

# LMBBS Winter Newsletter 2012/2013

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## Winter Foreword

On behalf of everyone in the LMBB Society, I hope you all had a peaceful Christmas and wish you all a happy and healthy New Year. To those of you who have suffered ill health over the past few months, we wish you a speedy recovery.

With Spring just around the corner, if you haven't already booked your place at Conference 2013, it is time to dig out those booking forms. There are two aspects to the booking

process this year, delegates book their accommodation directly with the hotel and then complete the conference booking form and return it to me, Chris Humphreys. The Hilton, Northampton telephone number is 01604 702851; ask for Becky Roberts and quote reference GLMBE. The staff at the Hilton Hotel are friendly and helpful, but please contact me if you are experiencing any problems and I will be only too pleased to assist.

We have had another excellent year for fundraising, with many of our youngsters taking part, so thank you all, young and old; you will agree that their stories as reported inside, are inspirational. Thank you also to our benefactors, your help and support is very much appreciated.

LMBBS is extremely proud of our young members, their courage and determination often through difficult times is inspiring. We have had a graduation, excellent exam results, fantastic fundraising achievements and incredible bravery shown in dealing with the various aspects of the syndrome. Shane Ryan, who you will remember from previous newsletters has had a particularly exciting year, rowing for Ireland in the Adaptive Rowing Team. We are very excited to announce that Shane will be coming along to our Conference in April for a question and answer session, to give his perspective of events leading up to the 2012 Paralympics and to inspire the younger generation further.

We hope to see you then!

**Chris Humphreys**

### **Notifications**



Stephen Sherwood underwent a kidney transplant in November, donated by his Mum, at Queen Elizabeth Hospital, Birmingham. Stephen and his Mum have made excellent progress, with both being discharged within a week of surgery. Stephen sent this message:

“I would like to say a very big thank you for all the lovely warm messages I received from our family at the LMBB Society and am looking forward to yet again attending the brilliant annual conference, all being well. “

We wish Stephen and his Mum well, as they continue with their recovery.

Vicky Merchant also underwent a kidney transplant in November and is making good progress. We wish her a speedy recovery and hope to see both Vicky and her fiancé Wayne at Conference in April, love and best wishes from us all.

We send our love and condolences to Jacqui Jones and family, on the sad loss of Jacqui's parents. Jacqui's father left instructions that all donations should be sent to LMBBS and we sincerely thank the family for thinking of us at this very difficult time.

We also send our condolences to Peter Jones on the sad loss of his Mother, Mrs Grace Jones. Once again we are overwhelmed at receiving a donation at this sad time and give heartfelt thanks.



Congratulations to Danielle Sales who graduated in November with an HND in Photography. After the ceremony at the beautiful Canterbury Cathedral, Danielle celebrated with her very proud family and friends. Danielle's photographs can be viewed on her Facebook page, 'Danielle Sales Photography'.

It has been a year of special birthdays for the Sales family, with Danielle celebrating her 21st birthday and Hollie celebrating her 18<sup>th</sup>. They had a joint party in the Autumn, attended by close family and friends and both girls had a fantastic time; congratulations to you both.

### **Conference 2013**

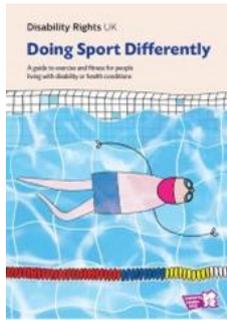
If you haven't already booked your place at Conference 2013, now is the time, as places in the Hotel are limited. As previously stated, if you are experiencing any problems, difficulties or confusion about the new booking system, Chris Humphreys will be only too happy to help you, either by email: [chris.humphreys4@ntlworld.com](mailto:chris.humphreys4@ntlworld.com) or telephone: 01633 718415.

We are delighted that two of our members, Shane Ryan and Hannah Young will be giving personal perspectives on their sporting achievements, which very much ties in with our theme for Healthy Living and Exercise.

As usual, Professor Beales will give an update on all things LMBBS and the Specialist Clinics and Dr Torsten Baldeweg will return to give us an update on the 'Memory Test' Study that was carried out at Conference 2012. We will have a Clinical Psychologist attending and also a Transition Care Co-ordinator, both of whom will give short introductory taster talks during the morning programme and will hold workshop sessions during the afternoon.

With our final speaker awaiting confirmation, it promises to be another informative conference with something for everyone.

We look forward to meeting you all in April and to another excellent weekend, gaining a wealth of knowledge and catching up with friends old and new.



## Doing Sports Differently

'Doing Sport Differently' is a comprehensive guide to accessing sports and leisure opportunities in your area. It is written by and for people with lived experience of disability or health conditions, to inspire involvement in sport and fitness and improve access to grassroots sport.

Following the Olympic and Paralympic year, the guide hopes to inspire disabled people to get active by demonstrating how to overcome barriers to participation and get involved with sports locally. 'Doing Sport Differently' shows the varying ways in which individuals with a disability can engage in sport, be it playing, coaching or watching.

'Doing Sport Differently' is part of the 'Doing Life Differently' series produced by Disability Rights UK. There are also guides on: Careers, Work, IT, Transport and Money. Each book provides a practical toolkit, packed with advice from people with a disability, and including real-world examples.

Download your free copy: [www.radar.org.uk/publications/doing-sport-differently/](http://www.radar.org.uk/publications/doing-sport-differently/)

*'Give it a read – especially if you don't think exercise is for you. It may change your life.'*  
**Baroness Grey-Thompson DBE**

www.disabilityrightsuk.org Tel:020 7250 3222 Twitter: @DisRightsUK #doingsportdifferently



## LMBBS walk for Emmy 2012

Two years ago we organised our first fundraising event for LMBBS and were amazed at the support we received for our Sponsored walk around our local

reservoir. We decided to have another go this year and again our family and friends all wanted to show their support. The reservoir is a 10km walk and at the beginning of the year, my husband Jason, decided that this year he was going to run the route along with our family friend Rob.

