translate as

eating a healthy diet and the danger here is that after 6pm you just eat anything, undoing any earlier healthier choices. It is also really important to get the balance right with this diet otherwise you risk all sorts of nutritional deficiencies and possible longer term health issues. In reality it doesn't matter in health terms when you eat different food, the balance of your diet is crucial for health and if you eat more calories than you need at any time of day you will gain weight.

5. The Clay Cleanse diet involves eating a spoonful of clay each day. Those advocating this diet claim this removes toxins and negative isotopes from the body to help you detox and stay in shape. However this is just downright dangerous. High levels of lead and arsenic have been found in clay products and the Food Standards Agency have issued a warning against eating clay, clay-based detox drinks and supplements. Avoid this one at all costs!

What about detoxing and juicing?

Detoxing has become a huge health market, with special products or juice only advocated for a few days. Remember, before trying a detox diet, that our body is well-designed with built-in mechanisms to remove waste and toxins. There is never a need to detox, however if you have over indulged it is worth cutting back a little by making healthier choices, for example, include more fruit and vegetables in your diet, drink extra water and avoid alcohol for a couple of days.

Juicing was a big story in 2014 with many trying a juicing only diet to lose weight. Including a small glass of juice in your diet every day is fine, but juicing isn't the magic answer to achieving your '5-a-day' or weight loss either. Did you know only one 150ml glass can count as 1 of your 5-a-day as you miss out on the pulp and fibre once you "juice". Even if you blend rather than just extract juice it is still important to eat your other portions of fruits and vegetables as foods. If you are making your own juice try to include some vegetables in it to limit the amount of natural fruit sugar e.g. try carrot and apple juice.

If you have heard about a diet that you'd like to

try as it has worked for family or friends, please give your BBS dietitian a call or contact your GP so that we can modify it if necessary to ensure it is nutritionally safe for you now, but that it will also maintain your well-being and health in the longer term.

So what can I do now to help me lose a few pounds?

Watching portion sizes is key. Try to fill up on lower energy dense foods like fruit and vegetables. Buy smaller portions of foods if possible and store foods where it isn't easily accessible e.g. freeze bread and get out only the amount you need each day.

It can be useful to record your intake for a few days to see if there are any situations when you eat more than usual. Is there anything you can change to avoid the situation or anything that would distract you from taking that extra biscuit? For example, if we go food shopping when we feel hungry, we always buy more than we intended to and studies have shown that we also buy more higher fat and sugary foods as we think these will make us feel better instantly. However, these foods provide a very short term energy high and then we are left feeling both hungry and guilty! Try shopping after a meal as you may find less 'naughty' foods end up in your trolley or you could consider trying online shopping as those 'too good to miss' offers at the till shouldn't end up in your basket!

The other key to weight loss is to get more active. Adults should aim for at least 150 minutes of moderate activity a week (20-30 minutes per day) and school aged children need 60 minutes of activity a day.

Fitness apps and activity trackers were also big news in 2014. More and more people are wearing activity trackers like the Fitbit Flex, Jawbone Up and Garmin Vivosmart activity tracker. These devices count your steps and download all sorts of other data to your mobile phone or computer. Talking pedometers are also available at a fraction of the cost of these activity trackers. A talking pedometer or activity tracker can be a really motivating tool to help us increase our activity levels. I have tried to find out from the internet how accessible wearable fitness trackers are for a visually impaired

person. Interestingly the Fitbit App was app of the month on the RNIB website in September 2014. (If you want to check this out go to www.RNIB.org.uk/fitbit). There were a few other individual's reviews that compared different products on the market. Using a fitness tracker or pedometer allows you to monitor the number of steps you do in a day, allows you to set a target and can allow you to compete with friends to see who can do the most - this happens with some of the apps but if you use a pedometer you can still compare, encourage each other by posting your achievements on social media like Facebook, or set up a group email between your LMBBS friends. It is amazing how much more we can do when we are getting support and encouragement from our friends and family (or just competing with them!).

I've used an activity tracker and found it really motivating. It also helped me make positive lifestyle changes. Before using the tracker I felt I was busy and active every day; well I was certainly tired in the evening! I was really surprised to find that I didn't always do 10,000 steps especially on my work days. The tracker made me always walk from my house to the train station on a 'work' day and if necessary on the reverse journey too! If I have a weekend day full of chores (washing, cleaning etc.) the tracker makes me check that I still meet my step quota and if not I do something to make sure I meet my goal.

If you were considering using a talking pedometer or activity tracker I would suggest initially recording your usual weekly activity and then setting a goal with your family, friends, dietitian or doctor... make it realistic, it is much better to achieve a small goal than fail to meet a big challenge.

I hope this makes you feel inspired - good luck!

We'd really love to know what you'd like to hear about in this diet and lifestyle section - it is your newsletter after all. If you have any dietary queries that you would like answered in a future newsletter, please send them to Tonia and one of your clinic dietitians will respond.

Direct Payments

Direct payments and personal budgets are offered by your local authority to give you more flexibility over how your care and support is arranged and provided. They are given to both people with care and support needs, and also to carers.

A personal budget or direct payment will be created after an assessment by social services. If the council decides that you need any kind of support, you will receive a personal budget and can choose a direct payment instead of letting them arrange services for you.

Why choose a direct payment?

If you need care and support, this had in the past been provided direct from your local council. Direct payments were introduced to give people more choice and control over how their care and support was arranged, to help them live more independently.

The direct payment is paid to you by the council so that you can decide how you want to meet your care and support needs. Many people choose to employ their own personal assistant, although there are many other ways direct payments can be used.

Who can have direct payments?

In most cases, if you or the person you're looking after are assessed and social services decide you need support services, they must offer you the option of receiving direct payments to arrange care and support yourself, instead of having it arranged for you. If you want a direct payment, but do not wish to manage it yourself, a "nominated person" can receive the direct payment and manage it on your behalf. If a person lacks capacity to request a direct payment, an "authorised person" can request a direct payment and manage it on their behalf.

Consenting to direct payments

You have to be able to consent to direct payments to receive them.

To give consent, a person doesn't have to completely understand how direct payments work. It is enough that a person understands that direct payments would give them the opportunity to make choices for themselves. Giving consent is not the same as being able to manage the direct payments alone. If someone is capable of giving consent to have the choice of direct payments, they may still need support to manage the direct payments.

Managing direct payments

The council should set out your obligations and responsibilities in a direct payment agreement that

you may be asked to sign. This could include:

- keeping records and accounting for how the money is spent to social services
- taking on the legal role of an employer if you're using the payment to pay for a care worker; talk to the council about local organisations who can help manage the administration and other responsibilities of being an employer

Direct payments can only be spent on things that will meet the assessed needs of the person. If you spend a direct payment on something that doesn't meet your needs, social services can recover the money from you or terminate the direct payment agreement.

Everyone who gets support from social services should have their care and support plan reviewed at least once a year. If someone's needs have changed, they should contact social services to request a review of their care plan. If needs have changed in a way that affects the details within the current plan, the council may conduct another assessment of needs, or a financial assessment.

