

LMBBS Spring Newsletter 2012

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Foreword

2012, and what a year it is proving to be.

In 1987, a pilot meeting was held by a small group of parents of youngsters with LMBBS, to initiate a support group. As we reach our landmark 25th year, we reflect on the saying 'from little acorns grow large oak trees', and that is certainly true in the development of LMBBS. With the introduction of the Bardet-Biedl Clinics in 2010, held across the four centres in Birmingham and London, we have seen huge growth in our membership and are involved in exciting new projects.

We are overwhelmed by the achievements of many of our members; Richard Parker is to be congratulated on his progress in the art of Seido Karate. Hannah Young is progressing very well with Blind Cricket, and many more of our younger members are to be commended for their enthusiasm in the pursuit of a healthy and active lifestyle, enjoying swimming, horse riding and gym sessions, amongst many other activities.

We are particularly excited to congratulate Shane Ryan from Southern Ireland, 'our first Olympic entrant in the Paralympics'. Aged 18 years, Shane is the youngest member of the team to be selected for the rowing event at the London Paralympics; the full report is coming up.

We are very grateful to report that 2010/11 has been another excellent year for fundraising, particularly considering the current financial climate and we thank each and everyone who has contributed. Keep up the good work.

This time of year is, of course, conference time and this year is looking to be our most successful conference to date, with a record attendance. If you missed out on our conference this year, booking forms will be available from late October and early booking is

recommended. Conference dates for 2013 are 19th/20th/21st April. A full Conference Report will be available in the summer.

As mentioned, the Society has grown hugely and is involved in many exciting projects; however, we are proud to say that the Society remains firmly focused on its original aims which are to preserve and protect the health and promote the welfare of persons affected by LMBBS and their families and to advance the education of the medical and educational professions and the general public on the subject of LMBBS and its implications for the family. We always have been and always will be committed to this aim. Enjoy your newsletter and don't forget to keep in touch with all your news; we look forward to hearing from you soon.

Chris Humphreys

Congratulations!

Congratulations to James Humphreys on his 30th Birthday, which he celebrated on 5th January with his family and friends. James enjoyed lunch out and rounded the day off in true style, with an evening at a rock-climbing centre. 'Adrenaline Junkie', James, received a gift of a helicopter ride and an indoor sky-diving experience; however, January's high winds meant the helicopter ride was postponed till March, when he will also enjoy the sky-dive. James is also eagerly awaiting the action packed rides of Drayton Manor Theme Park in April, when he attends the LMBBS Family Conference.

Congratulations to Drina and Michael Parker on the long awaited safe arrival of their first grandchild, Grace Eliza, on 9th January 2012, weighing 7lbs. Grace is pictured with her delighted parents, Gareth and Kate.

Congratulations to Alison Saxon and her partner, Kevin, on the birth of their grandchild, Olivia Louise, on 11th December 2011, weighing 8lbs. Our congratulations also to Olivia's delighted parents, Stephen and Amy. We are also pleased to announce Alison's and Kevin's engagement, which will be officially celebrated this coming summer. We look forward to news of the wedding which will take place in the summer of 2013.

The Fundraising Standards Board

We are very happy to report that our application to become members of the Fundraising Standards Board (FRSB) has been approved. The FRSB is the independent self-regulatory body for UK fundraising and is backed by the Office for Civil Society, the Scottish Government and the Welsh Assembly Government. The FRSB helps members comply with fundraising best practice in order to raise standards and build public confidence in fundraising; members are able to use the 'give with confidence' tick on all fundraising materials. As members of the Fundraising Standards Board, we agree to follow the Codes of Fundraising Practice and are committed to The Fundraising Promise which represents a commitment to the highest standards of good practice and ensures that all of our fundraising activities are open, legal and fair.

The Fundraising Promise

We Are Committed to High Standards

- We do all we can to ensure that fundraisers, volunteers and fundraising contractors working with us to raise funds comply with the Codes and with this Promise.
- We comply with the law including those that apply to data protection, health and safety and the environment

We Are Honest and Open

- We tell the truth and do not exaggerate
- We do what we say we are going to do
- We answer all reasonable questions about our fundraising activities and costs.

We Are Clear

- We are clear about who we are, what we do and how your gift is used
- Where we have a promotional agreement with a commercial company, we make clear how much of the purchase price we receive
- We give a clear explanation of how you can make a gift and amend a regular commitment

We Are Respectful

- We respect the rights, dignities and privacy of our supporters and beneficiaries
- We will not put undue pressure on you to make a gift and if you do not want to give or wish to cease giving, we will respect your decision
- If you tell us that you don't want us to contact you in a particular way we will not do so

We Are Fair and Reasonable

- We take care not to use any images or words that cause unjustifiable distress or offence
- We take care not to cause unreasonable nuisance or disruption

We Are Accountable

- If you are unhappy with anything we've done whilst fundraising, you can contact us to make a complaint. We have a complaints procedure, a copy of which is available on request. If we cannot resolve your complaint, we accept the authority of the Fundraising Standards Board to make a final adjudication
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Paralympic Dream

Congratulations to Shane Ryan from Limerick in Southern Ireland, for being part of the first Irish crew to qualify a boat for the London Paralympics in rowing. Shane says, "It is a dream come true to be rowing. It's very exciting, especially as it is in London and we at the Paralympics are gearing it as the 'HOME GAMES'. We are currently training very hard and are very motivated to reach the goal that we have set ourselves."

