

LMBBS Winter Newsletter 2011



Contact Details

Julie Sales, LMBBS Secretary and Clinic Support Worker, can be contacted on 01892 685311 or via email at Kevin.julie1@btinternet.com.

Tonia Hymers, LMBBS Newsletter Editor and Clinic Support Worker can be contacted on 01255 551886 or by email at toniahymers@btinternet.com.

Chris Humphreys, Conference Organiser and Clinic Support Worker can be contacted on (01633) 718415 or by e-mail at chris.humphreys4@ntlworld.com

For fundraising information or to join the Friends of the LMBBS please contact Anne Crotty on (01255) 507977 or by e-mail at anne_and_terry@yahoo.co.uk

The LMBBS web address is www.lmbbs.org.uk. All of these contact details are posted on our web site.

Foreword

Welcome to the Winter Newsletter 2011. This edition will bring you up to date with the LMBBS Conference 2012; places are filling up fast, so, if you have not yet returned your forms, please make it one of your New Year's resolutions.

You will also hear that we have had enormous success with our fundraising, in particular our marathon runners, which certainly brings to mind the old saying 'There is no gain without pain'. A big THANK YOU to everyone who has contributed towards fundraising this year; your efforts are very much appreciated and we have a very happy smiling Treasurer.

Thank you all, once again, for the continuing messages of concern and support that you have shown during my illness. I may have missed last year's conference, but I have no intention of missing Conference 2012, so come on, e-mail or post your booking forms and I look forward to catching up with you there.

All that remains is for me to wish you all, on behalf of the LMBBS Committee, a very happy Christmas and peaceful and prosperous New Year.

Chris

Congratulations!



Some of our members have had reason to celebrate since the last newsletter.

Julie and Kevin Sales celebrated their 50th Birthdays with a hot air balloon ride for Julie and their daughter, Danielle, and a trip to Anfield, to watch a Liverpool match for Kevin and their daughter, Hollie.

Allan Clark and Tonia Hymers both celebrated turning 40; Allan went to Majorca with his family and Tonia was surprised with a trip to Paris by her husband, Rob. Tonia finished her birthday week off with a family party, Hollywood style!



Jill & Bob Staples have become Grandparents for the second time, with the arrival of Elizabeth on April 27th, weighing 8lbs 8ozs, a sister for Daniel. Jill says, "Elizabeth is just starting to crawl and is such a happy, gorgeous baby and is always laughing."



Finally, there was cause for huge celebration in the Humphreys household, when, on 10th August, Chris and Phil Humphrey's granddaughter gave birth to their first great-grandchild, Rhys, weighing in at a hefty 9lbs 11 ½ oz. Phil already has him marked down as 'future No 8 for Wales'. Rhys' mum and dad, Lisa and Dave are members of the LMBBS Childcare Team.

If you are about to celebrate a significant event in your life, we would love to hear from you; you can send your news at any time to Tonia Hymers, toniahymers@btinternet.com or Chris Humphreys, chris.humphreys4@ntlworld.com



Working together to fight diseases caused by cilium dysfunction

Articles in previous Newsletters have referred to LMBBS's role as a founder member of the recently established 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 at 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 thought to be functionless, defective cilia are now believed to underlie many devastating genetic conditions, including LMBBS, Retinitis Pigmentosa, Alström Syndrome, Polycystic Kidney Disease (PKD), Primary Ciliary Dyskinesia (PCD), Usher Syndrome and several other rare conditions – the list keeps on growing.

As a founder member, LMBBS has a seat on the Board of the Alliance (which I was persuaded to occupy, having being lured out of retirement) and, by the time you read this article, the Alliance should finally have registered charitable status.

The long process of drawing up and agreeing the Alliance's Articles of Association and other constitutional documentation has not hampered planning for its first major event since its launch – a "Cilia 2012 Conference", which is planned for 17-18 May 2012 in London. Although the Conference is intended to stimulate and encourage drug companies, medics, researchers and other cilia scientists, and is not aimed at patients or support groups, representatives of LMBBS will be invited to the evening reception at the BMA on Wednesday 16 May, and LMBBS and the other Ciliopathy Alliance members will be on site throughout the Conference, manning an information desk at the adjoining exhibition.

Reservations are already being made, and this high profile, international Conference is expected to generate significant impetus to the fast-developing research into ciliopathies and their treatment.

Michael Parker

Transport For All

Transport for All believes in a fully accessible, reliable and affordable transport network for disabled and older Londoners. Membership is free and gives you access to all the latest news about accessible transport in the capital.

Transport for All (TfL) also provides an Advice and Advocacy service to deal with questions and complaints on transport in London – like how to replace a lost Freedom Pass, for example, or planning a step-free route. They are particularly keen to hear people's complaints and pass them on to transport providers!

TfL has also recently published a comprehensive 48 page booklet containing information, a map, contact numbers and helpful tips about ALL of London's transport services and travel schemes. Please contact Transport for All for your free copy.

For further information go to www.transportforall.org.uk/services/helpline/

LMBBS Weekend Family Conference 20th-22nd April 2012

The Hilton Hotel, Northampton

I am delighted to say that bookings for next year's conference are going exceptionally well and places are filling up fast. I know that there are many of you thinking 'Oh plenty of time, I'll deal with that later', but please be aware that the Conference is growing, year on year, and we are very likely to run out of rooms at the hotel. To guarantee your place within the conference hotel, we urge you to contact Chris Humphreys as soon as possible.

The programme is now available on our web page and includes talks by Professor Beales; Dr Helen May Simera; Ophthalmologist, Marie Tsalomous and Endocrinologist, Dr Barbara McGowan

There will be many activities available over the weekend. Richard Zimble and Steve Burge will host a 'music jam' for budding musicians. Sue King will display and demonstrate Visual Aids and Equipment. There will be a Dietician, Psychologist and Benefits advisor, hosting informal workshops and offering one to one or group discussion opportunities. There will also be an opportunity for adults with the syndrome to talk about how they cope with everyday life and answer any questions you may have. There will be many activities available for the children and, of course, there will be the usual resource and merchandise table, tombola and grand raffle and quiz.