Social services can charge for care and support. This means that you may need to make a financial contribution towards your personal budget amount. Your local social services must tell you if you'll need to contribute, and how much, and this will be detailed in your personal budget. Their charges must be in accordance with the law. Usually, the council will subtract any charge you need to pay from the personal budget amount, rather than asking you to pay.

You should be able to get help managing direct payments if you need it. Contact your local authority's social services department to find out what assistance they provide. Social services may give help directly or through a local direct payments support service.

Local voluntary organisations may also be able to provide tailored support, and Disability Rights UK has specialist expertise in direct payments.

Employing people and using agencies

GOV.UK has tips on employing someone if you decide to use your direct payment to hire a person directly. If you get direct payments and recruit a self-employed care worker or contract with an agency, you won't have the responsibility of being an employer.

You can find out whether someone is self-employed or if they count as your employee by using HMRC's employment status indicator online tool. You may still need advice on, for example, recruitment, taking references, background checks and insurance.

In some situations, employing a family member to provide care or administrative support may be an option. However, the council needs to agree it is necessary for you to use direct payments to employ a spouse or partner, or a close relative you live with. For example, during the care planning process, you may explain that only the family member could fulfil the role – for example, for religious or cultural reasons.

If you choose instead to use an agency for your care services, they will take on many of the employment responsibilities. When choosing an agency, you'll need to decide what sort of service you're looking for and the tasks you need help with. It's a good idea to contact more than one agency as they may offer different types of services. You can find out about local home care agencies by:

- asking social services
- getting in touch with direct payments support services
- contacting the UK Home Care Association
- speaking to other people who get direct payments
- contacting the Care Quality Commission, which regulates all care providers

Managing direct payments for someone else

If someone doesn't have the mental capacity to request direct payments, it's possible for an "authorised person" to request the direct payment and take on responsibility for them. This will usually be a carer, family member or friend.

An "authorised person" getting direct payments on behalf of someone else who lacks capacity must:

- act in the best interests of the person who lacks capacity
- make sure that the person has as much input as possible into decisions that affect them
- let social services know as soon as possible if it seems that the person might be regaining the mental capacity to make their own decisions

Direct Payments and BBS

Many individuals who have BBS are successfully utilising Direct Payments, using them to employ a personal assistant or a cleaner/home help. Having a personal assistant allows for much greater independence and enables individuals to attend appointments, go shopping, attend events and so on. Having a cleaner can also make a huge difference and means that instead of using that last bit of energy for cleaning purposes, it can be used to attend a social event or club instead. What many do not realise is that Direct Payments can help families and young people too and just a few hours a week can make a big difference. Having a family

helper can enable parents to spend quality time with individual children, or help out during busy times, during the school run for example. Older children benefit from being able to be independent from mum and dad and having a personal assistant can be the first step towards independence that may not otherwise happen. Below are two case studies highlighting how Direct Payments can help:

Family 1:

"I have been receiving direct payments for about a year and a half. I only get 4 hours a month for each child but in the school holidays these will be increasing. I get a budget in a separate bank account and employ two carers. You can choose anybody you want, although they have to be CRB checked. I chose two ladies from a special school. They are very good and to be honest I was so nervous the first couple of times they went out with them, I was a nervous wreck, but now I know the boys enjoy it and it gives them a break from the same routine and us too.

My boys this year have done their own Xmas shopping which is amazing, with the help of their carers obviously, but it's about increasing their independent skills and to be honest they really look forward to it each month. They take them anywhere they want to go for example: cinema, shopping, to the restaurant which is their favourite. I think it's a really important part of their life now and I'm so glad I have got it up and running, but I can understand how hard it sounds at first. When I was offered it I said 'no I don't want anybody else looking after my children', but now I know it's not just for my benefit it's for the boys too."

Family 2:

"Getting the money and hours was easy as the boys have a great social worker! We get 10 hours a week... 6 for our eldest and 4 for our youngest. Our eldest goes out most Saturdays with his Personal Assistant and our youngest has 4 hours every other Saturday. We save hours for the holidays and have also used the money for babysitting so we can have the occasional night out.

Managing the finance is easy, it goes straight into the boys' Direct Payments account... A company sorts out all the bills... tax, NI... So you just sign the cheques!

It really is invaluable for us and we know we are very lucky.... Some parents we know do not get anything!!!

If you would like to apply for Direct Payments, a social services assessment is the first step. Contact details for your local team will be available online."

Jeans for Genes Grant Programme

Supported by



In 2013/2014, LMBBS were successful with their application to Genetic Disorders UK for a grant under their Jeans for Genes programme. The grant came into effect in December and we welcomed two new members to the team at the beginning of January, Jacqueline Kearnes and Angela Scudder. Jacquie and Angela are Children's Development Workers and together they have some exciting projects lined up for the coming year. In addition, they attend the BBS clinics, providing family support, so some of you may have already met them.

Jacquie and Angela officially launched their programme at the LMBBS Family Conference in April. They introduced the Young Person's BBS Action Group, they met with families and provided information and support and introduced the BBS Programme of Events for 2015. We are particularly excited about the Young Person's BBS Action Group, which will give our young people a say in the ongoing development of BBS Clinics and the Society. Our first 'Have Your Say' newsletter will be available to download soon from the LMBBS Website.

The programme of events for 2015 kicked off with a special family day at London Zoo on Saturday 16th May. The sun shone all day and everyone had a fantastic time. In June we will be co-hosting an accessible cycling event at Herne Hill Velodrome in London, along with Wheels for Wellbeing. A second family day will be held at Twycross Zoo in the Midlands on 11th July and we also have activity weekends booked at Avon Tyrrell outdoor activity centre in September and at the Calvert Trust fully accessible activity centre in October. We will finish the year off with a fun-filled family Christmas Party at Great Ormond Street Children's Hospital. Full details for all these events are on the LMBBS website: www.lmbbs.org.uk.

Meet the Team:



Jacquie Kearns
BBS Child Development Officer

I'm Jacquie and I am very excited to be part of the BBS support team as the new Children's Development Officer. I have already attended

a few clinics and met with some families and I am very much looking forward to the conference and meeting with lots more.

I have previous experiences of working for a small charity, supporting families whose children have a rare syndrome in a very similar role. I hope to use the experience and knowledge I gained there to enable me to make a difference to children and adults with BBS and the families.

A little about me, I am married to John and have two grown up children, Matthew and Rebecca, both of whom have flown the nest but I probably see more of now than I did when they lived at home.

I have a brother who has both physical and learning needs and he is my reason for going into this field of work. I remember how my parents struggled to get support for him and them as well as an appropriate education setting with adequate resources.

I decided to study special education, specialising in multi-sensory impairment at university and worked for many years in a school for children with specialist needs, which was a fantastic time in my career and taught me how individual people are.

I look forward to meeting many individuals in this exciting new opportunity I have been given.