Shane began rowing in 2007, when he joined Castleconnell Boat Club, which was the first Irish club to promote adaptive rowing. He competes in the LTA category, which means he is able to use his legs, trunk and arms and he competes with the Irish Adaptive Rowing Team. Shane has already enjoyed considerable success as an individual, winning gold in 2010's LTA Open World Indoor Rowing Championship and he has travelled extensively, competing in places such as Poland, Munich and Boston. All of the competitions that Shane has competed in are regular rowing competitions with events for adaptive rowers, which makes the sport very inclusive and means he is mixing with the top rowers in the world. Shane is the youngest member of the LTA coxed mixed four crew and 'Paralympics Ireland' say his appearance at London 2012 should be the first of many Paralympic honours.

Paralympics Ireland is the National Paralympic Committee for Ireland; they are a registered charity and their aim is to ensure that Paralympic sport is accessible and offers the ultimate dream to those who reach elite standards of performance, the opportunity to represent Ireland at the Paralympic Games. Held every four years, in parallel with the Olympic Games, this is the premier multisport event for elite athletes with a disability.

Rowing is the most recent addition to the Paralympic programme and appeared at the Games for the first time at Beijing 2008. All races are held over a 1,000 metre course and each country is only allowed to enter one boat in each classification. At London 2012, the programme will feature three classes; 'LTA' (legs, trunk and arms), 'TA' (trunk and arms) and 'AS' (arms and shoulders). There are two mixed-gender events, plus the men's and women's single-sculls. Rowing events at London 2012's Eton Dorney venue run from Friday 31st August to Sunday 2nd September and will begin with heats, with two boats from each heat qualifying directly for the final. The remaining boats will then compete again, giving them a second chance to qualify for the final and to row for gold.

Shane is one of Ireland's LTA Mixed Coxed Four team, and will be rowing with Kevin DuToit, Sarah Caffrey and Ann-Marie McDaid, coxed by Helen Arbuthnot. The team finished fifth in the 2011 World Rowing Championships, which ensured that Ireland qualified a boat for the first time ever at the Paralympic Games. This is an immense achievement and Shane's family and friends are understandably very proud of him. Shane's mum, Marie, says it is an ideal sport for anyone with a visual impairment; most rowing clubs include adaptive teams, as it is now included in the Paralympics.

Shane has said he would love to attend an LMBBS conference in the future and tell everyone about his experiences and we would love to hear them. In the meantime, if you would like to read more about the Paralympics or Shane's team, check out the following websites:

www.london2012.com/paralympic-sport
www.paralympics.ie/sport/rowing/

Paralympics Ireland also have a Facebook page and you can follow Shane on Twitter @ShaneRyan4

Need 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

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 or at 38 Pocklington Court, 74 Alton Road, Roehampton, London, SW15 4NN

Great Ormond Street Hospital Children's Charity announces plans to build a Centre for Children's Rare Disease Research

Great Ormond Street Hospital Children's Charity made the announcement on Rare Disease Day that it aims to raise money to build a Centre for Children's Rare Disease Research.

The Centre, estimated to cost £66 million to build and equip, will bring together clinical and research expertise from Great Ormond Street Hospital and UCL, in particular the Institute of Child Health. Once opened, the opportunities for children with rare diseases to participate in studies and help doctors and scientists advance understanding of their condition and find effective treatments will increase. Work carried out in the new Centre will mean that the hospital can start to help more children more quickly. Great Ormond Street Hospital is well placed for a centre of this kind. The hospital's clinical teams see many children with rare conditions from all over the UK and overseas, across a wide range of clinical specialities. It is the largest recipient of nationally commissioned NHS funding in the country, in recognition of the doctors seeing more children with rare diseases than probably anywhere else in the world.

The hospital's research partner, the UCL Institute of Child Health, is central to the hospital's plans. Professor John Tooke, Vice Provost (Health) at UCL said, "Together, rare diseases represent a major health burden, particularly in childhood. Tackling rare diseases, not only provides much needed help for these often neglected conditions, but can also provide unique insights into what is happening in more common conditions..." "...A particular focus of our effort is the UCL Institute of Child Health, which has longstanding strengths in this area. The Institute is a key contributor to UCL's approach to genetic analysis and treatment and currently there are four gene therapy trials running at Great Ormond Street Hospital. Cell therapy and regenerative medicine are other core strengths, for example, the recently publicised children's stem cell engineered trachea transplant."