At the end of January, Jason began his training. He had never gone running in his life, and started by walking/running a three mile route, a little at a time. After just 28 days of going out every night, in the dark, whatever the weather, even snow, he was running the whole way. By the time we got to the beginning of June he did his first trial of running the reservoir and ran nearly all of the 10 km. He did this twice more before the event and managed to run the whole circuit; by this time Jason had also lost over four and a half stone!

The day of the walk/run arrived and we were very lucky with a dry day; all our friends and family were there to support us and if we included all the kids, there must have been about sixty people. We even had a visit from Jason's Nana and Grandad to start us off and my Auntie brought my 92 year old Grandma to the half way point to see Emmy finish her part of

the walk. Emmy really struggled with the walk towards the end but through a lot of determination she achieved her goal.

Jason and Rob started off first and ran round the opposite way to the walkers so we could spot them across the reservoir. They passed us and amazing Jason ran the 10 km in 46 minutes; quite an achievement for someone who had never run at all just six months before.

We are very grateful for all the help and support that everyone has shown again for our event. Also this year our family members have gone the extra mile, Jason's cousin ran a half marathon, Jason's brother Justin has done a tandem paraglide and Jason's Auntie Shar and her husband Mark asked for donations to LMBBS for their wedding gifts. People's generosity never ceases to amaze us, their support is overwhelming.

Claire Anstee



### **Our Son, The Paralympian**

Shane was born in Cork in early August in 1988, a bouncing baby boy at 8lbs 4oz. After being whisked off to an incubator after a forceps delivery, a nurse came and told us of his 'lucky charms'; Shane was born with an extra finger on each hand and extra toe on each foot.

At his six month check up, all seemed fine although we were told to watch his weight. Along the way an optician whom I met told me to keep a watch on his eyes, as sometimes babies who are born with extra digits have problems with their sight.

Around the age of five, after his sister Jessie was born, we noticed that he seemed unsure of his footing in the dark, an optician referred him to an ophthalmologist and a diagnosis of Laurence-Moon-Bardet-Biedl Syndrome followed. We attended an LMBBS Family Conference in the first year of his diagnosis, around 1994, where we met families who had similar experiences as ourselves, things clicked into place when talking about the day to day struggles we were experiencing, but one thing we did notice was that not all children were experiencing the same degree of symptoms and we realised that even though Shane would be facing difficulties for the rest of his life, his symptoms seemed to be less severe than some others we had met.

Life continued as normal over the next few years, Shane cycled his bike (too fast at times), played some hurling and football with the local GAA Club, became obsessed with

Playstation games along with everyone his own age and loved watching vintage comedy such as Fawlty Towers; he could be heard laughing several rooms away! We attended a few of the LMBBS Family Conferences; Shane and Jessie were delighted with the theme park visits.

Shane progressed from primary to secondary school. At this stage his sight was dropping and the print was getting smaller in the books, but he still managed; his weight was also on the increase. The vice principal of the school was fantastic in applying for extra resources for him. Even though he didn't need a personal assistant at all times during school time, a member of staff always kept an eye on him from a distance when he was changing class or doing practical work. Again this helped him to lead as normal a life in school as possible while making sure he was safe. Shane also embarked on a touch typing course outside of school, which was to stand him in good stead in future years.

During his senior cycle in secondary school, Shane decided to rely on a laptop together with a distance camera, which allowed him to capture and transfer what was being written on the white board onto his laptop. A desktop electronic magnifier allowed him to read the text books and he carried a portable electronic magnifier, which allowed him to read text messages, menus in restaurants etc. At this stage he also benefited from the help of a personal assistant in the classroom to make sure he followed what was going on in class and to help with all his technology. The school again accommodated him by holding all his classes in the same room rather than him having to change rooms for different classes.

Another aid that he started to rely on was the long cane, after receiving training on it with the NCBI, Shane began to see the benefits of it... using it to get around on the busy footpaths in town was a revelation, it was like the parting of the seas! No longer was he bumping into people, or they into him... if we were in a hurry we would ask him to take out his cane and we all travelled much faster around town! People were genuinely very helpful to him when they saw the cane, and he didn't have to explain himself to them, his independence was increasing and he never looked back.

Field games such as rugby, hurling and football were becoming a challenge at this stage due to his failing sight. Through the Irish Blind Sports he went on two skiing trips and got to go away for water skiing weekends (all without parents, which made them even better). Trying out these sports helped to boost his confidence and they were also great fun and he made some good friends on the way. He also undertook some Independent Living Skills training with the Irish Guide Dogs and participated in some of their sporting weekends.

It was around this time that the NCBI contacted Shane and asked him if he would be interested in trying Adaptive Rowing, where the boat is adapted to the individual's disability; it was based in Limerick which was a definite plus. Training began on the rowing machine and he progressed well. Shane was always physically strong and he was able to channel this strength into his training. After a while and with a lot of dedication and long hours from his coach, Joe Cunningham, an Adaptive Rowing crew was formed which trained on the river in Castleconnell, Limerick several times a week; during one summer they were on the water at 6am! His times on the rowing machine were improving and he entered a few indoor rowing competitions in the Adaptive Category. Shane won the Irish Indoor and British Indoor

Rowing (BIRC) titles and also came second in the European Indoor Rowing Competition held in Rome.