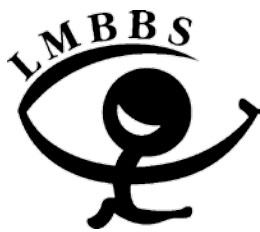


Angela Scudder
Child Development Assistant

Hi, my name is Angela (Scudder), I'm the new Child Development Assistant. I am mummy to Zac (9) and Zara (6) we live in Beckenham Kent, just south of London. Zac

has a diagnosis of BBS. He started special school two years ago which was a big step, as some of you will know. I'm pleased to say it was the best thing we have done. He's come on so much in all areas and his health has greatly improved. But as always with BBS, we take it a day at a time.

I am very excited at the programme of events we have lined up and look forward to meeting you over the coming months.



LMBBS Get Active Challenge for Children and Young People

Supported by



We are calling on all our young members up to the age of 18, to 'Get Active' with our LMBBS Pedometer Challenge. Seeing how many steps you do and setting yourself challenges can be a good incentive to get more active! Every child that takes up the challenge will get a free LMBBS goody bag including a £5 Argos voucher to put towards the purchase of a pedometer. We launched our 'Get Active Challenge' at this year's Family Conference and we have around 20 young people already taking part with fantastic results. Parents have reported a significant increase in activity levels and tell us that their child is really enjoying taking part!

To join this fun scheme, email your address to: toniahymers@btinternet.com.

What is a Pedometer?

A pedometer is a simple device used to measure the number of steps taken by a person each day. By keeping track of steps, children and young people can discover how far they travel as a result of their activities.

How Does a Pedometer Work?

When positioned correctly, a pedometer will record a step each time a person moves their hip up and down. A pedometer also measures other physical movements or actions that move the hip, such as cycling or bending to tie your shoe.

Tips on Using Pedometers with Children and Young People

Keep a Pedometer Log. We will send you a log sheet with your Argos voucher, to help your child keep a record of their activity levels. You record their standard step count for one week and then, with a baseline count in hand, your child can work towards increasing their step count.

Reduce screen time! Encourage your child to limit their "screen time". Have them track their

steps before they reduce their screen time and after, so they can see how many more steps they take.



*Skye and Ryan Hueting
Get Active*

Make it fun!

- ✓ Challenge your child to guess how many steps it will take to get to a favourite destination.
- ✓ Consider getting pedometers for the whole family.
- ✓ Keep track of the family's steps and see who has the most.
- ✓ Challenge your child to set a target daily step count; encourage them to meet or beat their goal!

Choosing a Pedometer

Choose a pedometer that fastens securely to clothing and is simple, easy-to-use and accurate. Generally, a pedometer in the 'middle' price range (approximately £8-£12) will offer an adequate level of performance. Note that lower-priced or lower quality pedometers can often lead to frustration due to lack of accuracy and durability. If your child would prefer a talking pedometer, you can buy them from the RNIB for £7.99. www.rnib.org.uk

We would love to hear about your child/young person's achievements during the LMBBS Get Active Challenge, so don't forget to keep in touch so they can let us know how they are getting on. Email Tonia at: toniahymers@btinternet.com.



Activities for Over 18s

Following our successful grant application with J4G, we have been able to develop activities and family days for our younger members which has no doubt caused some frustration for our older members. We are working on filling in this gap and it hopefully won't be long before we are offering activities and days out for our over 18 members. In the meantime, take a look at VICTA's website, which offers some fantastic activities for the 18-29 age group. Activities range from a day out at Blackpool Pleasure Beach to a four day break in Barcelona. Go to: www.victa.org.uk/2015-activities for more information.



UCanDOIT teaches people with disabilities how to use computers in their own homes, with their own computers. They also fund refurbished second hand computers, free of charge, in certain circumstances.

Training is given on a one to one basis in your own home and on your own computer. You arrange lesson times with your tutor, which can be in the evenings or at weekends. You first have an assessment with your tutor, followed by 10 sessions which last between 1½ to 2 hours each - usually one lesson a week.

Who can apply? People with physical disabilities, sensory impairments or communication difficulties.

No computer? If you do not have a computer, UCanDOIT can sometimes provide funding for refurbished second hand computers, free of charge.

Areas covered? They cover Greater London, South Wales, Merseyside, Manchester and other parts of North West England, Birmingham, Hampshire, Kent, Sussex and Scotland. In Scotland they have tutors in Edinburgh, Glasgow, Perth, Dundee, Inverclyde and South Ayrshire. Before you apply, please contact the office to confirm that their tutors can cover your area.

Cost of lessons? The cost of the course is free if your household weekly *disposable* income is £100 or less. If it is more than £100 a week charges will increase.

How to apply? You can download an application form online or alternatively, you can request or

complete a paper application form by contacting the office on 020 8673 3300. Application forms are also available in a CD format for you to listen to.

Topics covered

UCanDOIT believe that each Learner is unique and each course of lessons is designed to suit the needs and abilities of the individual. Listed below is what they expect to cover over the course of 10 lessons but one of the reasons that they are so successful is their ability to be flexible.

- Basic Computer Usage
- Basic File Management
- Email
- Internet

There may also be an opportunity to include the following:

- Shopping online
- Banking online
- Social Networking eg. MSN, Myspace, Facebook, Yahoo
- Skype
- Podcasts
- Digital Photography
- Downloading music
- Catch-up TV such as the BBC iPlayer

For more information or to apply, call 0208 673 3300 or go to www.ucandoit.org.uk.

Ciliopathy Alliance Update

Drina and Michael Parker

Articles in previous Newsletters have referred to LMBBS's role as a founder member of the Ciliopathy Alliance. The Alliance brings together patients, patient support groups, associated charities, doctors and researchers representing individuals and families living with "ciliopathies" – syndromes or diseases caused by defects in the function, or structure, of cilia. As some of you may recall from presentations to our LMBBS Family Conferences, cilia are small hair-like protuberances, a bit like antennae, found on the surface of virtually every cell in the human body. Once believed to be functionless, defects in cilia formation or function are now believed to underlie many devastating genetic conditions, including Bardet-Biedl Syndrome, some forms of Retinitis Pigmentosa, Alström Syndrome, Polycystic Kidney Disease (PKD), Primary Ciliary Dyskinesia (PCD), Usher Syndrome, and several other rare conditions but also some much more prevalent forms of diabetes. The list keeps on growing and it is now thought that ciliopathies affect about 1 in 200 people in Europe. The Ciliopathy Alliance aims to promote research into rare diseases with defective cilia and to provide support for patients with ciliopathies, their families and carers. Since 2000, major discoveries in cilia biology have been achieved in an amazing diversity of disciplines, including cellular and molecular biology, genetics, clinics and biophysics. These breakthroughs are contributing to a better understanding of ciliopathies.

The Ciliopathy Alliance Family Conference, which was organised in 2013 by the Ciliopathy Alliance for families and scientists, had disappointing support from patient groups and families. This may be because the majority of families regard the ciliopathy element of their particular disorder as less significant or relevant than the disorder itself. This is far from the case. We all need to be aware of the importance of small patient groups with common symptoms working together, as this increases the medical database for the benefit of all groups. There are immense practical benefits which could result from the work of the Ciliopathy Alliance.