Great Ormond Street Hospital Children's Charity is delighted that John Connolly (until recently the Global Chairman and Chief Executive of Deloitte) has agreed to Chair the fundraising appeal board. A successful fundraising appeal will lead to the centre opening in 2018. John Connolly said, "I'm delighted to have been asked to spearhead the appeal on behalf of Great Ormond Street Hospital Children's Charity. We need to raise £66m to build and equip the Centre, which will be located next to the hospital and the institute. Without these funds the project simply will not happen and the opportunity will be lost. I know from personal experience that much more needs to be done to help children with rare diseases and am convinced that The Centre for Children's Rare Disease Research will make an enormous difference to the health of children who suffer from rare diseases, not just in the UK, but all over the world. The scientists and doctors I've met from the hospital and institute are just starting to unlock the potential of 21st century medicine. They now know so much more about how the human body works, why it goes wrong and also how they might put it right. But they need our support so that they can grasp the unique opportunity in front of them and accelerate their valuable work to help many more children with many different conditions, some of whom still have little hope of diagnosis or treatment, let alone a cure."

Alastair Kent, Chair of Rare Disease UK, the national alliance for people with rare diseases and all who support them, is fully supportive of Great Ormond Street Hospital Children's Charity's intentions: "There can be few things more distressing for parents than to learn that their child has a rare disease that is little understood and about which little or nothing can be done. This is a very exciting development that families with children affected by these diseases will be thrilled to hear about. For too long the opportunities for sustainable research have been lacking. The new Centre at GOSH will have the critical mass to generate real expertise to help move us towards the point where more of the rare diseases of childhood are no longer untreatable; rather they will become treatable, curable or preventable. We look forward to a productive collaboration with GOSH in supporting the development of this Centre in the years to come."

Richard's Promotion and Kokoro Award

Some of you may have previously read my article, 'Difference doesn't mean Deficit' about Richard Parker who has LMBBS and is registered blind. Richard started training privately with me some four years ago and is now a student of the UK World Seido Karate Organisation.

Life is a struggle. Richard has to fight to make progress in Seido Karate as little comes easily to him. We value what we have to fight for. It makes us tougher-minded and better able to appreciate the gifts we do have. When we see progress in others who engage in their own struggles, we feel closer to them and have a better understanding of their life.

As Richard's karate instructor, I can see clearly the progress he has made since he started training with me, when initially we worked on balance and coordination. Indeed, in December 2011, he took his examination for the rank of advanced blue belt (7th kyu). Kyu is Japanese for 'grade' and refers to a rank designation, signifying a level of achievement below black belt. Richard needs to progress up to 1st kyu before he can take his black belt. Each grade is tougher than the last one.

In order to pass the 7th kyu examination, Richard had to show that he had mastered the previous syllabus and could demonstrate it at a higher level. This includes the warm-up pattern that we do to stretch the body in various ways before we start training. He also had

to demonstrate that he can deliver new material which includes punches, strikes, blocks and kicks with both power and control.

Our Seido self-defences are demanding. Richard had to deal with an attacker in front of him who aimed to hit him. He had to determine when the attack was coming, prevent it and then respond in kind in a controlled manner. These defences start in a straightforward way and then become more complex and demanding as they progress.

Finally, he had to show that he could execute a set series of karate manoeuvres against one or more imaginary attacking opponents. We call this 'kata'. The kata are highly complex and link back to the origins of karate. In our Seido Karate style, we have over thirty katas and each one must be mastered before you can progress to the next. Katas form the repository of all technical knowledge and need to be performed with balance and grace but demonstrated with speed and power. These katas demand balance, coordination and focus to a high degree for any student, but Richard has met the challenges the techniques demand and proved equal to them. You will see from the picture just how well he is using his balance to perform kicking techniques with focus and power.

Richard had to master four katas in order to pass his latest examination. Each of those katas has between fifteen to twenty steps in them and follows complex shapes that ask for 90-degree and 180-degree turns.

It is hard to imagine how a blind person, who has never even seen one of these katas performed, would be able to replicate it and do so with balance and the ability to deliver the proper attacks in the correct sequence. It was wonderful to see Richard achieve this and how he is getting better the more he practises.

Richard demonstrated that he had the skills and knowledge to merit promotion to his new grade.

At the time of Richard's promotion, Christmas was almost upon us. Each year, we hold the Seido Christmas dinner at our local pub, The Gate Inn, at Bryants Bottom. It is a chance for students to mix informally with each other and have fun.