To guarantee your place, please contact: chris.humphreys4@ntlworld.com or telephone 01633 718415 . We look forward to seeing you there.



Fundraising Roundup

What an amazing summer it has been! You have been walking, running, cycling, jumping out of a plane, selling things, dancing and donating. Many of these activities were in response to our SOC(K) Appeal. You have been so generous with time, money and energy that we are well on our way to holding our Annual Residential Weekend and Conference next year. Some of your fundraising articles can be found in this newsletter and there will be more to come in Spring 2012.

Our congratulations and thanks go to the Gwent Police Choir, who held a concert and raised over £850 for the Society; to Allan Clark, who walked the West Highland Way; he and his friends raised over £6,000; to Graeme Roache and his dad, Robert, who did a 36 mile tandem cycle ride from the East coast to the West coast of Scotland raising over £1,500, (this included matched funding from Robert's employer, Arqiva); to Howard Dickson, a friend of Julie and Kevin Sales, who ran the Tonbridge Half Marathon and raised £750; this has been matched by the Fidelity UK Foundation, bringing his total to £1,500; to Karen Masters and friends who organized a music and dance evening, raising £1,300, (including matched funding from Barclays Bank); to Darron Jones and work colleagues from MITIE, family and friends who took part in the Cardiff Half Marathon, raising around £5,000; to Alan Jones, who also tackled the Cardiff Half Marathon and raised over £130; to Heather Busby, a colleague of Jason Anstee, who took part in the Great Eastern Run and raised over £800; to

our own Dr Victor Hernandez, who ran in the TUI Marathon in Spain and raised nearly £500; to Brian Pugh who did a Parachute Jump Solo (assisted free fall) and raised over £600; to Sarah Green, Beauty Editor for 'You and Your Wedding', who sold the contents of her beauty cupboard and raised £350 for LMBBS; to Laura Murphy who held a Toy Sale outside her house and raised the fantastic sum of £100 and to our lovely Dr Helen May-Simera, who tackled the Beach to Battleship Iron Distance Triathlon (Iron Man) in California and has raised over £1,200 so far.

Many of these achievements will be boosted by Gift Aid so, as you can imagine, our Treasurer must be smiling. Well done, all of you, and huge thanks, also, to all of you who have made other donations and filled collection boxes (some of you as "Friends of LMBBS") and helped in any way to enable the Society to continue its work. Every penny that you have sent is treasured. We could not manage without your unstinting support.

There are other ways in which, with your participation, we can raise much-needed funds for the Society. If you would like to join the Weather Lottery, please contact me for further information. I have marked envelopes available, in which you can send your used printer ink cartridges and old mobile phones to Recycle4Charity; they are increasing the types of ink cartridges that they will take and for which they will send donations to the Society. Details can be found on www.recycle4charity.co.uk. Please contact me if you would like a Christmas catalogue for Yellow Moon. All purchases made from it will earn the Society up to 20% cash back. If you shop online at www.yellowmoon.co.uk, please don't forget to quote our unique Source Code SLM10001.

Earlier on, I mentioned the 'Friends' of LMBBS. We are often asked why we don't charge for membership to the Society and many members express an interest in making regular donations or fundraising for the group. As a 'Friend' of the LMBBS, you will have all of those options open to you. This scheme is completely voluntary and is separate from your membership with the Society.

You can become a 'Friend' of the LMBBS in three ways:

1. You can take a collection box and collect for the Society, or organise a fundraising event
2. Complete a regular payment form and make a monthly donation to the society from as little as £1 per month
3. Or you can combine both of the above

If you feel you would like to become a 'Friend' of LMBBS, simply contact me: Anne Crotty, Fundraising Co-ordinator, 13 The Vineway, Dovercourt, Harwich, Essex, CO12 4AX; 01255 507977; 07743 179412; anne_and_terry@yahoo.co.uk

Once more, a huge 'Thank you' to all of you who have helped and are helping the Society to raise the funds it needs to continue its work. We could not manage without your generous gifts of time, money and energy.

Anne Crotty

Hardest Hit Campaign

The Hardest Hit campaign, organised jointly by the Disability Benefits Consortium (DBC) and the UK Disabled People's Council, brings together individuals and organisations to send a clear message to the Government: stop these cuts. The campaign is supported by many groups, including RNIB, Deafblind UK and the Macular Disease Society. Many of you know, only too well, that cuts to benefits and services are stopping those with disabilities and those with long-term conditions and their families from living fulfilled independent lives. In October, the Hardest Hit campaign held events across the country to highlight that message and, on 22nd October, over 5,000 people took to the streets in towns and cities across the country, to add their voices to the call for a change of direction on welfare reform and an immediate end to cuts to vital local services. The campaign secured national press coverage and raised awareness amongst the general public, the media and politicians of its key messages.

To add our voice to the campaign, we wrote to Maria Miller, the Minister for the Disabled, on behalf of everyone at the LMBB Society, asking for her support in protecting those that need it the most. We wrote, "We at the Laurence-Moon-Bardet-Biedl Society have first hand experience of these issues. Throughout the country our members are already experiencing cut backs in the level of care they receive...".

We also expressed our concerns about the changes to Employment and Support Allowance and the introduction of the Personal Independence Payment (PIP), arguing that "PIP draft assessment criteria currently focuses on a much narrower range of support than DLA and therefore fails to recognize barriers preventing disabled people from fully participating in society".

We received a reply from a member of the correspondence team at the Department of Work and Pensions, which included the following excerpts:

"...over the past year, the Minister for Disabled People has made it a personal priority to meet regularly with disabled people, their families and disabled peoples' organisations. Many such organisations are already working closely with the Government to help shape its welfare reforms, including improvements to the Work Capability Assessment and the introduction of the Personal Independence Payment, which will replace Disability Living Allowance. "

"...Employment and Support Allowance for people in the Work Related Activity Group has always been intended to be a temporary benefit. For people in this group, there is an expectation that with the right help and support, they would move towards the workplace..."