Michael and Drina Parker continue to represent



LMBBS in the Ciliopathy Alliance, with Michael on the Board of Trustees. Following the great success of Cilia 2012, an International Conference held in London, it was decided to hold similar events every two years, and a second International Conference, Cilia 2014, was held at the Pasteur Institute in Paris, from the 18th to the 21st November last year. Like Cilia 2012, Cilia 2014 was a huge success, attracting 411 delegates coming from 27 countries in 5 continents, including 30 patients and patient representatives, with Michael, Drina and Richard Parker representing LMBBS. The delegates were mainly researchers and clinicians from all over the world, but Michael and Drina's one criticism of the Paris event was that patient involvement was extremely limited, partly because of the layout of the conference centre.

Drina said, 'The greatest interaction took place on the final evening of the conference at the Gala Dinner on a riverboat on the River Seine. Tables were carefully arranged to include scientists, clinicians, patients and patient groups and there was a lively and stimulating exchange of ideas. On our table, a Scandinavian researcher, on being introduced to Richard, exclaimed, 'I have been working on proteins in a lab for 10 years and you are the first person with a ciliopathy I have met!'

The biggest drama of Cilia 2014 was the physical ejection from the meeting of a Mr David Noakes, of Immuno Biotech, and promoter of GcMAF. It is possible that some readers will recognise this name, as he is the same person, promoting the same therapy, who the LMBBS Committee barred from attending the 2014 LMBBS Family Conference. David Noakes claims beneficial effects of a human protein, GcMAF, on two BBS1 children. These claims are not supported by Professor Beales, and the Cilia 2014 Conference organisers have subsequently issued a statement to confirm that

they "do not at all endorse such highly problematic approaches, neither scientifically/academically nor business-wise." Furthermore, in Britain, the Medicine and Healthcare Products Regulatory Agency (MHRA) is investigating the malpractice of Immuno Biotech, and the authorities in Guernsey, where it is based, have banned it from importation.

The next international conference, Cilia 2016, will take place in Amsterdam where more patient involvement will be addressed and, in the light of the unsupported BBS therapy which created embarrassment for the Cilia 2014 organisers, greater scrutiny to contributors will be applied!

Fundraising Round-Up

The Laurence-Moon-Bardet-Biedl Society has continued to raise monies in very diverse ways, despite the ongoing tough economic climate and the Committee are very grateful to all members, family and friends who have contributed to our fundraising efforts. Every bit of the money goes directly where it is needed: information and education, family support and towards staging our annual family conference, which is a real arm of support and friendship to all those who attend.



Our main fundraising event of 2014 was a cycle ride from London to Paris, organised by two of our parents. This raised in excess of £4500 and the society is very grateful to all those who rode and who donated.

Many of our members have taken on personal challenges and organised some pretty diverse fundraising events. These include:

- Maria Dowswell's 12 hour radio show (see separate article)
- Keira McCarthy held a non uniform day at school, raising £193
- Peter and Jane Taplin, friends of The Oates' family, opened up their narrow gauge railway in their garden as part of a village fun day and raised £120. The Taplins have been doing this for a few years now and this, together with a generous £1000 donation given two years ago brings their total donations to around £1800.
- Abbie Humphries made and sold loom bands to her friends and family and we received a most lovely hand written letter about it, with a cheque for £76 which she raised.

The Oates family hosted a village BBQ, raising

My name is Abbie Humphries and I am 12 years old. I have two young cousins Joshua and Ryan who both have LMBBS. I decided to raise some money for the LMBBS charity by making loom bracelets and selling them to friends and family and I am pleased to send you a cheque for all the money I raised which was £76. I have sent you a yellow and black bracelet as a gift. Thank you for all the good work the charity does for Josh and Ryan and everyone with LMBBS.

Yours sincerely, Abbie Humphries

- Emma Rogers sold 'Krispy Kreme' doughnuts at her annual village fair and raised £185
- The Year 8 students at Moulton School held a cake stall, raising £75
- Connor Hymers spoke about LMBBS in his school assembly which led to pupils of Manningtree High School choosing LMBBS as one of the charities to benefit from their fundraising week. They raised £150 for the Society.
- Darron Jones staged a charity cricket match, raising £1500



£1100, at which Tom and Katie's Granddad and his best friend pledged to undertake the ice bucket challenge if £100 was collected in a bucket! Of course this was achieved and everyone was hugely entertained as the children from the village doused them in two enormous buckets of water.

Ryan Jones gave an 'After Dinner Speech' and asked that his fee be donated to the Society.

Debbie Nicholas, sold 'Debbie's Home Made Preserves & Baking', raising £150 and her friend Tracy Smith donated £100.

Two of our carers, Jason and Amanda Wilbraham hosted a charity evening on our behalf and raised £1910. The Wholly Big Mac Soul Band headlined the evening and there was a disco and raffle.

A special mention and extra big 'thank you' goes to Nicola Hueting and Helen Ward who ran in this year's London Marathon to raise money for LMBBS.

Nicola writes, 'thank you so much to everyone who sponsored me... with your help I have managed to raise over £1500, which, for a small charity is a significant help. The atmosphere was amazing and with all the crowds, it was actually an enjoyable



experience. Many thanks for all the support and encouragement, it has meant a lot.'



Helen raised around £2,300 which she hopes will 'help towards some of the great work the charity does for children and families with BBS'. She writes, 'the day was amazing, the crowd really got me through those last six miles and the finish down the mall was everything I expected it to be. I can't wait to sign up for my next one...so watch this space!'

We are very excited to have recently spoken to Oliver Mason from Rogerstone Cricket Club. They have chosen LMBBS as the charity which they would like to support during the forthcoming cricket season and are including our logo on their team strip as well as organising some charity events on our behalf throughout the season. We look forward to reporting back on this next time.

Although we are unable to mention you all in person, we are so thankful to everyone who has fundraised or donated to the LMBBS. Our heartfelt gratitude goes to you all, your efforts and generosity will make a big difference to our small charity. We are always pleased to hear of your ideas for fundraising and are very open to new and diverse ideas, so please do get in touch if you have any fundraising suggestions. I look forward to hearing from you.

Emma Oates

Marathon Fundraiser

My name is Chris Leavesley and I live in Halesowen, West Midlands. I am by no means a proficient runner, but I do love to run and push myself. Over the past three years I have entered a number of races and 'fun-runs' and this year, I plan to enter my first full marathon. I am not planning to break any records, just complete the 26.2 miles.



Why am I doing this? I have to be truthful and say that I know very little about LMBBS. I have no relatives with the condition, but I have a friend, Claire Eccles and through reading her blog on Facebook about her two boys, I can see how hard she works to maintain a loving family life, which has reminded me of my own childhood.