Twenty years ago, we had a young student called Jacob Gibson training with us. Tragically, he died of cancer and we asked his parents if we could establish a trophy in his name to reflect the fighting spirit he had demonstrated when battling the most cruel of foes. Each year, we look to award the Jacob Gibson Kokoro Trophy to a student who typifies Jacob's fighting spirit. 'Kokoro' means 'large spirit'.

Richard has shown so many of those fighting qualities in his life and continues to reflect them in his karate practice. Our committee agreed that he would make a fitting recipient of this powerful symbol of the human spirit. Richard's parents, Michael and Drina, were present to see him receive the reward from me, on behalf of our club.

One of Richard's main characteristics, enabling him to make good progress with Seido Karate, is his consistency. He trains with me every week and regularly practises independently at home and, by reinforcing his training, he is able to tackle more demanding material. I do not impose any limitations on Richard. Sometimes Richard also attends our club training sessions where he interacts with other students at the dojo (training hall) and

afterwards socially at the local pub. He is well-known and well-liked because he tries so hard, never complains and has achieved so much in overcoming his impairments.

Nothing is easy for Richard and each session presents him with real challenges. His success is hard won but we all are delighted to be a part of it. The path is a long one but Richard's feet are firmly on it.

Roger Thyer-Jones

6th Dan

UK World Seido Karate Organisation

Fundraising Round-Up

The year 2011 was brilliant from a Fundraising point of view; huge thanks to all of you who raised around £25,000 for Society funds.

The SOC(K) Appeal was well-supported in a variety of ways by many people, including Sandra Dale, who presented me with a sock, filled with coins! Some stories were included in the last newsletter and there are more elsewhere in this one. Well done to Genny Martin, who completed the Sheffield Half Marathon in May and raised nearly £400. My apologies to you, Genny, for leaving you out of the last newsletter.

Since then, we have received £1,000 from the Monmouthshire Freemasons in Wales, £500 from Iain Marshall, £200 from the Bor Family Charitable Trust, £500 from the Kirby Group and Sonia Roberts, a friend of Julie's, raised £300 from a sale of handmade Christmas cards.

At the end of the year, we received a magnificent donation of £10,000 from the friend of one of our members. What a wonderful way to finish the year. The members of the committee are carefully considering how best to use this generous donation.

After the good start to last year, when we received grants totaling £8,000 towards our Annual Weekend, I was unsuccessful in accessing any more grants. I will be 'back to the drawing board' very shortly but must stress that we cannot rely on this source of income. We can't rest on the hard-earned laurels of 2011, I'm afraid. So, keep up the good work, folks! Our 2012 Appeal will be launched at the Annual Weekend in April.

We have decided not to re-register with the Yellow Moon Scheme this year as there was insufficient uptake from our members. However, you can still join the Weather Lottery and we are getting quite good sums of money from Recycle4Charity, so let me know if you would like some envelopes in which to send off your used printer ink cartridges and old mobile phones. The company now takes Laser Cartridges; they will arrange free collection if you have a minimum of 25 cartridges. Please contact me for details.

If you are not already a "Friend of LMBBS", and you feel that you would like to help the Society by making regular donations or fundraising, please let me know.

I am sorry that I cannot name all of you who have donated, raised funds or helped in any way to support the Society so well in the last year. Every penny that comes our way is greatly appreciated and we could not manage without your dedication and enthusiasm, year in year out. Thank you.

Anne Crotty

BBS Patients from Northern Ireland

We have received clarification from the Northern Ireland Regional Genetics Service of the procedure to follow for Northern Ireland BBS patients to attend the specialist clinics in the UK. Unfortunately, Northern Ireland is not covered by the National Specialised Commissioning Group (NSCG), who fund the clinics, so for any patients from outside the UK to attend, a consultant has to make a referral and also has to make a request for funding. The health board will not automatically fund families who self-refer or who are referred by any other route.

To sum up, any Northern Ireland families who want to be seen at the BBS clinic need to ask their main consultant to refer them and to apply for funding. The Northern Ireland Regional Genetics Service are keen to point out that this is not an issue specific to BBS, but happens with all the NSCG commissioned services because Northern Ireland is a devolved administration.

Official launch of the Northern Ireland Rare Disease Partnership

A new report, launched by the Patient and Client Council at Stormont on Rare Disease Day in February, captured how people affected by rare diseases in Northern Ireland frequently face long delays in accessing a diagnosis for their condition and suffer a poor experience of Health and Social Care in Northern Ireland.

The report, which is based on a survey conducted of 132 people (both patients and carers) affected by over 60 different rare diseases, reveals:

- 29% of patients wait between 1 and 5 years for a correct diagnosis and over 20% wait over 5 years
- 34% of patients are misdiagnosed – 20% of which received inappropriate treatment as a result
- Patients have to attend multiple appointments with different health professionals to obtain a diagnosis and it is frequently a battle to do so
- 57% of people caring for a person with a rare disease do so for more than 20 hours a day
- Over 40% of patients described their experience of the health and social care service in Northern Ireland as “poor” or “very poor”, and nearly a quarter described it as “average”. Only a third of patients described their experience as “very good” or “excellent”
- Patients also reported feeling ignored by doctors, and that there is a lack of information and support for rare disease patients.