"...The Government has therefore decided to introduce a one-year time limit on entitlement to contributory Employment and Support Allowance. By rebalancing the benefit system in this way, the Government believes it is being fair to recipients as well as making the support provided affordable to the taxpayer...."

"...The Government will ensure that when it introduces the Personal Independence Payment from April 2013 it treats disabled people fairly regardless of their place of residence and does not diminish disabled people's ability to get out and about..."

Despite the standard assurances in this reply, we continue to be concerned about how the proposed changes will affect our members and are keen to hear about your experiences of how the welfare

reforms are affecting you. In the meantime, we will continue to add our support and voice to groups and events such as the Hardest Hit Campaign.

<http://thehardesthit.wordpress.com/>

Mum's Graduation Day



As many of you will already know, LMBBS Newsletter Editor and Family Support Worker, Tonia Hymers, gained a First Class Honours Degree last year, after six years of hard work. Unfortunately, due to her LMBBS commitments, she was unable to make her graduation ceremony until this year. Not one to blow her own trumpet, we asked her sons to write a piece about the events of the day... (Chris Humphreys)

“When we arrived in our cab, Mum, dressed up in special robes, and Nanny were waiting for us; they had come early to get ready. Me, my brother Daniel, my Dad and Grampy got out and paid the fee to the taxi driver; we went over to Mum and Nanny and Dan said to Mum “You look ridiculous”. I laughed and then Mum asked if I was embarrassed; I nodded.

We then went through the building to the back where there was a beautiful courtyard with several fountains. Grampy took some pictures of Mum dressed up in her robes and then we all sat down; we looked in a booklet and had some drinks and food. After some more photos, we had to go inside for the ceremony; after a few mishaps, we found the entrance to a theatre-like room with tiered seats. Mum had to sit apart from us so she could go up onto the stage. I knew Mum was nervous.

The ceremony started with some music played by a band; then there was a procession of important looking people. Then there was a speech and the ceremony was declared open. The graduates had to line up in groups of graduates at a time. There was a lot of graduates and a few interesting speeches; it seemed to take hours until it was Mum's turn; when she was on stage, we stood up and when she took her certificate, we all cheered and shouted; I was really proud. A while later, there was a closing speech and everybody left. We waited outside in the courtyard and when Mum came out, me and Dan gave her a huge hug. We were really proud.”

Daniel & Connor Hymers.



Your Society Needs You

Over the past eighteen months, 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.



LMBBS Clinics



Healthy Eating, Healthy Living

The message to encourage healthy eating is everywhere, on television, in magazines and on posters in hospitals and GP practices, however, the reality is that following a healthy diet and trying to lose weight can be a challenge! The benefits of keeping to a healthy weight include feeling better about yourself, reducing your risk of Diabetes and keeping cholesterol and blood pressure low.

Portion Sizes - How Much Food Is Right For Me?

Have you noticed how the way we eat/live has changed massively over the last ten to twenty years? Different foods are available in local shops, people rely more on convenience meals and we are never far from food; snack food options are sold just about everywhere!

Have you ever thought about what has happened to portion sizes over this time? On a recent visit to a local Italian restaurant, a diner sent back their bowl of pasta as it wasn't big enough, which makes you wonder how our perception of portion sizes has changed. A few years ago the Food Standard Agency (FSA) decided to look into changes in portion sizes in the UK to see whether there was cause for concern.

What has happened to portions of food for sale in shops?

The FSA found that portions of ready meals have increased. Another clear trend was the increased range of portion sizes/pack weights available for sweets, chocolates, ice creams and savoury snacks. Smaller packs of savoury snacks or confectionery are usually only available in multipacks and only from larger retail outlets. This obviously impacts on the amount of these foods we eat. If we 'impulse buy' a bar of chocolate or bag of sweets at a train station or newsagent this is most likely to be a large bar/pack as smaller portions are not available. There are also 'sharer' type packs for energy-dense foods such as luxury cookies, American muffins, premium brand crisps and chocolate confectionery.... but do we always manage to share these foods or do we just eat more than we should?

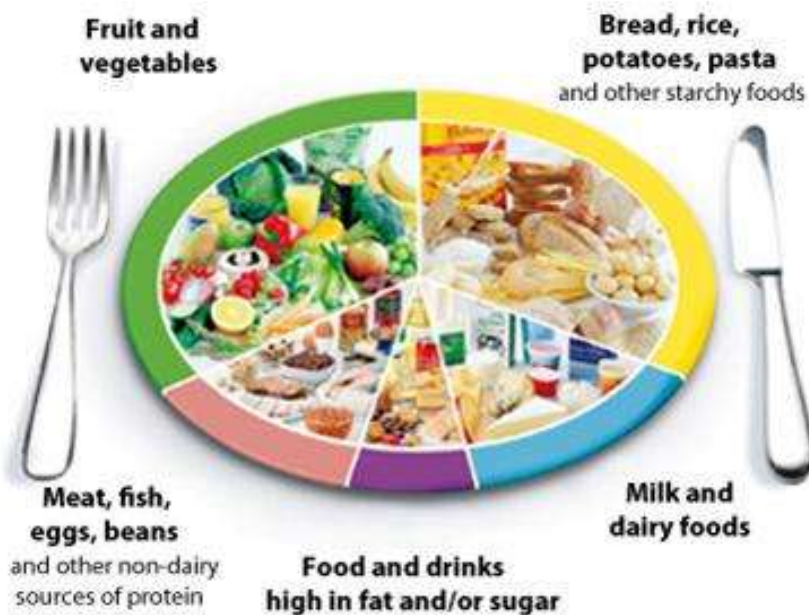
What is happening to food portions eaten outside of the home?