As a child I had a fantastic Dad and strong and supportive Mum. When I was 8 years old my father was diagnosed with Multiple Sclerosis (MS). They

both worked hard to maintain a loving family environment, but as my Father's illness progressed, my Mum had to do more and more to keep two strong-willed boys in line. It was only when I was older and had a family of my own that I realised how much Mum had done for us. In short my Mum has been my rock. It is for this reason that LMBBS is my chosen charity this year.

To summarise, I am raising money for LMBBS to say 'THANK YOU' to my Mum and 'well done Claire, I see all the traits in you that I admire so much in my Mum'.

These are the events I am involved with and the dates:

- ✓ Action Heart 5 mile Run: 22/2/15
- ✓ Coventry Half Marathon: 1/3/15 (Claire, Lee and the boys will be at the finishing line)
- ✓ British Heart Foundation Half Marathon: 22/3/15
- ✓ Halesowen to Stourport Team Cycle Ride: 6/6/15
- ✓ Shenstone 10k Team of 5-10 runners
- ✓ Tandem Parachute Jump: 18/7/15
- ✓ Birmingham Half Marathon 18/10/15

We (LMBBS) are overwhelmed at Chris' commitment and dedication to raising funds for the LMBBS in honour of his Mum and friend, what a truly inspirational person. We are behind you all the way Chris and wish you lots of luck in your endeavours. We will bring you an update and photos in the next newsletter.

Buddy Dogs

Claire and Brian Pugh

Our son, Christopher, has Bardet-Biedl Syndrome (BBS1). He was diagnosed at the age of four, after four long years of fighting with doctors to get answers to lots of questions.

Christopher is a very happy-go-lucky young man and he rarely lets things get him down. He still attends main stream school and will do so until such a time comes when we feel he cannot cope with it anymore. He loves school and has many friends.

Christopher has regular visits at school from the mobility advisory service and visual impairment team. He started using a symbol cane about 18

months ago and this has helped him when we are out and about. He has use of a wheelchair for any distance walking, as he struggles with back ache after a few minutes of exercise. We had a visit from Fleur, Christopher's Mobility officer, to discuss different aids that could help him and she talked to us about Buddy Dogs. We had never heard of a buddy dog, let alone thought of one for Christopher. Fleur explained to us what a buddy dog was and gave us some literature to have a read through. We actually sponsor Guide Dogs, so we were surprised to learn that a Buddy Dog is a Guide dog that either didn't quite meet the mark to progress to being a Guide dog, or it's a retired Guide dog. After a lot of discussion, Brian and myself decided that we would apply to see if Christopher would be eligible for a Buddy Dog. A few weeks later, we had a call from Guide Dogs saying someone

would be out to visit us to discuss things and do an assessment of the family environment.

This was a very exciting time but we still had a lot of questions to ask:

- ☺ Would we be allowed a Buddy Dog as we already have a dog?
- ☺ We only live in a small house, would it be ok?
- ☺ What if we got a Buddy Dog and decided it wasn't right for us as a family?
- ☺ What if the dog didn't like us?

The list went on!

Karen from Guide Dogs came to visit us and she put our minds at ease, answering all our questions, but she also had a lot of questions for us. She wanted to know things like:

- ☺ How would everyone in the house feel about having another dog?
- ☺ Do we have a lot of children visit us?
- ☺ Where would the dog sleep?
- ☺ Would it be allowed upstairs?

Again, the list of questions went on, but she explained to us that she had to ask all the questions because if we decided to go ahead and were successful, she would be able to match us with a dog suited to our family and lifestyle.

Well, we passed the assessment, so it was just a case of waiting for the right dog to become available. After about 8 months, Karen called to say she thought she had found the right dog for Christopher. It was a very exciting time!!!

On Saturday 26th July, GRANT the Golden Labrador came to visit and he was a huge hit with us all. He was very gentle and laid back and he followed Christopher around all morning. Christopher took him for a walk and it was so lovely to watch him create such a wonderful bond with Grant in such a short space of time.

Grant was previously a Guide dog for two separate owners but unfortunately he couldn't stay with his last owner and was too old to be retrained with a new guide. So, luckily for Christopher, Grant was put into retirement.

Grant moved in with us on Saturday 2nd August and we haven't looked back. Christopher has to do everything for Grant, he grooms him every week, feeds him twice a day, walks him twice a day and gives him so much love, they have such a special bond. Grant takes Christopher to school every morning and meets him every afternoon; as you



can imagine he's very popular with all the children. He wears a special Guide Dog/Buddy Dog Jacket and he knows he is working once this goes on. School are very accommodating and allow him on the premises when wearing his jacket.

If anyone ever said a dog could have such an impact on Christopher's life, I would never have believed them, but it is so true. We have noticed a significant drop in Christopher level of vision in the past 18months and again more recently. But what we have also noticed, is the amount of confidence Christopher has now. He hasn't used his wheel chair since Grant arrived and has actually maintained his weight for the first time ever. He enjoys going out walking and caring for Grant which is more than we could ever have hoped for. Grant is so special to us all, he's a real 'gentle giant' and gets on so well with our other dog, Lulu.

As BBS parents, none of us know what is round the corner for our children. I hope this story gives you a little insight into what a huge difference a Buddy Dog can make and what it could do to help a child or young adult who has BBS. For more information contact Guide Dogs for the Blind, we are so glad we did.

Education, Health and Care Plan

An Education, Health and Care Plan (EHC Plan) is a document which replaces old Statement of Special Educational Needs and Learning Difficulties Assessments (LDAs) for children and young people with Special Educational Needs. Professionals and the family together consider what outcomes they would like to see for the child or young person and the plan identifies what is needed to achieve those outcomes. The definition of Special Educational Needs (SEN) has not changed: 'A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for them'.

If your child has Special Educational Needs and you do not feel that they are getting the support they require, then the first step would be to raise your concerns with your child's school, early year's provider or college and they will be able to advise you and/or make a referral for an EHC Plan assessment. If you would prefer to make the referral directly, then contact your local authority and a member of the SEN team will be able to take your referral and guide you through the process. The Local Authority must respond to the request within six weeks.

An EHC Plan can be issued to a child or young person between birth and 25 years old and commenced operation from September 2014 when the Children and Families Act 2014 became law. The new system will initially run alongside the old system; the deadline for all changes to be complete is April 2018, when it is expected that all statements of SEN will have been reviewed and EHC Plans will be in place.

Existing Learning Difficulties Assessments (LDAs) must be transferred to EHC Plans by September 2016, for the following groups:

- Child/young person moving from school, including school sixth forms, to a post 16 institution or an apprenticeship.
- Conversions of non-statutory EHC Plans into the new template provided by the DfE, if the child does not have a Statement of SEN.
- Young people who receive support as a result of an LDA, who intend to be in education beyond 31st August 2016.

According to the Department for Education (DfE), local authorities (LAs) MUST transfer children and young people with Statements to the new arrangements during 2014-15, however in practice,

we are seeing many schools assessing those on statements and in some cases making the decision that the child or young person does not warrant an EHC Plan, thereby losing the provision previously agreed. If you are struggling to obtain the support needed for your child or young person, or just need further information, advice and support, there is a list of contacts at the end of this article.