Rare Disease UK has been involved in the establishment of a new organisation, the Northern Ireland Rare Disease Partnership (NIRDP) which was also officially launched on Rare Disease Day. The NIRDP has been set up to bring together those living with a rare disease, and the clinicians, researchers and others working in the field, to work collaboratively to raise awareness, improve professional training and service provision, and campaign for those living with a rare disease in Northern Ireland.

NIRDP Chair, Christine Collins, said, "The findings of this important Patient and Client Council report reaffirm the need for a strong grass roots organisation here in Northern Ireland, working in partnership to improve services and offer support to those living with rare diseases and their carers. We want to bring together the expert knowledge, skills and commitment of the clinicians and researchers and the experience and insights of those living with rare diseases, to put an end to the situation where people rattle around the health system without a diagnosis and fail to get the treatment, care and support they need."

For more information, visit: www.nirdp.org.uk

Behind the Scenes at the LMBBS

Members of the Laurence-Moon-Bardet Biedl Society enjoy twice-yearly newsletters and a Conference Report; can attend a weekend family conference and hear about the latest research and meet other families or individuals living with the syndrome; have access to information leaflets and an online webpage and can call the LMBBS helpline for information or a friendly ear. Members also have access to LMBBS Support Workers who assist with attending the specialist clinics, providing support before, during and after appointments.

None of this would happen without the dedication and commitment of the management committee, who take care of the day to day running of the Society and, over the next few issues, we will meet them and find out more about what they do. The committee is keen to encourage members to get more involved in their Society and hope that hearing about the different roles might bring some 'new faces' forward. In this edition, we meet Anne Crotty, Fundraising Co-ordinator.

Anne Crotty has been Fundraising Co-ordinator for the Society since 2004. She is a retired Midwife Teacher and, together with Terry, her husband, became involved with the Society soon after the diagnosis of their grandson in 1997. She spent the first half of her life travelling from place to place as her father and her first husband were in the Army. She has served as a Steward for the Royal College of Midwives and as an Elder of her local church. Anne and Terry have, in the past, represented the Society at the Sight Village Exhibition in Birmingham and have now become directors of LMBBS Clinics Ltd (non-remunerative).

Speaking about the role of the Fundraising Co-ordinator, Anne says her job is to encourage, plead, beg, thank and inform all those who are interested in raising funds to enable the work of the Society to continue. She says, "It is varied and interesting work but not all of it needs to be carried out by the Co-ordinator and if anyone feels that they would like to be involved, please contact me or a member of the committee."

The Role of the Fundraising Co-ordinator involves applying for funding, seeking new 'Friends of LMBBS', applying for Gift Aid, sending letters of thanks, writing reports for the newsletters and generally encouraging fundraising:

Applications for grants/funding from a variety of sources. This is usually a time-consuming process which frequently results in disappointment. It can be stressful as more and more organizations require the forms to be completed electronically and with deadlines to be met. The guidelines need to be studied to ensure that we meet the criteria and each form has to be tailored to meet the requirements of the Trustees; we cannot just 'cut and paste' the same information onto each form. Requirements can range from a simple letter to a form of up to fourteen pages of questions and answers, with a word limit for each answer. We cannot let rejection letters get us down, however; we just have to constantly look for new funders to approach.

Encouraging the "Friends of LMBBS" and seeking new members. What would we do without our loyal band of "Friends"? They give money, time and energy, year in, year out, quietly and consistently. This year, I will be contacting them to update their details and it will be good to thank them individually at the same time.

Applying for Gift Aid from HMRC. This is another time-consuming but very rewarding task. It, too, has become an electronic process which will probably make it easier in some ways, once I have mastered the new system! The use of the Justgiving website means that I don't have quite so much to do but 2011 was a brilliant year for fundraising and I have a nice pile of sponsor forms to tackle. Many, many thanks to those of you who have used sponsor forms as well as Justgiving; this reaches people who would not otherwise give, but the process of collecting the sponsor money is often harder for you than undertaking the challenge that was sponsored! There is an element of frustration in this part of the Gift Aid process, as we often lose Gift Aid because sponsors don't complete the forms properly; for example, I have spent many hours just trying to find out people's postcodes and I cannot claim when people give their company as their address. It is very important to be 'squeaky clean' in applying for Gift Aid as, not only can we be randomly inspected, but our Society needs to be as accurate and trustworthy as possible, in all that we do.

Letters of Thanks. Another important aspect of the Role of the Fundraising Co-ordinator is to send letters of thanks to everyone who supports us. It would be easy to have a standard letter to send to them but how much better it must be to receive a personal and encouraging letter. I am glad to say that I have a steady stream of these to write throughout the year!