Over the past two decades portion sizes in UK fast food outlets and restaurants have increased. The option to "supersize" meals has become popular at many food outlets. This "supersizing" is when we are encouraged to buy a larger meal for little extra cost. As more people get used to eating these supersized portions, normal portion sizes start to look too small and it can be difficult to know what a healthy portion is. Did you know that if you order larger portions it can become a habit to eat this amount resulting in larger amounts eaten at every meal? If we eat extra calories on a regular basis, and it is more energy than our body needs, we **will** gain weight.

Did you know?

- A study by the World Cancer Research Fund found that burgers have doubled in size since 1980.
- Pasta servings are nearly five times bigger.
- The plates and bowls we eat from at home have also increased, with the average dinner plate being two inches wider than ten years ago - this is important because more food is needed to cover the plate.

The Eatwell Plate:



Department of Health in association with the Welsh Government, the Scottish Government and the Food Standards Agency in Northern Ireland
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The amount of food we need to eat depends on our age, body size and how active we are; everybody in your family will need a different amount. The eatwell plate was produced by the Department of Health to show the different types of food we need to eat (and in what proportions) to have a well balanced and healthy diet. This applies to everyone over the age of two years. Children under the age of two have different nutritional needs.

The eatwell plate can help you get the right balance from each of the five food groups:

Carbohydrates: These are our energy foods and include bread, potatoes, rice, pasta, breakfast cereals and chappatis. Wholegrain foods and granary/seeded breads are better for you as they provide slow release energy. We should aim to eat some of these with each meal. Some people think carbohydrates are fattening but they are not; it's what you put on top of them!!

Milk and dairy products: These foods help to keep our bones strong and we should aim to consume two to three portions a day. These foods can be high in fat and we should therefore choose low fat options such as low fat yoghurt or semi skimmed milk.

Fruit and vegetables: These provide us with lots of antioxidants to keep our bodies healthy. It is good to aim for a minimum of 5 a day, with one portion being roughly one handful. These foods also contain a lot of fibre so are great for filling us up if we are hungry. They are also low in calories so help to prevent weight gain. One portion of your 'five a day' can be one glass of unsweetened fruit juice, a piece of fruit mid morning or a salad with your meal.

Meat, fish, beans and pulses and eggs: These foods are also known as proteins. They are needed for children to grow and adults to repair themselves and we need about two portions a day of these foods. Some meats can be high in fat and we should therefore try to take off any visible fat and not fry these foods; grill, bake or steam them instead.

Fatty and sugar foods: These foods only have a small place in our daily diet. If we eat cakes, biscuits and chocolate too often, they can make us gain weight, so we should try to keep these foods as treats only.

Tips to help control portion sizes:

- Only cook what you need at mealtimes. If you do have leftovers, immediately freeze, refrigerate or place in the sink covered in washing up liquid so you avoid eating seconds.
- Use smaller plates or bowls at mealtimes. A small plate full of food is much more satisfying than a large half empty plate. For children of primary school age or younger, try to keep using a special child's plate as these are smaller.
- Avoid eating anything straight from the packet as it is easy to eat more than you realise. For large sharing types of savoury snacks – try to be aware of the suggested number of servings and try to divide it into these portions so you don't overeat.
- If you are eating out and given the choice of a regular or larger-sized portion, choose the regular portion. If you save money with the regular option, why not save the extra pennies and use them to treat yourself to something special.
- Never skip breakfast: you will feel hungrier later on and end up eating more and higher calorie foods.

A great way to control your calorie intake without drastically reducing your portion size is to increase the amount of vegetables on your plate and thereby reduce the amount of protein and starchy foods. Aim to increase your vegetable intake so it covers half of your plate, the remaining half can then be divided between equal amounts of starchy foods (rice, potato, bread, pasta) and protein foods (meat, fish, chicken etc).

If you are concerned about your weight or your child's weight, the following ideas and suggestions may also help:

- Try to have wholegrain starchy carbohydrates such as granary bread, whole-wheat pasta, and wholegrain cereals such as Shreddies or Cheerios. These have a lower glycaemic index (low GI), which means they will keep you full for a long time.
- Use low calorie options of high calorie foods, for example, replace full fat milk with skimmed milk, try 'light' hot chocolate, sugar free jelly, 'light' salad cream and low fat hummus to name a few.
- Down size your treats. Instead of a full size chocolate bar go for a mini size bar.
- Don't go shopping on an empty stomach. You will be more tempted to buy junk food.
- Eat at least 5 portions of fruit and vegetables every day - these help fill you up but have a low energy content. Try a piece of fruit as your mid-morning snack rather than raiding the biscuit tin.
- Eat slowly and chew your food well. This will make your meal last longer and will make you feel fuller - it takes your brain 20 minutes to recognise when you are full!
- Finally, if you feel full whilst eating your meal **STOP!** Don't feel you have to clean your plate.

Exercise is also important

This can be difficult for many who are struggling with sight and mobility but you don't need to run a marathon to keep fit! Just burning up an extra 100 calories a day could mean the difference between keeping healthy and adding inches to your waist. Try some of the exercises listed below.

The following activities will burn around 100 calories:

- Leisurely walk for 35 minutes
- Vacuum, dust and polish for 30 minutes
- Push supermarket trolley for 25 minutes
- Walk the dog for 25 minutes
- Climb the stairs for 12 minutes
- Carry heavy shopping bags for 15 minutes

Sarah Flack, BBS Dietician (GOSH) November 2011

Waseema Azam BBS Dietician (QEH and BCH) November 2011

As both Sarah and Waseema have shown, we can achieve great long-term health benefits, by being more aware of what we are consuming and by making simple and fairly small changes now. Our thanks go to both for their continued support and encouragement and we look forward to hearing more in future editions.

We would also be very interested to hear from any of you who have found effective ways of staying fit and active, so please get in touch and share with us what works for you.