Shane sat the Leaving Certificate in six subjects and did very well and secured a place studying a computer related business course in the Limerick Institute of Technology. He moved to student accommodation and installed his rowing machine in his bedroom, over the next three years he enjoyed his course with the help of the disability services in the college and his personal assistant Mary, whom Shane was delighted to find out was from a rowing family. His rowing commitments were increasing and he crossed the city a few times a week for training on the water, together with daily sessions on his rowing machine (or better known as an 'erg' i.e. ergometer). His other hobby at this time was learning the drums and he took lessons from a drummer from a local band which he occasionally went to see when they gigged in the city.

The intensity of the training was starting to make a marked improvement on Shane's health. His weight was well under control and dropping, his blood pressure was improving and the impact it had on his overall appearance and wellbeing was very apparent. He started to update his wardrobe, the XXL clothes changed to XL, then L. Shopping for clothes was no longer the chore it used to be and even his shoe width size went down!

Shane graduated with a degree in E-Office Administration after his third year in the college and he decided to take a year out to concentrate on his rowing training and impending qualification for the Paralympics. Trials were held for those competing for the places and he slotted into the number three seat in the Mixed Coxed Four boat; two of the crew were visually impaired, one member was an amputee and one had Multiple Sclerosis. With three of the crew based in London, getting the crew together for water training was at times a struggle; it either took place at the National Rowing Centre (NRC) in Cork or at a rowing club in London. With the assistance of the airport services, he was able to travel independently from Shannon to London, where he would meet up with other members of the crew and they would spend the weekend on the water. Shane at this stage had become very independent and did all his own organising on the rowing front – we were just told when and where to drop him off and pick him up.

The build up to the Paralympic Games was a busy time for the Irish athletes. The full Paralympic Squad met several times in organised residential camps where they trained with their own disciplines and got together as a group for sessions that would help them deal with the intensity of what was ahead of them, including interviews with the national radio and television. Following a final camp in Portugal they travelled to London for the games in August.

Family members and friends travelled to London to cheer the crew on. The rowing events took place at Eton Dorney over three days and unfortunately the budget for the games did not extend to television coverage of the rowing events so family and friends at home were unable to watch the races. Although they were hoping to come higher in the overall rankings, their races went well for them and they maintained their times. Competition with the other nations was stiff and the Ireland crew finished in 10<sup>th</sup> position. There was no doubt that the Paralympic Games was for elite athletes, the training which the athletes went through matched that which the athletes competing in the Summer Olympic Games endured.

Did we think that when we were handed Shane's diagnosis twenty years ago that he would reach such heights? A quote is hanging in the Rowing Club dressing room "*Build your weaknesses until they become your strengths*" (Knut Rockne), and I guess that is what Shane has done, and we are so proud of him.

Marie Ryan

The full version of this article is available via the Society's Website.

### **Volunteers Please!**

Have you a spare day or even a few hours once a year and would like to do something to help the LMBBS? Then Sight Village may be for you. Sight Village is a two-day exhibition, in Birmingham and London, offering the latest in everyday living aids, technology, specialist holidays, general advice and much more.

Sight Village is held in Birmingham every July and in London every November and we try to have an LMBBS Stand at one or both events every year, to raise awareness of the syndrome; it is a great event and one we recommend both to visit and to attend as an LMBBS representative.

Exhibitors, including large and small Charities as well as the major exhibitors in the field of vision, travel from all parts of the UK. The atmosphere is friendly and 6<sup>th</sup> Form Volunteer Guides are provided by the local school. There is always time to look around the exhibition and find out about the latest technology and it can be very fulfilling, chatting to the visitors to the LMBBS stand, who are often teachers or social workers, supporting people with the syndrome wanting to extend their knowledge.

Steve Burge, who manned the BBS stand at Sight Village, London in November said, "The show was very busy in the morning and a lot of people came to the stand asking about LMBBS. It is great that we are able to get our message out to the visually impaired community, as there were loads of people from both the educational and employment sectors who come across families and people, young and old, affected by the syndrome".

Steve was assisted by his friend Jane, who had this to say about her time at Sight Village:

"When Steve asked me to help on the LMBBS stand at the Sight Village event at Kensington Hall, I was delighted to say yes, not only because I would get to spend some time with one of my dearest friends, but also I hoped it would give me a clearer insight into Steve's condition and also how others manage their lives on a day to day basis. The whole event was organised very well and we had a great position for the LMBBS stand and many people stopped by to discuss the syndrome with Steve and also to just chat. It was great to witness so many aids and equipment available to assist visually impaired people and to see the stands so busy with interested people."

To Steve, Jane and all our volunteers who made it possible for the LMBBS to attend Birmingham and London Sight Village in 2012, a big thank you. If any of you are interested in helping out in 2013, please contact Chris Humphreys at [chris.humphreys4@ntlworld.com](mailto:chris.humphreys4@ntlworld.com)

or by telephone on 01633 718415 and she will be only to be pleased to provide further information.

## Fundraising Round-Up

Our heartfelt thanks to all of you who have been involved in fundraising in 2012; you have been cake baking, organising cricket matches, skydiving, boxing and more. We have had several youngsters working with their schools to raise money, families have been walking, cycling, and swimming and we have also received donations, some in memory of loved ones and others raised through family celebrations; it is humbling how so many of you remember the Society through good times and difficult times. We thank you from the bottom of our hearts



### Well Done Connor

Connor Hymers decided to fundraise for LMBBS during his school's Charities Week and designed a 'shoot-out' game using Nerf Guns. This was obviously very popular with all the students and he raised £50 over the week. Well Done Con and a big 'Thank You'!