What is in place for children and young people without an EHC Plan?

SEN Support will be the support available in school for children and young people who have special educational needs but do not have EHC Plans. SEN support replaces School Action/School Action Plus (in schools) and Early Years Action/Early Years Action Plus (in early years settings).

SEN support can take many forms. This could include:

- a special learning programme for your child
- extra help from a teacher or a learning support assistant
- working with your child in a small group
- supporting your child with physical or personal care difficulties, such as eating, getting around school safely, toileting or dressing

Statement v EHC Plan:

Many of the legal requirements for EHC assessments and plans are the same as for statements, for example, the right to express a preference for a school placement remains the same and the EHC Plan will still be reviewed and updated on a yearly basis to inform necessary amendments.

A positive development is that EHC Plans do not necessarily cease when a young person leaves school and can be maintained up to the age of 25. EHC Plans also have enforceable elements of health and social care.

The four underpinning principles:

Section 19 of the Children and Families Act 2014 makes clear that local authorities, in carrying out their functions under the Act in relation to disabled children and young people and those with special educational needs (SEN), **must** have regard to:

1. the views, wishes and feelings of the child and his or her parent, or the young person;
2. the importance of the child and his or her parent, or the young person, participating as

1. fully as possible in decisions relating to the exercise of the function concerned;
2. the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions;
3. the need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes.

The Education, Health and Care Plan has 12 sections:

A: The views, interests and aspirations of the child and their parents, or of the young person

An aspiration is a hope or ambition of achieving something, for example, to be independent, healthy, gain employment, go to college and so on. The aspirations of the parents of the child should be recorded as well as those of the child.

B: Special educational needs (SEN)

A 'need' is a state of requiring help. It's not just the diagnosis that is considered, but the needs that arise from this, for example, the young person may need help with their personal care or they may need help with their learning such as constant repetition or materials adapted to be accessible.

Each and every SEN must be specified whether it is to be provided for by the school/Further Education college, the LA, the health service or any other provider and if a need requires more than one type of provision, for example physio and occupational therapy, it must be split into more than one need.

C: Health needs related to SEN.

Some children and young people with SEN may need to use dentists or other health professionals trained for people with SEN for their dental or other health needs. Parents should try to ensure that these needs are recorded so that commissioners of services are aware of the demand. This need could be specified in section C of an EHC Plan.

D: Social care needs related to SEN.

An EHC Plan assessment **must** include an assessment of a child or young person's social care needs. If appropriate, this will entail a statutory assessment under children's or adults social care legislation.

E: Outcomes - how the extra help will benefit your child

An outcome is a benefit or difference made to an individual as a result of an intervention. It should be personal and not expressed from a service perspective. A young person may wish to be able to travel independently, so the outcome would be to be able to travel independently, on foot and by public transport, in and around a set area, by the time they are 19.

F: Special educational provision (support)

A provision is the action of providing or supplying a service (physiotherapy, speech and language therapy) or a resource (Ipad, laptop). **All** special educational provision required to be put in place to support a child/young person in education and training should be specified. If it is needed it must be included, without regard to cost or convenience. Health authorities cannot veto health provision's inclusion in this section. These are often so fundamental to education they must be recorded as educational provision unless there are exceptional reasons for not doing so.

G: Any health provision reasonably required by the learning difficulties or disabilities which result in the child/ YP having SEN

Provision should be detailed and specific and should normally be quantified, for example, in terms of the type of support and who will provide it. Health care provision reasonably required may include specialist support and therapies, such as medical treatments and delivery of medications, occupational therapy and physiotherapy, a range of nursing support, specialist equipment, wheelchairs and continence supplies.

H: Social care provision

Provision should be detailed and specific and should normally be quantified, for example, in terms of the type of support and who will provide it, including where this is to be secured through a social care direct payment. It should be clear how the provision will support achievement of the outcomes, including any provision secured through a Personal Budget.

I: Placement - type and name of school or other institution

These details are only included in the final plan so that the LA does not pre-empt consideration of

any preference for an institution which the parents or young person may state in favour of a non-maintained institution.

J: Personal budget arrangements

Any amount of money specified in this section must be enough to secure the provision specified.

K: Advice and information

The list of the information gathered during the EHC needs assessment should include brief details of who gave the advice and when. Copies of all the advice and information gathered during the statutory assessment process should be attached to the EHC plan as appendices.

An EHC Plan can only be issued after a child or young person has had an Education, Health and Care Needs Assessment. The Local Authority will then make the decision of whether to issue an EHC Plan or not. If the LA refuses to issue an EHC plan, parents must be informed of the reasons and be made aware that they have the right to appeal to the SEN and Disability tribunal.

If the decision is made to issue an EHC Plan the LA must first issue a draft EHC Plan for the parents to consider. Only at this stage will parents be asked to name the type of school/college they want their child or young person to attend, for example, mainstream or special school and the name of the individual school/college they want to add to

the EHC plan. The LA will then consult with the proposed school/college about being named in the EHC plan.

In addition to educational needs the draft EHC Plan should also detail health care and social care provision. The LA will then finalise the plan.

Once finalised, the Local Authority and the local health care provider both have a legal duty to secure the educational provision and health care provision as specified in the plan.

If you need help or advice regarding your child's application for an Education, Health and Care Plan Assessment, you may find the following contacts useful:

Useful Sources of Information:

National Websites

www.sossen.org.uk

SOS!SEN offers free friendly, independent and confidential support for parents and carers of children with Special Educational Needs. Helpline: 020 8538 3731 (term time only)

www.councilfordisabledchildren.org.uk

The Council for Disabled Children is the strategic delivery partner for the reforms and produces regular updates on the reforms.

www.ipsea.org.uk

Independent Parental Special Education Advice.

www.childrenslegalcentre.com

Coram Children's Legal Centre provides free legal information, advice and representation to children, young people, their families, carers and professionals, as well as training and consultancy on child law and children's rights.

www.gov.uk/schools-colleges-childrens-services/special-educational-needs-disabilities

Government information on Special Educational Needs and Disability (SEND)

www.sendpathfinder.co.uk

Read information packs from the pathfinders which contain a wealth of updated information about the new reforms.

Local Information you may find helpful, some areas will be better than others!

Local Offer

The Local Offer is a guide to the services available to you locally and can be found on your local authority website.

Parent Partnership

An impartial service developed to help you understand how special educational needs are assessed and managed. Your local parent partnership will give over the phone advice and can also go to annual reviews to offer support.

Parent carer forums

A parent and carer led organisation which represent the views and experiences of services for children and young people with SEN (and their families). You can 'Google' your area; many will have worked with the LA over the past few years on EHC plans and may be running workshops.

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 492916 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](https://www.skype.com/user/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.