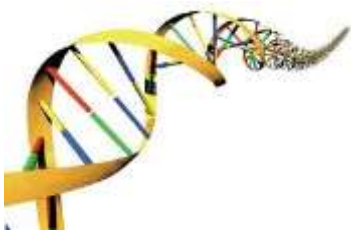


End of an Era

Nuffield House, Birmingham has been home to Renal Patients since 1994 and to LMBBS Clinics since June 2010. It was an old, but family orientated setting with cheerful and welcoming staff.

We happened to have a BBS Clinic on Nuffield House's very last day and the hospital was literally packed up around the staff and patients, who, fortunately, seemed oblivious to the chaos. One of the patients commented that they felt it was more 'organised than the last time they had attended', which indicates the organisational skills and professionalism of the hospital team. As we left at 1.45pm, the doors closed for the last time on Nuffield House.

The next BBS Clinic was to be held at the new Queen Elizabeth Hospital and we were apprehensive as to how our small specialist service would fit in to this new setting. Julie Sales, LMBBS Support Worker, attended the clinic and was delighted with how the day went; our patients received the usual very warm welcome and expert care and attention we have come to expect. Our thanks go to Karen Brooks, Julie Griffiths and all the staff for making the transition so easy.



BBS Clinics Genotype/Phenotype Study

The Bardet-Biedl Syndrome Clinics Team is currently trying to correlate genetic changes with clinical information. The hope is that, in the future, they will be able to give more detailed information specific to the genetic change that has caused BBS in each affected person. This might also help them to tailor each person's care more to their individual needs. For example, they would like to be able to predict when people affected with different genetic changes in BBS are likely to start experiencing problems with their vision and if some people are particularly likely to suffer with high blood pressure or diabetes.

At each clinic, blood is taken and sent to the laboratory to test for known BBS mutations. Patients are also asked to complete a questionnaire about how the syndrome affects them and how old they were when the different symptoms came to light. The team then compile the data, linking the questionnaire to the BBS gene and look for obvious correlations. To date, there has been a good response and already the team are seeing interesting links between genotype and phenotype; however, to strengthen the study, more data is needed. Although the form asks for your name and date of birth, all personal information will be kept confidential.

A questionnaire has been included with this newsletter so, if you would like to help, please complete it and send to: Kath Sparks, c/o Sam James, Level 5 Southwood building, Great Ormond Street Hospital, Great Ormond Street, WC1N 3JH.

Thank you from the BBS clinical team: Dr Elizabeth Forsythe, BBS Clinical Nurse Specialist, Kath Sparks, and Professor Philip Beales.

Thank You

We would like to share with you this lovely 'thank you' that we received from the mum of a child who attended a clinic recently:

"The LMBBS Support Worker took the time to answer all of my questions by email so I was well prepared and knew I could contact her if anything came to mind; I appreciated this accessibility. It was reassurance rather than assurance that we required and everybody helped us with this, especially the Support Workers. Most people were aware that we needed to be sensitive with our son (because this was the first time he was hearing about his condition in such detail) and I was grateful for this. I felt we all had time to say what we wanted to say, I didn't feel rushed and it all ran very smoothly and efficiently. I can't believe how many people were involved in the afternoon; I wasn't expecting that; you made me feel my son is important and worth investing time and resources into. I know BBS is rare so I guess I thought we'd be forgotten about, so I was stunned and relieved to find that we really do have people out there who are looking into BBS; thank you so much. I think having the LMBBS Support Workers there made the clinic extra special, their sensitivity and empathy helped put us at our ease and I really appreciate them giving the time to attend the clinic and making it a less scary, clinical experience."

A Dream Come True - Julie Sales



My daughter, Hollie, began to lose her sight in 2004, at the age of 10. To start with, she coped very well, having her work enlarged and things adapted around the house and in school. In 2006, Hollie was registered visually impaired and, as her eyes began to deteriorate, more help was quickly put in place to try and alleviate the stress.

Following three more significant sight losses, Hollie understandably became very distressed, which affected her confidence and her memory. She would forget where she was and forget the names of her family members. Various tests came back clear; however, week after week, she was getting more distressed and confused and her eyesight had, by this time, deteriorated quite considerably.

In January 2009, everything came to a major head. Hollie returned home from school terribly distressed and didn't know where she was or who I was; our GP confirmed that she had had a nervous breakdown. Hollie didn't go back to school and was on complete rest, which we thought, after a month or so, would see her slowly improve but this didn't happen. She was totally exhausted all the time and had terrible confusion. The worst part for Hollie was that she completely lost her memory; she didn't remember how to do the simplest tasks and we had to re-teach her everything, how to get out of bed, how to walk, wash, dress and eat. It was devastating for her and for us all to see. A visit to her paediatrician in February confirmed that she had severe ME. From then on, she was only allowed to do an activity for 10 minutes at a time, which would slowly be increased by 10% (1 minute) a week.

Very slowly, Hollie began to improve. Home tutors came into the house for 10-15 minutes at a time and then Hollie would rest. We have slowly increased the amount of time that she has with any activity and now, after three years, Hollie is managing to attend a Health Needs School locally for one to two hours, with additional visits from home tutors. Her confusion has slowly improved and she is managing better now, but we still have to be aware of her limitations and things still have to be done in a very precise way.

Through those very black days, Hollie would sit with me on the sofa and we would watch cookery programmes on the TV. These became her favourite programmes, and still are today, especially the Hairy Bikers, as they make her laugh.

We decided, about 18 months ago, to see if we could arrange for Hollie to meet the Hairy Bikers and contacted 'Dreams Come True' for an application form to start the process. She had to put down two choices and she chose to either meet JLS or the Hairy Bikers. When asked which she would prefer, she chose the Hairy Bikers (Si King and Dave Myers). It was the first time that Dreams Come True had been asked for the Hairy Bikers and, when the team contacted their agent, the duo were very happy to meet Hollie. With their very hectic filming schedule, it would take another year before Hollie fulfilled her dream but, in a way, we were quite glad for the wait, as that extra year gave Hollie more energy to spend extra time with them.