### Thanks Greg

Greg Dowswell's school, 'The Academy Selsey', were having a dressing up day for charity and each student would be asked to donate a minimum of £1 to participate. The school asked for suggestions from the students where they thought the money raised should go.

Greg wasted no time in going to see the headteacher and told her all about LMBBS, the effects on his sister and the family and the benefits of attending the conference. She must have been impressed as after checking out the LMBBS website, she named LMBBS as the school's chosen charity. Well done Greg!



### Give As You Live

Shop online and raise funds for the LMBBS at the same time - at no extra cost to you.

We have teamed up with Give As You Live, an online tool which allows you to raise money whilst shopping on the web. Give As You Live works with your favourite online brands including Amazon, Marks & Spencer, Sainsburys, Topshop, Argos, Debenhams, Toys R Us and over 2,000 others to donate a percentage of the value of your purchase to the Society at no extra cost to you.

Give As You Live is completely free to sign up to and you won't pay a penny more for your shopping. Shops usually give commission to the companies who bring people's attention to their products (think Go Compare or Money Supermarket). Give as you Live passes this money onto the charity of your choice instead. Any organic searches or shopping that you do gets picked up by the Give as you Live app and lets you know how much money you're raising for LMBBS, simply by buying the products you love.

Give As You Live will tell you when you're on a website which is part of the scheme and when you make your purchase we will receive a free donation at no extra cost to you. It's that simple.

All you need to do is follow the three easy steps below.

1. Visit [our page on Give As You Live \(www.giveasyoulive.com\)](http://www.giveasyoulive.com)
2. Click on 'register as a user' and complete the form. It will only take 30 seconds – make sure 'Laurence Moon Bardet Biedl Society' is selected as your chosen charity.
3. Download the file and get shopping!

So, if you shop online anyway then why not raise valuable extra funds for us with Give As You Live.

**Amanda & Jason Wilbraham** organised an LMBBS Charity evening on 19<sup>th</sup> October 2012, selling 144 tickets and featuring the well known 'The Wholly Big Mac Soul Band' with a disco and raffle between appearances. It was a fantastic evening and raised £2,395, including a donation from Barclays Bank. Well done and thanks to all those who supported the event and donated raffle prizes.

### **Supermarkets give to Charities**

Many of the large supermarkets are now giving up to £1,000 to charities. If you would like to approach your local Manager and ask if they are participating, contact Chris Humphreys on e-mail: [chris.humphreys4@ntlworld.com](mailto:chris.humphreys4@ntlworld.com) or telephone: 01633 718415 with the name of the manager and store and Chris will send you the appropriate letter.

### **Gregg's Bakery**

Have you a Gregg's bakery in your area? Do you know any of the assistants who could nominate LMBBS as their chosen charity? We recently had a donation of £1,000 so again please contact Chris if you think you can help and would like a covering letter.



Since 1999 Action Challenge have been taking individuals, groups, charities and corporate clients on inspirational adventures across the UK, Europe and the Globe! They work with most of the UK's best known charities, and their challenge events have helped to raise over £30 million for these good causes.

The challenges are sometimes tough, often life changing, usually unforgettable, and always rewarding. So, whether it's climbing Kilimanjaro with some friends, walking the 100km to Brighton overnight with 3000 other adventurers, cycling 1000km from Lands End to John O'Groats, or as part of a speeding peloton heading out from London to reach Paris within 24 hours – they have the challenge for you!

2012 has been a year for sporting achievements; inspiring a nation to set personal goals, take up a new sport or activity and start on a journey to succeed in a chosen challenge. Action Challenge have responded to the market demand for short duration, low-cost, tough yet achievable challenges with a wide appeal and consequently developed a portfolio of challenges which offer something new and exciting for charities and participants alike.

In May 2012 over 1,500 walkers and runners set off from Richmond's Old Deer Park headed for Brighton – and this September will see a further 1,500 walkers take on a 50km and 100km trek along the Thames Path from Putney to Henley.

For 2013, Action Challenge are launching a third event in 'The 100KM Series', which compliments both the Thames Path and London 2 Brighton Challenge, offering a different take on the 100KM theme – the 'Trans Pennine Challenge'. A 100KM run and walk across the Pennines from Manchester to Sheffield, drawing participants to join from all over the country.

LMBBS have registered with Action Challenge for the three events in the '100KM Series' and invite the daring and adventurous among you to make 2013 a year to remember. For more information go to [www.actionchallenge.com](http://www.actionchallenge.com).



## New Year, New You

With the New Year upon us, have you been thinking about making changes to your diet and lifestyle to see if you can reduce your weight a little? Have you tried to lose weight before but found it incredibly difficult? Perhaps you've managed to lose weight before but were disappointed to find that you regained this loss over time? If you think you are ready to try again - read on for some tips which may help motivate the start of "a new you".

In order to lose some weight you either need to reduce your energy (calorie) intake or increase your activity levels (to burn off more calories). Combining both approaches leads to the best weight loss results. Remember, eating fewer calories doesn't necessarily mean eating less food - it means changing some of your food and drink choices to help keep you satisfied and feeling full.

Most of us know that for a healthy diet we need to eat lots of fruit and vegetables (5 portions/day), choose low fat and sugar foods, eat starchy foods (pasta, rice, bread) to help fill us up and protein (meat, fish, beans, pulses, tofu). But how many of us can say we make these diet choices every day?

## Interesting facts about weight gain and weight loss

How much weight do you think you'd gain in a year just by eating 100 calories more than your body needs every day? 100 calories is approximately a banana or a chocolate coated biscuit bar or one and a half plain digestive biscuits. Over a year this extra 100 calories each day could result in a 5kg or 11lb weight gain. As you can see it is easy to eat this extra amount; year on year this can really make a big difference to your weight.