Encouraging Fundraising. Over the last three years, we have launched a specific appeal to raise money for the Society – a National Coffee Morning, a 'Summer Sundae' and a 'SOC(K) Appeal'. You have all responded brilliantly to these initiatives and we are working on a new initiative for 2012. Last year, we produced a fundraising pack and we are working on a Fundraising Guidance leaflet to put in it. Any other suggestions for useful items to include in the pack would be gratefully received.

The Internet. There are quite a few fundraising avenues on the internet, for example through social media, e-Bay and search engines. We have yet to use these as much as possible so, if anyone has expertise in this field and would like to offer their services, please see a member of the committee".

As you can see, the workload of the Fundraising Co-ordinator is ever-growing and , as Anne says, there is no need for it all to be done by the Co-ordinator. If you feel you have the relevant skills to support our fundraising co-ordinator please contact Chris Humphreys.

FIVE-A-DAY – it's easier than you think!

Did you make a New Year's resolution this year? It may surprise you to know how many of us make resolutions related to diet and weight. Apparently, 41% of Brits have made a resolution to lose weight and 35% to eat more healthily. But, by February, 24% of us say we have already broken one or more of our New Year's resolutions – an estimated 10 million Britons. So, if like me you are one of those 10 million, perhaps it is time to focus on a positive dietary change and have something you can eat more of without any guilt! I'm sure you know that, every day, we should eat five portions of fruit and vegetables. However, how many of us can say we do this? As a nation, on average, we eat less than three portions a day and only 15% of adults actually meet the 'five-a-day' target. If you're not one of those 15%, read on for some ideas to help you achieve this goal.

Why should we eat 'five-a-day'? Fruit and vegetables are packed with goodness. They contain essential vitamins, minerals, fibre and phytochemicals (naturally occurring plant substances) that are vital for good health. Many of these nutrients also act as powerful antioxidants. Antioxidants can protect the body from the harmful free radicals found in pollutants which can cause disease. Research has shown that people who eat plenty of fruit and vegetables have a lower risk of developing many diseases, including high blood pressure, obesity, heart disease, stroke and some cancers.

Fruits and vegetables are naturally low in energy (calories) and their high water and high fibre content are beneficial in helping us maintain a healthier weight. Here's how - water has no calories, but it adds volume to a meal - this can help you feel fuller for longer. Fibre too bulks up food and also slows the rate at which foods are chewed and digested; this again can help you feel fuller for longer. Therefore, eating fruit and vegetables helps you feel satisfied and less likely to eat more than you need.

How much fruit and vegetables should we eat? Both the UK guidelines and the World Health Organization (WHO) recommend that all adults should eat at least five (80g) portions of different fruits and vegetables each day.

Children too should be encouraged to eat at least five portions a day. There is no recommended portion size for children. However, a useful guide to a portion is the amount that fits into your child's hand. This obviously increases as they get older until a portion size becomes the same as an adult portion.

So what is a portion?

One portion (80g) or any of the following:

Fruit

One banana, orange, pear, apple *or* similar sized fruit

Half a large grapefruit

A slice of large fruit such as melon or pineapple

Two satsumas, plums *or* similar sized fruit

A handful of grapes, cherries *or* berries

One heaped tablespoon of dried fruit e.g. raisins, sultanas

Three heaped tablespoons of fruit salad *or* stewed fruit

Vegetables

Three heaped tablespoons of vegetables (raw, cooked, frozen or tinned)

Three heaped tablespoons of beans and pulses e.g. baked beans, kidney beans (only one portion of beans and pulses can count towards your five-a-day)

Remember that potatoes, yam, plantain and cassava do not count towards your five-a-day because they are starchy foods.

Do fruit/vegetable juices and smoothies count? A glass (150ml) of 100% fruit or vegetable juice does count as one portion. However, remember no matter how much you drink, it can only count as one portion. This is because the juicing process removes most of the fibre from the fruit.

A 150ml smoothie also counts as one portion. However, some smoothies may contain two portions if they contain at least 150ml of fruit juice and at least 80g of crushed fruit or vegetable pulp.

In order to control weight gain, remember fruit juice/smoothies have a very similar calorie content to fizzy drinks like cola. If you have fruit juice as one of your five-a-day, try to drink water, sugar-free squash, diet fizzy drinks or tea/coffee with low fat milk, at other times.

Are frozen, canned and dried vegetables and fruit as healthy as fresh ones? Although nothing beats the taste of fresh fruits and vegetables in season, frozen, canned or dry products that contain little or no added sugar, fat and salt are healthy alternatives. They are often harvested and packed at the height of the season when nutrients are at their peak, so they can provide us with nutritious options all year round.

So now for five-a-day! It may sound daunting - so start by increasing by one extra portion only. Once you've done this for a few weeks, add another portion, then increase again until you are regularly eating five or more.