Dreams Come True contacted us in August 2011 to say that the Hairy Bikers were filming near Portsmouth, and that they would love to meet her. On Sunday 18th September 2011, we travelled down to Portsmouth to stay in a hotel for the night, ready to meet them the next day. It was like a mini holiday; we had a lovely afternoon and evening before the big day. The following morning, we were so excited; Zoe, from Dreams Come True, met us at the hotel and took us to our destination.

From the moment we walked into the room, Dave and Si made Hollie feel so at home, giving her a big hug, and letting her know how pleased they were to see her. We all watched as they carried on filming, and cooking, and always interacting with Hollie. They kept cracking jokes and generally being as funny as they are on the TV. Hollie had pride of place sitting next to the director, watching it all in awe. We all got to try all the dishes that they were cooking. Hollie also got to be filmed with the clapper board and to say 'Hairy Bikers Take 1'; she was so chuffed. All through the day she kept turning to me and saying 'This is amazing', which made our day!

Just when we thought it would all be over, they announced that we were having lunch with them all. That was such a special time for Hollie. They sat and chatted with us, while we ate the delicious food they had cooked. After lunch, they presented Hollie with some of their cook books and goodies, each one signed individually. After more photos and more hugs for Hollie, we watched them film another recipe, and they were still making us laugh. Hollie finally said she was tired, so we said our goodbyes. We spent a lovely four and a half hours with them all, and it was definitely a 'Dream Come True' for Hollie.

This is Hollie's account of the day:

My day out in Portsmouth

*In an old farm house in the middle of nowhere, I met two men. They had taken over the kitchen. They were Si King and Dave Myers, otherwise known as **The Hairy Bikers**.*

*In their kitchen, they were filming a new series called 'Britain's Best Dish'. This series is all about recipes and the history of them. I was lucky enough to be there because the organisation, 'Dreams Come True', made my dream come true. I got to meet **The Hairy Bikers**. It was amazing!*

Whilst I was there, they cooked ham hock and homemade piccalilli. I was sitting with the director whilst they were cooking, then, after they finished, we got to taste everything. It tasted very nice.

After they had finished filming, we got to have lunch with them outside in the garden. We had homemade moussaka, fish pie, ham hock and salads, followed by autumn pudding with cream.

After lunch, we watched some more filming. They made blueberry and lemon curd muffins. Sadly, I didn't get to try these.

The whole day made me feel very special. As soon as I arrived, they gave me big cuddles and kisses. The crew were very nice and looked after us all day. I was very happy. Before we left, they gave me some goodies to take home. There were loads of things like books on cooking (5 of these!), some pictures, a wooden spoon, and an apron. They were really nice people.

It was such a wonderful day that I will never forget.

We would like to say a huge 'thank you' to Si and Dave and their team for agreeing to meet us and making us feel so welcome and to Zoe, from 'Dreams Come True', for making it happen.

Julie and Hollie Sales



If you know a child who would benefit from having a special wish come true, there are a few groups in the UK who are willing to help. Dreams Come True and Rays of Sunshine have already granted the wishes of two of our young members, Hollie, who you have just read about and Daniel, who went behind the scenes at Legoland. The aim of both these groups is to grant wishes to children who live with serious or life-threatening illnesses or disabilities in the UK, and wishes can be anything from having a special day out, being a princess or pop star for the day, to a trip to Disneyland Paris. More information and application forms are available online. These groups also desperately need donations and funds raised to enable them to continue their very special work.

Rays of Sunshine - www.raysofsunshine.org.uk

Dreams Come True - www.dctc.org.uk

Exhibition News

We have exhibited at three venues this year, attending Sight Village Birmingham, Sight Support, Wales and Sight Village London. Our thanks go to all those who represented the Society, raising our profile and providing invaluable information to the many educational, medical and welfare professionals who attend these events. Chris Humphreys, who attended the Birmingham and Newport events, said "It is always a humbling experience and we enjoyed meeting many interesting visitors as well as catching up with old friends".

Richard Zimble, who has LMBBS, gave us this overview of his experience at Sight Village, Birmingham:

"I travelled to Birmingham from Welshpool by train on Tuesday 12th July, arriving at Sight Village in time for the opening. On the Thursday, I was going to be helping out on the 'Look' stand, so I went there first to drop off some leaflets and introduce myself to some of the people that I would be working with.

I then went to the British Blind Sports stand, where they were demonstrating Blind Cricket, one of the sports that they offer; I had a go at both batting and bowling. I love Cricket and am going to, hopefully, start playing soon. I then found a guide to help me around the hall to go and see the different stands in the Exhibition. The guides were amazing; they had either helped out at last year's Sight Village or had been given some basic sighted guiding techniques before it started. They had a map of the layout of the different stands and I got to visit all of the stands I wanted to see. The guides were excellent at guiding and I felt very safe.

On the Wednesday, I helped out on the LMBBS stand for the day. I got to talk to lots of different people and gave them a personal description of how I live with the syndrome. I also gave out some leaflets and took some donations for the Society. I enjoyed doing this as I feel, now that I am an adult with the Syndrome, I want to continue being involved and help out at different events as much

as I can, to promote the work of the Society and also to give people a better understanding of how someone with the Syndrome copes with it through their own personal life.

On the Thursday, I went to two of the talks, one in the morning and one in the afternoon and they were brilliant. I got to learn about the holidays that Torch Trust do and what they are all about and I got to hear about what the company Toby Davey does, which is putting audio description into theatres amongst other things.

Overall, I had an amazing time at Sight Village 2011 and can't wait for next year's event."

We welcome any volunteer who would like to help out at an exhibition in the future; accommodation is arranged and all expenses are paid. Please contact a committee member to register your interest; thank you.