Often when people are wanting to lose weight it is recommended that they should aim to lose one to two pounds per week. How much less do you think you need to eat to lose one pound? One pound of fat contains 3,500 calories. So you need to eat 500 calories a day less to achieve a weight loss of one pound a week.

However, to achieve long term weight changes, I recommend making small diet changes and not thinking about calories at all! How many of us have tried cutting all 'naughty' foods out - this can only work in the short term. This approach is often followed by eating more of these foods than before as we keep thinking about the foods we're not allowed anymore. Remember small changes to your diet result in impressive changes to your weight and health in the long term.

### **So how much weight should you aim to lose?**

Adults should aim to lose five to ten percent of their body weight. If you can maintain this amount of weight loss it will have positive benefits for your health. So if you weigh 80kg this would mean aiming to reduce your weight to between 72 and 76kg.

### **So how to get started?**

Choose one or two small dietary changes to start with. When you've successfully achieved these goals, you can add in new targets or build on the goals you've already made. At this stage you may find it useful to find someone to share your weight loss journey with, either someone else trying to lose weight or someone to support you. Your support 'friend' doesn't have to be a friend or family member, perhaps a local health professional, someone from the LMBBS clinic team or the LMBBS Facebook group might be perfect to keep you motivated. Share with them the good and bad times, let them know how they can support you best, maybe with a weekly phone call, or by going with you to the gym once a week or just listening when you need it.

It is important to remember that losing weight is not simple and can be quite challenging at times. It is completely normal to have the odd 'bad day'. How we treat the bad days is often the secret to success in the long term. It is important to just get straight back on track with your healthy eating plan and activity goals. This is the time to think about the progress you've made, perhaps your clothes are feeling a little looser, you are now eating five fruit and vegetables a day or you can walk further. It is also the time to refocus on your longer term goals, for example, weight loss, reducing your risk of type 2 diabetes or improving your diabetic control.

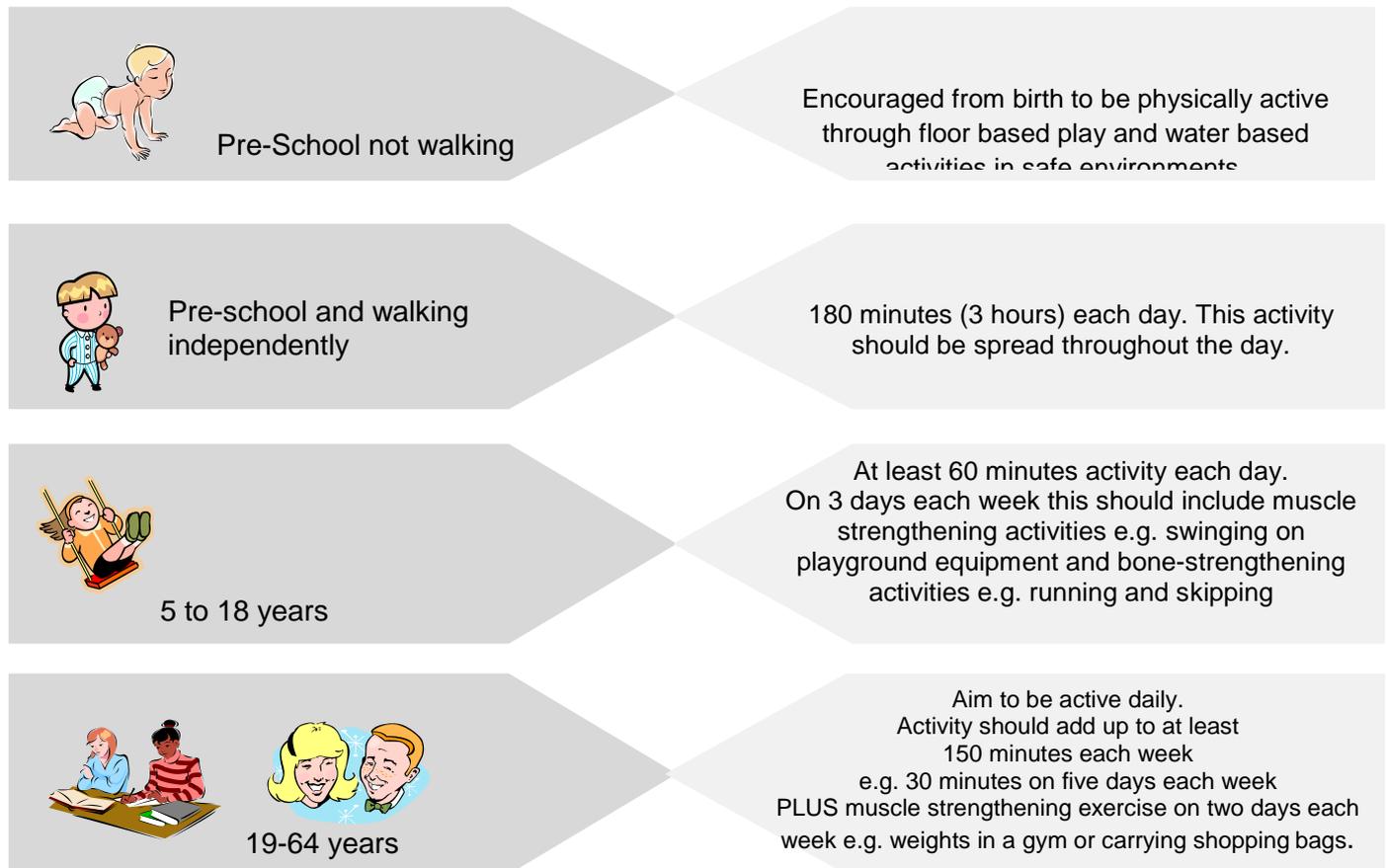
The following healthy eating tips may be diet changes you'd like to adopt as your personal goals to help you lose weight:

- Always eat breakfast. Research has shown that people who eat breakfast find it easier to control their weight and are slimmer than those who don't.
- Aim to eat more fruit and vegetables each day. Remember one serving is roughly a handful of any fruit or vegetable. Fruit juice and dried fruit can only count as one of your portions. Potatoes, cassava, yam and plantain do not count as they are starchy foods. Aim to work towards achieving your 5-a-day.