Try dividing your five portions throughout the day. Why not try eating one or two portions with each of your meals and try making fruit or vegetables your first choice for a snack?

The following sample menu may give you some ideas:

Breakfast

A bowl of porridge with a sliced banana or a glass of pure fruit juice.

Mid-morning snack

Why not try celery, cucumber, pepper or carrot sticks on their own or with two tablespoons of salsa or low fat hummus, if you prefer.

Lunch

Add a combination of sliced tomato, lettuce and cucumber to your usual sandwich. Alternatively, you could try having a side salad - make it interesting - why not add some fruit pieces too. Lemon juice or balsamic vinegar make ideal low calorie salad dressings.

Mid-afternoon snack

Try ditching the biscuits and have a portion of fruit instead e.g. two satsumas or an apple. If you're out, why not pop a small pack of dried raisins in your bag/pocket - this is also a perfect after school snack.

Dinner

Try having two portions of vegetables with your meal or add extra vegetables into your meal - they are easy to add to a spicy chilli, a hearty winter casserole or pasta bake.

More top tips

Buy in season: Opting for fresh seasonal produce means you will get the best value for money. They are more likely to be locally grown produce too.

Think of rainbows: The easiest way to ensure a good mix of phytochemicals, vitamins and minerals is to eat a variety of different coloured fruits and vegetables. So, whilst it's important to 'eat your greens', it's just as important to eat your reds, oranges, yellows, blues, purples and whites too. The following list may help you think of how to build this rainbow idea into your meals:

Red e.g. raspberries, cherries, tomatoes and peppers

Green e.g. cucumber, peas, apples and grapes

Purple/blue e.g. blackberries, blueberries, plums and aubergine

Orange/yellow e.g. apricots, grapefruit, carrots and swede

White e.g. onions, cauliflower, parsnips and bananas

Avoid adding butter, cream, oil, margarine and cheese sauces: Even though fruit and vegetables have a low energy content, remember how you prepare or serve them will determine their final calorie content.

Watch your intake of dried fruits: Whilst dried fruits like apricots, prunes or raisins count towards your five-a-day, once fruit is dried, it also becomes a concentrated source of sugar and calories. Try to keep to a maximum of one serving of dried fruit a day.

Remember to read food labels and look out for the 'five-a-day' logo: Vegetables in convenience foods such as ready-meals, pasta sauces and takeaway meals count. However, try to choose foods with a lower salt, sugar and/or fat content.

Cut down on your protein (meat and fish) portion sizes: Bulk up your meals by adding vegetables to stews and casseroles, to give extra flavour, texture and nutrition! Alternatively, try covering half of your plate at main meal times with vegetables.

Raw or cooked?: Nutrients in fruit and vegetables are easily destroyed during cooking by heat, so, whenever possible, eat them raw. Try steaming, microwaving or poaching vegetables in preference to boiling. This allows you to retain the maximum amount of nutrients.

Short on time: Buy pre-washed bagged salads or cut-up vegetables and fruit.

Be adventurous: Try one new fruit or vegetable every week/month – you'll be amazed at how good you find it tastes! Why not visit shops/markets that have foods from different parts of the world and then go home and experiment!

Still sounding impossible? If you've read this and still wonder how you or your child can be persuaded to eat more fruit or vegetables, read on for some more ideas...

If you / your child dislikes vegetables - try hiding them in food! Studies have shown in both children and adults that hiding vegetables in foods helps to both increase vegetable intake and reduce total energy (calorie) intake. So why not try pureeing a batch of vegetables and then hiding them in your evening meals e.g. pasta bake, casseroles, chilli, shepherd's pie. To make this a more practical suggestion, it is worth bulk cooking vegetables and preparing a sauce base for several meals. It is easy to hide a range of puréed vegetables in a tomato sauce which can then be made into a pizza topping sauce, spaghetti bolognese and lasagne too.

However, hiding vegetables in other foods can not be recommended as the only strategy to increase vegetable consumption. If your child does not like many vegetables - try serving a small helping of a new vegetable e.g.cauliflower that the rest of the family is eating, without any comment. Don't mention the cauliflower at all (this is much harder to do than it sounds and I'm glad there are no hidden cameras in my house!). It is likely that, after about 10 exposures to this new food, they will try it and may even like it. Initially, younger children will experiment by putting the new food in and out of their mouth and then, given time, this will change to them actually eating it. Remember, not talking about the new food is key - so ask all your family/guests to get on board with this approach. Not eating it can become a great game, a fun way to wind parents up and a recipe for a less than happy meal time.... So, before being tempted to say 'just try it', take a deep breath and talk about anything else instead!