Regional Rep: Scotland

Allan has three children Callan, Luca and Jorja with his wife Jacqueline and both their sons have BBS; Allan has been a committee member since 2009. Allan works for Macmillan Cancer Support in Scotland and manages the Macmillan Carers Services for his local council, supporting those affected by cancer. He is also a committee member of the Dunbartonshire Disability Sports Club and is an active member of the Dumbarton District Disabled Children's Forum. Allan can be contacted on 07795 265991 and via email at Allan.Clark@west-dunbarton.gov.uk.



Regional Rep: Wales

Camilla Brown is the new LMBBS Regional Representative for Wales. She lives in Cardiff and has two sons, Joey and Jack; Jack has BBS. Camilla can be contacted by telephone on 07795 636037 and via email at milly_brown68@yahoo.co.uk.

We are delighted to report that we now have a Northern Ireland Representative, Sharon Fegan. Full contact details will be available on the website and will appear in the coming Conference Report.

Full contact details are on the back page of the newsletter.

New York Adventure

Danielle Sales

My name is Danielle Sales and I have Bardet Biedl Syndrome. I was diagnosed along with my sister in 1997 and I have suffered with weight problems since a very early age. I was born with six fingers and six toes, I have learning difficulties, chronic fatigue, psoriasis, emotional issues, and polycystic ovaries. At the moment my eyes are OK, but there is a possibility that I could become visually impaired.

My sister had a 'Dream Come True' experience in 2011 and cooked with the Hairy Bikers and I asked at that time if I could apply too. They said yes, and so I asked for a trip to New York. I cannot thank Dreams Come True enough for this wonderful experience. Here is my story of my time in New York.

Monday 2 June

I went to New York with my mum on Tuesday 3rd June until Sunday 8th June. The night before our flight we stayed at the Plaza hotel, at Heathrow as our flight was 9.45 in the morning. When we arrived it was very grand, with white marble floors. We checked in, dropped our bags off in our room and headed to dinner. We went posh and started our holiday off in style. Like many with BBS, I love my food! We decided to have a nice bottle of Prosecco and I had scallops to start, followed by steak and cheesecake. It was all very yummy. Off then for an early night.

Tuesday 3 June

We got up bright and early, very excited for our trip. We got a taxi to the airport which only took ten minutes. My mum had already checked in online the day before, so we just had to drop off our bags and then head to security. We had a look around the shops and before we knew it, we were heading for our gate. Once on the flight, which was only half full, we asked if we could move seats near the window with more leg room, which we did. We were supplied with food and drinks throughout the flight, and entertained with numerous films. It did seem to go quite quickly and before we knew it the time had come to finally arrive in New York at 12.30pm local time.

Once off the flight, and through security, we proceeded to get a yellow cab, which was exciting and headed to New York City. We arrived at our hotel, The Intercontinental Barclay hotel at around 3pm (8pm UK time), which was stunning and beautiful.



We checked in and then went to find the concierge to ask about numerous things that we could do while we were in New York. After unpacking, we decided to go and visit the Rockefeller centre/Top of the Rock. The view was amazing, but it was a bit cloudy on that day and it poured with rain on our way back. After finding a nice salad bar we decided it was time for bed!

Wednesday 4 June

Wednesday, we decided, would be a shopping day, with sight-seeing along the way. We had our breakfast nice and early, lush Eggs Benedict was our favourite. This set us up for the whole day, and was much needed with all the walking that we did. We walked to 42nd Street, past the Chrysler building, window shopping as we went. Past Bryant Park, we went straight into the sunglasses shop for my Ray Bans. We then headed to Times Square and down Broadway to Central Park, again, visiting a few shops along the way, thank goodness we went out with light suitcases!! At Central Park, we went on one of the bike buggies with a tour guide which was fun. We then headed to 5th Avenue for some more shopping, including a visit to the Tiffany store. Finally, we made our way back to the hotel, all in all a six hour walking day. We had a nice rest at the hotel before asking the concierge for some good places to eat. They made us reservations at a lovely Italian restaurant that could cater for my mum who is gluten free. It was delicious.

Thursday 5 June

Thursday morning was a bit disappointing with rain, so we decided to have a nice leisurely breakfast, and do some more shopping before we visited the Empire State building in the afternoon. By the time

we got to the Empire State building the sun was shining and the view was incredible. After that, we visited Macy's, one of New York's oldest and most famous department stores. After, we went back to the hotel and had a drink and again asked the concierge to recommend somewhere nice to eat. This time we went to a steak bar, which again was delicious. I was very happy that I got my steak with mac and cheese! After dinner, we visited Times Square again but at night. It is very special and buzzing with people, neon lights and the Broadway shows, amazing.



Friday 6 June

I was so excited about this day when I got up, as this was the day we were doing a once in a life time opportunity and a very special experience, which I will never forget: a helicopter ride around the city. It was incredible and the best part of my trip.

Afterwards we walked to the 9/11 memorial fountains and museum, which was very emotional and so interesting. In the museum they had parts of the fallen buildings, trucks from the wreckage and videos about the day. Throughout the museum you see the beginning, during and aftermath of that tragic day, and how brilliantly the people coped. We were so tired after such an emotional and exciting day that we decided to have dinner at the hotel and were in bed by 8!



Saturday 7 June

Today, we went on the 'Sex in the City' tour, where we got to see the places where they filmed the show. We got off the bus at various locations from the series and films; we had a cocktail in Steve and Aiden's bar and visited the Magnolia bakery where the girls had cupcakes outside, we got to taste the cupcakes as well. The tour was great fun and took about 3 and half hours, it was nice to have a rest on the bus and it was also good to see a different side of New York. Once finished, we were dropped off at a different place, so we slowly made our way back to the hotel and did a bit more shopping on the way! In the evening we decided to visit the Rockefeller building again so we could see the sights at night. We found a nice Irish bar close by for our dinner, and then went to the 'Top of the Rock'; the night skyline was beautiful.

Sunday 8 June

Sunday was sad - checking out day! We said a special 'thank you' to the concierge team, for all their help. We were going to walk to Central Park, but there was a Brazilian parade going on down 5th Avenue, so we couldn't head that way. Instead, we decided to head down 42nd Street and had a lovely lunch in Bryant Park. It was such a lovely way to end our amazing trip. We then had to head back to the hotel for one last look before we hailed a yellow taxi to the airport.

We had a truly wonderful experience thanks to 'Dreams Come True'. If you are under 21, you too can apply to Dreams come True:
www.dreamscometrue.uk.com



Rare Disease Day 2015



We had an attendance at two Rare Disease Day events this year; Tonia Hymers, Angela Scudder and Richard Zimblar were at the House of Commons and Camilla Brown and Tom Rawlings were at the Welsh Assembly, Cardiff.

The House of Commons reception was attended by over 150 people including 35 MPs and Peers. For the third time Liz Kendall MP, Shadow Minister for Care and Older People, hosted the event. She said that business, society and public services need to work together on rare disease issues. She also expressed the importance of patient voice.