- Change the balance of the foods on your plate. At lunch and your evening meal, half fill your plate with vegetables or salad and divide the other half between meat, fish, beans and pulses and starchy foods e.g. pasta, rice, bread, potato. The extra vegetables help you feel fuller for longer and they are lower in calories than the starchy and protein foods they replace. This means you also eat less total calories at the meal time without eating any less food - a win-win situation!
- For adults - if you drink alcohol try to cut down a little. Alcohol is high in calories and these are extra calories on top of your food. Remember also that if you drink too much, your good intentions can go out of the window that day and possibly also on your recovery day too!
- Look at your snacks, such as crisps, cakes, biscuits, sweets and chocolate - try to choose healthier options, choose small portion sizes and gradually cut down on these treat foods to a maximum of five portions per week.
- If you eat a bag of crisps every day, why not cut down to alternate days and have fruit instead sometimes?
- Rather than potato crisps try puffed potato, rice cakes or corn based snacks such as Quavers, PomBears, Skips, Wotsits and Snack a Jacks as these have a lower energy content.
- Try water or low calorie drinks. If you have sugary squashes or fizzy drinks - change to 'no added sugar', 'sugar free' or diet drinks. Water is calorie free and a glass of cold water before or between meals can help fill you up. Why not try replacing sugary drinks with water?
- Change to a lower fat milk - if you are over five years of age, try skimmed, 1% fat or semi-skimmed milk rather than full fat milk. If you drink semi-skimmed milk, try 1% fat milk, a study showed the majority of people found the taste as acceptable as semi-skimmed.

The other way to help you control your weight gain or lose weight is to incorporate physical activity into your lifestyle. Do you know how much exercise is recommended to keep us at optimum health? Shown below is the UK government recommendation for exercise according to age. Select the age that is relevant to you or your child and look at your target for activity.

## UK Government Recommendation for Exercise



If you would like more information about ideal exercise amounts for you - chat to your BBS clinic team, your GP or look at this NHS website:

[www.nhs.uk/Livewell/fitness/Pages/Fitnesshome.aspx](http://www.nhs.uk/Livewell/fitness/Pages/Fitnesshome.aspx)

These exercise targets can look daunting, but remember that each ten minute block of activity counts, so it is easier than it first looks! The following tips may help you get more active and again, one or two of these could be chosen as your personal goals:

- Look for easy ways to fit more activity into your day-to-day life Can you stand rather than sit when you are peeling vegetables or talking on the phone? Getting off the bus one stop early or parking further away makes you walk further.
- Remember to slowly build up the amount of activity you do each day. This way the activity becomes routine, not just something you did for a couple of weeks.
- Perhaps it is time to increase an activity you like or used to enjoy doing, for example, horse riding or swimming weekly. If vision issues are holding you back, find out what VI activities are available in your area. Download your free copy of 'Doing Sport

Differently' for more information. [www.radar.org.uk/publications/doing-sport-differently/](http://www.radar.org.uk/publications/doing-sport-differently/)

- Record your planned activities in your diary or calendar, you then have the satisfaction of ticking off each activity and you can look back to see how much you've achieved.
- Set your own challenges in your chosen activity, this can really help to keep you motivated, for example:
  - If you can swim six lengths in 20 minutes, try to increase the number of lengths you swim in this time or increase the total time in the pool.
  - A pedometer (step counter) will let you know how many steps you do each day. Try increasing this number over time. VI pedometers are available.

For extra support why not contact your GP, Practice Nurse or someone from the BBS clinic team, such as your dietitian, clinical nurse specialist or BBS support worker, we would all be happy to help.

Sarah Flack  
Principal Dietitian, Great Ormond Street Hospital for Children NHS Foundation Trust

Contact details: 020 7405 9200 extn 5941 (Thursday & Friday)  
Sarah.Flack@gosh.nhs.uk

August 2012



### **Emma and Tommy-Boy's Coast to Coast Ride**

Emma Oates and her son Tom, 15, undertook a massive challenge in the summer to raise money for LMBBS. Along with a group of children and staff from St Aidan's School, they completed an incredible 225 mile, Coast to Coast, tandem bike ride from Flamborough to St Bees. Here's how they got on:

"We left Flamborough at around 11.15am after first dipping our wheels into the sea. It was quite a spectacle for onlookers who watched us carefully descend the steep steps to the beach with bikes in hand; this was particularly awkward with the tandem but Tom was determined that the wheel was

going in the sea. The ride across to Helmsley where we stayed on the first night was mainly flat with a few undulations and the group were in good spirits. As we were grinding away up a bit of a hill, I looked up to see our friend Mark, who had peddled out to meet us from Malton. We arrived at Malton Youth Hostel at 8.15pm and were greeted by my daughter, Katie and husband, Steve, with puppy in tow!! The Archbolds and Florence were all waving union jacks and cheering us in, what a treat and a real boost to us all at the end of the first fifty five miles. Thank you!!