Marathon Marvels

We have been overwhelmed by the incredible individuals who have gone to extreme lengths, not to mention pain, to raise much needed funds for the LMBBS; below are the stories of a few of them:

On the 16th October, Victor Hernandez ran in the TUI Marathon in Palma de Mallorca; he wrote:



"We had a hot and sunny day, reaching 24C by the end of the race, but the atmosphere was amazing. Most of the course followed the sea line of the city with the second 10K of the race in the historical centre of Palma. We ran in old narrow streets, in front of the La Seu (cathedral). The buildings were giving us some protection from the sun and we had a lot of people cheering. Most of the runners were running the Half-Marathon, so, when we left the city and they headed to their finish line, we found ourselves a little bit isolated. The last half of the marathon followed the coast and the tourist beaches. Tourists were sun bathing but, for us, the sun started to be an unpleasant companion. I ran a good part of this section with a couple of nice, friendly and experienced German runners who helped me to keep the pace. When I was heading to the last 10K, I had some cramps on both calves (the heat, not enough training,...who knows), so I had to walk/run and stretch for a bit. I don't think I lost more than 20 minutes from my final time, which was 4hours 57 minutes and 07 seconds. You can see me crossing the finish line at 2pm (hot,hot,hot...); it was a great feeling !!!

I think I raised around £500 and now I have to start thinking, what next!?"

I'm Up to Crazy Things Again - Howard Dickson



“In the past, I’ve done a number of strange and crazy things to raise money for charity. These range from pulling Post Office lorries to pushing prams round the town dressed as a sumo wrestler. So, when I saw and heard that Tonbridge was going to be hosting its own half marathon, I thought it was just too good an opportunity to miss out on.

Whilst I participate in a number of various sports these days, I didn’t actually realise how sluggish, my word for unfit, I had become!! Only after my first trip to the gym did I realise I was going to have to do some serious training for this. To make matters slightly more interesting, we moved house, then, the following week, went on holiday for a fortnight. So, instead of starting my 10 week training plan with a gentle 10 min jog, I jumped straight into week 5 of the schedule and was greeted by the need to do a 40 min run at race pace. Ouch, this was going to hurt.

Slowly but surely, the training intensified, the trips to the gym increased and the length of the runs got longer. I don’t know how but, within a few weeks, I was able to run for 90 minutes and, a couple of weeks later, this had increased to 2 hrs. I must surely be ready for the big day now.

The Thursday before the race, after an early morning trip to the gym, tragedy almost struck. I got into work and within half an hour couldn’t put any weight on my left foot at all. Surely all this hard work and effort wasn’t going to go to waste. Turns out I’d picked up a runner’s injury called “Plantar Fasciitis”; however, some good advice from a colleague and a bit of Googling to find some treatment meant I was soon raring to go.

So, the day of the race arrived and so did the sunshine; I wasn’t expecting to have to run in heat in the low 20s. Still, all good for the waistline!! At 10am on Sunday 25th September, Dame Kelly Holmes got the race under way and the longer the race went on the tougher it got!! 2hrs 14mins 36secs later, a very sweaty but happy Howie crossed the finish line - Now where’s that cold Guinness?!”

Cardiff Half Marathon



Darron Jones ran the Cardiff Half-Marathon along with his colleagues from Mitie, raising an incredible amount of money for the Society; he writes:

“The thought of doing the Cardiff Half Marathon filled me with dread; as most people will verify, I’m not the fittest guy in the world and have shied away from any form of physical activity for at least fifteen years. However, I was ‘persuaded’ by work colleagues to take part after they suggested raising money for LMBBS and, after the initial enthusiasm wore off, the original numbers of competitors fell from 24 to 8 of work colleagues, family and friends.

My original training plans were scuppered after two weeks through back problems, dodgy hips and knees, which resulted in all my training being done on a cross trainer to avoid any impact damage; I figured I'd get myself reasonably fit, load myself up with ibuprofen on the morning of the race and go for it, not something I would recommend or you will find in any training plan!!

Before the start, I was very apprehensive and didn't think for one minute I'd complete the race; however, it went better than expected. My legs started giving problems from about 4 miles and I let my early running partners, Russ and Rachel Carter, continue on their pace without me. At 10 miles, I thought my hamstring was going to explode but I managed to get around in a very unimpressive 2hrs 39mins.

The best of the bunch was Nathan Kersley at 1hr 33mins, closely followed 42secs later by Peter Hopson. Russ Carter will never again forget to put his plasters on and, at the finish, looked like he'd been shot in the chest twice! Alan Jones was a source of inspiration, constantly enquiring how the training was going and shouting across to me to "dig in" whilst running further up the course. The following day, I lost the ability to walk and the pain was incredible and not something I'll look to repeat in a hurry!

Massive thanks must go to Sue Bateman who 'coerced' many of our Company's suppliers to make donations. We don't have the exact amount raised yet as we're waiting to collect on some pledges but, between us all, it should be around £5000 for a very worthy cause."

Darron's daughter, Ellie, says, "*I'm very proud of Dad running the half marathon and helping to raise a lot of money for the charity*".

Congratulations Helen – You Did It!



Finally, we are very excited to report that the incredible Dr Helen May-Simera has successfully completed a full Iron Man (2.4 mile swim/112 mile cycle/26 mile run), both fulfilling a personal dream and raising over £1,000 for the Society in the process. She reports:

"We managed to get to the race check-in with plenty of time the day before the race, which was tricky as I had to be at work for an important meeting in the morning. But, thanks to my hubby Chris and friend, Beth, who flew to the States from the UK to support me, we got there with an hour to spare. At the race briefing, the director went over the course with us and told us that the current during the swim was so fast that even an empty Doritos bag could make it in 1 hour 30. This really calmed me down and as such I was able to get some sleep the night before.

On race morning, we all got up at 4am and went to the start of the race, which was on a beach. Chris said he had seen dolphins in the water before we all started, but I never saw them. I had never swum in salt water before and didn't appreciate it when I got water in my mouth; however, the current was incredibly strong and I felt really fast; I was actually surprised when I saw the exit coming up so soon.