Earl Howe, the minister in charge of Rare Diseases, described the event as "one of the landmark events of his year" and emphasised his commitment to making the UK a world leader in patient-centred research into rare diseases. He spoke about the 100,000 Genomes Project, owned and funded by the Department for Health and about the National Disease Register, which aims to collect data on all those with a rare disease in England.

Fiona Marley, Head of Specialised Services at NHS England outlined a number of initiatives through which the NHS plans to improve rare disease diagnosis and patient care. The reception also saw the launch of two short films, put together by Health Education England, one aimed at patients and their families and another aimed at healthcare professionals. You can watch them at: www.raredisease.org.uk/rare_disease_day_2015

Tonia Hymers, who attended the House of Commons Reception, said, 'it is a great experience, the building is beautiful and the nibbles and wine are generous. The reception provides an ideal opportunity to catch up with other patients and patient groups and swap experiences and contacts and of course the presentations are always interesting and informative.' There is much uncertainty at the time of writing, with the General Election looming, however it is heartening to see the progress made to date for those with rare diseases.

The reception at the Welsh Assembly was hosted by Darren Millar AM. The Deputy Minister for Health, Vaughan Gething AM, launched the Welsh Rare Disease Plan which sets out the Welsh Government's expectations of the NHS in Wales to treat rare diseases for people of all ages, wherever they live and whatever their circumstances.



Alastair Kent OBE, Chair of Rare Disease UK detailed the political progress made cross party to ensure patients with rare diseases can receive early diagnosis, correct treatment, and hopefully a cure.

Dr Rachel Butler, Head of Laboratories, All Wales Medical Genetics Service, explained the advances of genetic testing. Up until three years ago scientists had to ask blood samples the right questions to find a positive result. Now they can ask the sample 'What defect do you have?' People/Parents can even be tested to see what DNA abnormalities they carry. This breakthrough will lead to less babies being conceived carrying diseases. It will also lead to early diagnosis of babies presenting unusual symptoms. Medicines can be tailor made to the individuals DNA, meaning better treatment and survival of diseases such as cancer.

Rachael Humphreys, a patient affected by Behçet's Disease and a Trustee of the Behçet's Syndrome Society told the familiar story of wrong diagnosis, wrong medications and lack of understanding and support.

Camilla Brown who represented LMBBS at this event said, 'All round it was informative and heartening to know that so many talented people are working towards a better future for people with one of the 7000 and counting rare diseases affecting us today.'

Our thanks to Camilla, Tom, Richard, Angela and Tonia for their reports.



UNIVERSITY OF BIRMINGHAM

Researchers at the University of Birmingham are doing a project about the experiences, good and bad, of specialist clinics for people with rare syndromes, including Bardet-Biedl Syndrome (BBS).

They would like to talk to children (and their parents if under 16) and adults who have BBS. They would also like to hear from the parents/carers of people who have BBS but are unable to give their own permission to take part in the research.

It is important that those involved know that they have the syndrome, for example if they have BBS,

this must be something you would talk about when they are there, though they may not understand about the syndrome.

In particular we are looking to speak to people who have BBS and attend specialist clinics at Great Ormond Street and Guy's Hospital London, Queen Elizabeth Hospital, Birmingham and Birmingham Children's Hospital.

Those who take part will receive a £20 voucher. This project is funded by Sense.

If you would like some more information please contact Liz Ellis:

l.ellis.2@bham.ac.uk; telephone 0121 414 4392, or text 07745 244597.

Please ask your parent/carer to contact us if you are under 16 years old. Thank you!

Cricket in Nepal

Hannah Young

I would like to tell you about my magical experience in Nepal.

Last year, on 19th October 2014, I was lucky enough to represent my country in the first England female visually impaired cricket match played in Nepal. I said goodbye to my husband, Sean and my guide dog, Diane at Heathrow airport and flew out to start my adventure. It was a long flight from Heathrow to Delhi and then from Delhi to Kathmandu; I arrived very tired but happy to be there. We stayed in Kathmandu for the night, before setting off the next day on a long 8 hour coach trip. The roads in Nepal were very dangerous with sheer drops either side of the road; there are a lot of accidents. My team mates, who had better sight than me, and the coaches, were very scared going round the corners. I sat there laughing as I couldn't see anything, so it didn't bother me. It didn't help when the coach driver said, 'If you look to your left, you can see the lorry that fell off yesterday,' as we came round the corner, but we made it safely to Pokhara.

We stayed for three days, training and acclimatising, getting used to the heat. While we were there, we went up into the mountains on the cable cars and



visited two temples. We went to local markets and tasted the local food; they were celebrating the Diwali festival. We took a 40 minute flight back

to Kathmandu where we played our three matches against the female Nepalese cricket team. Unfortunately we lost the games but we didn't feel too bad, as they have been playing for nine years. We had a great time with the team and made some good friends. We visited the local blind school and saw how they live their lives, it was a great experience. We also went to the Ambassador's residence for a reception where we had a meal with the Ambassador, the Nepalese team and local dignitaries. I'm hoping this is the first of many trips.

We got back to England on the 29th October; I was very tired but very happy. I was not much company for Sean when I got home, as I slept just about non-stop for a week, it was a wonderful experience. I am a much more active person since being diagnosed with BBS. If you told me before my diagnosis that I would be playing cricket for my country in Nepal, I would not have believed you. It just shows that when we put our minds to it, we can do anything. I play cricket, football, tennis and I do sonic shooting; I didn't do any of these things before and I would just like to say that even though we have BBS, we shouldn't stop dreaming and trying to achieve our goals in life.

Contact Details

LMBBS General Contact BBS Clinics Adult's Service

Julie Sales
1 Blackthorn Avenue
Southborough
Tunbridge Wells
Kent
TN4 9YA
01892 685311
kevin.julie1@btinternet.com

LMBBS General Contact BBS Clinics Children's Service

Tonia Hymers
43 Balton Way
Dovercourt
Harwich
Essex
CO12 4UP
07805 685342
toniahymers@btinternet.com

New Families Contact

Claire Anstee
After 4pm, Monday - Friday
01604 492916 ansteeclaire@gmail.com

Adult's/Young Adult's Contact

Steve Burge
Flat 9
Pocklington Lodge
Rylett Road
Shepherds Bush
London
W12 9PQ
Mobile 07833 228 463
Skype: budge-2005
Twitter: @drumfeather.

Special Educational Needs Contact

Dianne Hand
0161 442 0989.
diannehand@live.co.uk

Fundraising Co-ordinator

Emma Oates
The Old Cow Shed
Knaresborough
Bishop Monkton
North Yorkshire
HG3 3QQ
01765 676578
07861 770164

Friends of the LMBBS

Kevin Sales
1 Blackthorn Avenue
Southborough
Tunbridge Wells
Kent
TN4 9YA
01892 685311
kevin.julie1@btinternet.com

Regional Rep: Scotland

Allan Clark
07795 265991
Allan.Clark@west-dunbarton.gov.uk

Regional Rep: Wales

Camilla Brown
07795 636037
milly_brown68@yahoo.co.uk