We woke at 7am on Tuesday morning to slightly more overcast conditions. After a good breakfast and quick check of the bikes, we set off from the youth hostel just after 9am. We climbed out of Helmsley on the main road towards Sutton Bank and then took a left turn down into Ryedale. We then turned up a grinding hill and climbed right onto the top of the North Yorkshire Moors. I was fairly tired at the top and the sun was burning through so we stopped to take a drink and apply lots of sun cream!

What happened next was unexpected and to be honest, fairly scary. We began the descent into Ampleforth which was a long sweeping road. With the weight of Tom and I, the tandem flies downhill but I am very conscious that I have to be careful because I have Tom on the back, so I tend to brake all the way down hills. Not understanding the effect this would have on the bike, I kept the back brake on all the way down. Because it was such a hot day, the rim of the rear wheel overheated and caused the tube and tyre to blow big time. It happened so quickly that I never had time to think, instinct just took over. The bike was snaking from the side to the middle of the road and it took all my concentration and nerve to bring it to a safe stop. I was very shaken up at the thought of what could have happened, both in terms of Tom and I crashing and the fact that the rest of the group were behind us.

Anyhow we were safe but the bike was not useable. Steve arrived like a knight in shining armour (well in a white van at least!!) with our spare tandem and we switched onto it for the next 40 miles whilst he drove the damaged one off to be repaired. He intercepted us later at Thornton Steward and I was relieved to be back on the original bike. The difficulty with the replacement tandem was that it is not road specific and has big wide tyres, so it was really really hard work for us to peddle and catch up with the rest of the group, which took its toll on me later in the day. By the time we reached Snape, I had lost it, no energy and sore legs. Tom was also struggling and although there were no complaints from the back of the bike, there was no power or conversation either and I could tell he too was feeling tired. So we were relieved to stop, take a rest and some food and drink. I was even more relieved when Tom's Deputy Headmaster, Mr Burt, offered to take the front of the tandem for a bit and I enjoyed the rest. We stayed at Grinton Lodge, between Layburn and Reeth at the end of day two, in the most beautiful surroundings and I was relieved to get showered and fed and get a good night's sleep.

We awoke on Wednesday to another sunny day. Everyone was in good spirits and I was in a particularly good mood because my friend Clare had pitched up to come and join us for days three and four. Clare and I have peddled many miles together and had some fabulous adventures on the bikes, so it was great to have her along. We began the day in very good humour with a descent into Reeth and then we began to peddle up Swaledale. The road here is undulating and I could feel the efforts of the previous day, especially in my thigh muscles which were hurting up the hills. We arrived at Mucker and stopped for a drink and a snack. Mr Park, Tom's teacher and organiser of the

ride, offered to take Tom and the tandem from here up to the top of the Dale and to be honest, I didn't put any argument up, I was more than happy to have a little rest.

We arrived over the Cumbrian border and the weather changed, blowing squally showers of rain across us as we attempted to have our lunch on the very top of the hill. Once eaten, and in view of the close shave we had yesterday, I decided that it would be better for me to go back on the tandem for the decent off the tops and down into Kirkby Stephen. I was quite nervous, conscious of how shaken I had been at Ampleforth the day before. I went ahead with Tom and Clare rode along side me until we reached the bottom. I tried to dab the brakes on and off instead of just holding them on, It was a good descent and we arrived at the bottom in one piece. Mr Burt offered to take the tandem for the next bit and happily I enjoyed riding his solo bike again, encouraging Tom to push hard as we made our way along the ten mile stretch to Appleby, where we stopped for ice cream. We ended the third day at Dufton youth hostel around eight miles out of Appleby and once showered and fed and the children were all in bed, Clare and I enjoyed some good laughs and a drink.

We awoke on day four to torrential rain. This was not what we wanted and the staff, Clare and I made light of it with the children in order to keep their spirits up. Despite the very heavy grey Cumbrian rain, the kids all remained upbeat and there was a lovely moment when we were all astride our bikes ready to go when they all rang their bike bells, it was like something out of a Queen Song and such a joy to see them maintain their good humour. We peddled on to Penrith and beyond, stopping for lunch in a great cyclist's café, where we were treated to hot soup and hot chocolate. The rain was beginning to die away and we continued to Keswick and then to the base of Honister Pass. Mr Burt agreed to take Tom up this hill which is about two miles long and includes two 1:4 sections. There was no argument from me and I happily climbed it on his bike whilst he a Tom grinded away to the top, where our Youth Hostel and place of rest for the evening was waiting for us.

Again, it was a bonus that Steve, Katie and Tom's friend Rebecca came to meet us for tea. We all stood at the top of the hill watching the kids peddle to the top, encouraging each other up, the stronger ones helping the weaker ones along, it was a joy to see. After our meal it was time to say goodbye to Steve, Katie and Rebecca. . .and reluctantly I had to let Clare go home too, after two great days cycling together.

We woke on the last morning to a lovely day! The descent from the top of Honister is particularly steep and I decided, in view of the Ampleforth incident, to walk down with Tom, whilst the tandem was carried in the minibus. We set off before the rest of the group and got on the bike about 2/3rds of the way down the hill, the steep bit behind us. We peddled on with purpose, almost able to smell the sea air and the end of our 225 mile journey. Morale within the group was high and I could sense the kid's feeling of pride and achievement. With just over thirty miles to go, we never stopped for lunch; we were all just so keen to get to St Bees. With around two miles to go, we could see the sea and this drove us on to the end. We arrived, tired but delighted at around 2pm and rushed down to the waters edge to dip the front wheels of our bikes into the sea.

All in all we had a great week, spent with an amazing bunch of children and staff. As a family we were very touched that St Aidan's chose the Bardet-Biedl Society as the nominated charity for the

ride and are very grateful to everyone who donated. We had pledges of over £3000 and have collected around £2600.