After a quick shower and change, I was on my bike. The first 70 miles were brutal as we had a 15 mph headwind and it was freezing. I could barely feel my fingers and toes but, after mile 73, we turned the corner and the wind was behind us, the sun had come out and it felt like a completely new day. It was a wonderful ride. My amazing support crew were leapfrogging me in the car so I had lots of cheering along the way. Every time I saw them, it gave me more motivation and encouragement.

Then, on to the marathon. To be honest, I think the endorphins had kicked in as I wasn't in that much pain and was able to pace myself pretty well. I would run from aid station to aid station, roughly a mile apart, then walk along whilst sipping water or eating snacks. It was an out and back course over some bridges, through downtown Wilmington, around a pretty lake and back. We had to do it twice and I was lucky as I had one loop in day light and one loop at night. So it felt like two very different loops. Also, so many of my supporters would run alongside me, which was a great distraction, and it felt like the time flew by. Crossing the finish line was an unbelievable experience; I sprinted to the end as I just wanted to be done.

I felt pretty nauseous after the race and that stayed with me for a few days. I was sore for a while, but it wasn't too bad, and I can proudly say I still have all of my toenails and I only had one blister. So, all in all, I think I survived pretty well. It was such a great experience. I can't wait to sign up again...

Can't wait to see you all in a few months."

Helen

Christmas Card Competition

This time next year, we would like to have lots of special LMBBS Christmas Cards being delivered around the country, which is why we are launching our Christmas Card Competition now. We want all our budding young artists to put on some festive music, crack open the mince pies and get in the festive mood. Send your designs, which should be in pen, pencil, crayon or paints and on A5 size paper, to Tonia Hymers at 43 Balton Way, Dovercourt, Harwich, Essex, CO12 4UP. The LMBBS clinic team at Great Ormond Street Hospital will judge the entries and the four winning designs will be announced in the next newsletter. The cards will then be sold at the Weekend Family Conference in April 2012. Good luck everyone; we can't wait to see what you come up with.

Our Tandem Adventure – Graeme Roache



"I attended last year's LMBBS Family Conference with my parents. This was our first visit and we were very impressed with all of the speakers and the huge contribution from the volunteers of the Society.

On returning home, my dad and I decided that we would do some fundraising on behalf of LMBBS. Since we both enjoy cycling and I own a tandem, this seemed like a good idea.

On 9th of August, my dad and I completed a 36-mile tandem cycle. We cycled from the East Coast to the West Coast of Scotland along the Forth and Clyde Canal cycle path. It was a beautiful day weather-wise and this made for a pleasant cycle which took us five and a half hours. It was such a relief to have a dry day (unusual for Scotland!) as, the following day, it was pouring with rain!!!

We began our cycle at the Carron Sea Lock in Grangemouth, heading homeward. Our first 'pit stop' was at the Falkirk Wheel where Mum met us with a promised treat of a 'hobnob'. We continued on to Bishopbriggs where we had a short lunch break. We met up with my Aunt Frances and Uncle Jim, who lived nearby, and had some photos taken.

We continued on to Lock 27 in Anniesland and then made our final push to the finish line at Bowling Basin. We were so elated at having completed the 36 miles, we decided to continue cycling until we reached home in Dumbarton - a further three miles.

This is just the start of our fundraising efforts and hopefully we can encourage more people to do the same. The whole experience was great fun and I look forward to doing it again next year."

Well Done Emmy!



Emmy Anstee loves horse riding and is a member of the Riding for the Disabled Association (RDA). We asked her mum, Claire, to let us know how Emmy was getting on; she wrote:

"Twelve months ago, we weren't sure that Emmy would be able to ride anymore with her local Riding for the Disabled Group. We'd had to leave one group because they only use small ponies and Emmy had gone beyond the weight limit. As you all know, weight management can be a constant battle for most who have LMBBS.

Emmy was registered with another RDA Group but, again, the only pony that she could use was under the care of the vet. We went along to the first meeting of the year, just to go and see everyone in the group, and Caroline, the wonderful lady who runs the group, had a surprise for us – she had bought a new pony so Emmy would be able to ride. Emmy was so pleased and even though we weren't prepared, she borrowed some boots and off she went. It was her first ride in months and great to see her back on a pony.

The group runs on a Tuesday lunchtime and, as Emmy is in school, she only rides in the holidays. Her next riding session was Easter and Caroline asked her if she would enter the RDA Fun Day which was to be held in July. She wanted to enter her in two categories, the 'Dressage' and 'Countryside Ride'. Through the Summer holidays, she also wanted to see if she could take her RDA Grade 3 exam.

We all took a day off work and school for the Fun Day; thankfully, the weather held off and what an amazing day we all had. Emmy had the Dressage event first; she was a little nervous but listened carefully to Caroline's instructions as they did the event. Next was the Countryside Ride and, just as they started, I suddenly realised that Caroline had taken her off the lead rein and she was riding independently. Now we were nervous!! Emmy was amazing; she rode the whole course off the lead rein, with Caroline walking by her side. It was very emotional for us to see her riding on her own.

The last event was a fancy dress ride in which Emmy, her sister Holly and her pony got to dress up. They loved it! We all gathered to hear the results of how everyone had done. Emmy won 1st place in both the Dressage event and The Countryside Ride event and Emmy had a face of complete

amazement; we were so overjoyed. To think a few months before she wasn't even riding at all! In the Summer, Emmy took her RDA Grade 3 exam and passed and, the following week, Caroline announced that Emmy had been given the 'Achievement of the Year' award in her riding group.

When Emmy was diagnosed, I just wanted to find something positive for her to be involved in, which led me to our local RDA group. For a child that has no depth perception and hates being off the ground, I was worried about how she would cope with being on a horse, but had been told that lots of visually impaired children enjoy riding.

Emmy loved it; we couldn't believe she didn't appear nervous and we've never looked back. I cannot begin to tell you how much the RDA has given Emmy confidence over the last three years. Caroline tells me Emmy is a natural, but the work she and all her volunteers do is just amazing for all the children who ride. I would recommend the RDA to anyone; they have given Emmy so much joy."

Claire Anstee

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.