Not long after the Coast to Coast challenge, Tom's headmaster, Mr Wood, nominated him for a Future Hero award at Harrogate local radio station, Stray FM. Future Heroes are awarded to young people who make difference to their community and Tom was awarded the Fundraiser award for his Coast to Coast venture. We were all invited to the award ceremony which was broadcast live on air on the breakfast show. We were all so very proud of him."



### **Cake and Cricket**

Darron Jones organised a cricket match between Usk Cricket Club and Newport Dragons to raise much needed funds for the Society. It was a wonderful afternoon on the only sunny day of the week, with an all day barbecue and an evening of entertainment provided by a band with an auction and raffle. Unfortunately, Usk Cricket Club lost to the Newport Dragons, but it didn't spoil the enjoyment of the day. Darron's daughter, Ellie, did some fundraising of her own, she writes:

'When Dad decided to arrange the cricket match, I had a good idea to have a cake stall (because I like cake!!) I asked my Nana, Grandma at the Farm, Aunty Lynda and Aunty Sarah to make me some cakes and I made one as well, a chocolate fudge cake, my favourite. Grandma's Welsh Cakes were the best seller but I didn't have any. My favourite were the flapjacks which Aunty Lynda made. Lots of people came and bought some and we made a lot of money. I had lots of fun and hope to do it again next year.'

The Humphreys family attended the event and had a fantastic day. They bought Ellie's fudge cake and thoroughly enjoyed it, well done Ellie!

Many thanks to all those who took part, on and off the pitch. An amazing £1,345 was raised for the Society, with an additional £540 raised from the auction of two jerseys, one donated by Ryan Jones, Patron of the Society and another donated by Jonny Fegan from Northern Ireland.

### **Flying the Flag for LMBBS**

My name is Keiran Taylor and I've just finished a three year extension course with subjects in cookery, art, drama, and gardening at Motherwell College. One of the classes I attended was Art Enterprise, which involved various activities and included an idea to raise money for charity. We were asked by our tutor, Heather, for ideas and to provide proposals as to what charity we should collect for. Not one to let an opportunity of fundraising for the Society go by, I suggested the LMBBS charity and everyone agreed.

I provided information and used the webpage and booklets to make people aware of and understand my condition. To raise the funds, we did a sponsored walk so that we could all be involved and get us out of the class with the weather being nice. So it was the following week we did our walk and everyone who attends the extension program paid a pound to take part; the bad news was that it rained during the walk. The money was collected and donated to LMBBS.

I start at another College in September and will definitely fly the flag for LMBBS and nominate it for any charity donations.



### **A Letter from Emily:**

'Summer so far has been very busy and exciting. Firstly I made my Confirmation in May, which was a lovely occasion with all my family attending.

In June I was invited to Stowe school in Buckinghamshire, which is an exclusive private school where Richard Branson went. I attended for a Kidscape weekend which is a charity based in London to help children who have low confidence, which I know a lot of BBS children have. I had an amazing weekend and everyone was really lovely.

In July, with the help of my mum and a few friends, we did a fund raising cake sale at our local church. We started baking on Saturday morning and met at the church for the first sale after the evening Mass. Lots of people brought cakes and by the end of the first sale we had sold out! We had to go home and make loads more cakes and baked practically half the night. It was worth it though because the next day more people brought cakes and along with the raffle we raised a pretty amazing £750 for the Society. I really enjoyed doing this and can't wait to do the next one.

The week after the cake sale, I had the opportunity to go on a canal boat holiday for a week with a group called Reach Out Plus ([www.reachoutplus.org](http://www.reachoutplus.org)). We started at Hemel Hempsted and went along the Grand Union Canal. The weather was amazing and I was really proud that I stayed the week, which was the first time I had been away on my own for so long. We are off to Ireland and France now for a family holiday, so I have been really lucky this summer to have done so much. The thing I am most proud of though, is my fundraising for the Society.'

Love Emily xx

## It's Good to Talk!

### New Families Contact



We are very pleased to welcome on board our latest volunteer, Claire Anstee, who 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 880386 or via email at [claire@anstee2.orangehome.co.uk](mailto:claire@anstee2.orangehome.co.uk)

### 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](mailto: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

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

### Your Society Needs You

Over the past three years, the LMBB Society membership has grown hugely, largely due to the success of the specialist clinics. With a growing and diverse membership spread across all of England, Scotland, Wales and Ireland, not to mention Europe and the rest of the world, it is hard for one committee to look after the needs of everyone as well as to keep driving the charity forward to bigger and better things.

Many years ago, we had regional representatives, whose role was to ensure that everyone was equally represented; however, over the years, people have moved on or lost interest. We would therefore like to ask if any of you would be interested in becoming a Regional Representative; we are especially keen to have someone based in Ireland and Birmingham. For more information or to express an interest, please email: [toniahymers@btinternet.com](mailto:toniahymers@btinternet.com).



In response to popular demand, LMBBS now has two FaceBook pages, 'Laurence-Moon-Bardet-Biedl Society', our 'international' page, and 'LMBBS UK' for UK based members only. This is proving to be an excellent way for the Society to keep in touch with its members, more importantly, though, it is

there for YOU to keep in touch with each other, so, if you haven't done so already, become a 'LMBBS FaceBook Friend' and keep up to date with the Society and its supporters.

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**We hope you have enjoyed this newsletter, don't forget, all of the contact details can be found at the beginning. The views and opinions expressed in this newsletter are those of the authors of the articles. They do not necessarily express the views and policy of LMBBS. Whilst every effort is made to check the accuracy of information reproduced, readers are advised to check with the original source before acting on it.**