If you or your child has gone off a vegetable that they used to eat, why not try preparing it in a different way. My little boy used to have carrots at least once a day, ever since he was weaned (they are so easy to hide in a puréed meal and cooked carrot sticks are a perfect, cheap and tasty first finger food). However, at the age of two, he decided to rebel and was adamant that he no longer liked carrots! He started to eat carrots again when I roasted them for a change. Okay, admittedly, roasting isn't the healthiest cooking method but, from there, I was able to reintroduce carrots into stir fries and then back to steamed, boiled and raw carrot sticks again.

Another great way to boost intake is to get your children involved with cooking. There is a range of child safe vegetable knives on the market - children love eating food they have made themselves so let them chop away or get them involved with presenting the food - lots of things can be made into faces on a plate which will need a number of different vegetables! A selection of different coloured fruit pieces can make a far more interesting snack than a whole apple. Then sit down to eat your hard work together and enjoy a fruit and vegetable packed delight!

If you are a little older - remember our tastes change over time, so give foods a second go. My daughter loves to remind me that she has more taste buds than I do as I am much older than her! Often, our tastes for stronger flavours develop as we get older - spinach, blue cheese and olives are all foods I developed a taste for later in life. So try not to think you don't like something - be prepared to try it again and you may just find that you now quite like it and, in a few more weeks/months/years, actually love it!

Please note: If you regularly see a specialist renal (kidney) doctor or dietitian - please discuss with them if you need to take care with the amount and types of fruits and vegetables that you can eat, before you make any changes to your diet.
Also, if you have impaired kidney function, it is best to avoid eating star fruit.

If you have any questions, why not contact your BBS clinic dietitian.

Sarah Flack, BBS Dietitian, Great Ormond Street Hospital for Children NHS Trust
February, 2012

FRIENDS of the LMBBS

Regular readers and those involved in the charitable sector will know that raising funds and applying for grants can be very 'hit and miss' and a charity's successful steady growth can falter in leaner times. At the LMBB Society, which relies solely on fundraising, donations and grants, income determines whether there will be a conference in a particular year or how

many newsletters will be produced. Producing or re-writing leaflets can be particularly costly and again relies on the charity being in a strong financial position. The financial stability of our small charity relies on *regular* donations and we are often asked why we don't charge for membership to the Society. This would indeed provide that much needed regular income, however it has always been our policy that membership is entirely free.

Several years ago, we set up 'Friends' of the LMBBS, a fundraising initiative, giving those members who wished to regularly support the society, the means to do so and we have slowly built up a strong, loyal band of 'Friends'.

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

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

If you feel you would like to become a 'Friend' and would like more information, please contact Chris Humphreys

Murder Mystery in Scotland

Richard Zimble

I first heard about this holiday when I visited the Vitalise stand at Sight Village in 2011. I had always wanted to do a Murder Mystery weekend and I had never been to Scotland before either, so this sorted both of those out at the same time. When I rang up Vitalise, they were so helpful in telling me all the details that I needed to know. I was then sent a booking form to fill in, which was in the format I required and Vitalise do send their information in all formats.

I then had to wait until November 2011 for more information of where we were to meet up and what time we had to get there. I was very impressed with the information that Vitalise sent, which included who the lead guide was and their contact details, and everyone else who was coming on the holiday and also what we needed to bring on the holiday as well.

When the day of the holiday came, I was so excited. I had to catch a train from Welshpool to Gourock and had to change twice, which was in Wolverhampton and Glasgow Central. The assistance was top quality and I felt at ease with my journey, especially as the guard on the train came round a couple of times to make sure I was ok and to see if I needed anything from the shop; it was a Virgin Voyager train.

When I arrived at Gourock train station, I was helped off the train and guided to the ferry port where the staff looked after me and even gave me a mug of coffee, as they knew I had a long wait for the other people who were coming on the same holiday. When everyone else arrived at the ferry port in Gourock, we were assigned sighted guides to help us onto the boat and to help guide us to the hotel at the other end in Dunoon.

It was a lovely calm boat trip that took about 20 minutes. We got to the Argyll Hotel for about 5pm and were given the keys to our rooms. The lead guide on the holiday showed me

around my room and told me where everything was; it was a nice sized room and had a lovely sized bathroom with a big shower and lots of space.

After I had changed for the evening, the guide met me outside my room and guided me downstairs to the hotel lobby. Once the group were together, we did an ice breaker exercise to get to know everyone who was on the holiday, saying who we were, where we were from and why we had decided to come on the holiday. We were paired up with a sighted guide, ready for the next day. We then went into the bar to get a drink before going in for the evening meal. Once we were settled in the dining-room, the actors came out and introduced themselves and started the first part of the Murder Mystery weekend. We now knew who the characters were, Lady Mary, Lady Isabel, Jamie Lamont, Lord Campbell and Father Simon and we were told which of the four clans we would be representing. I was in the Lamont Clan and the other clans were Campbell, Fletcher and Lamb.

We had a three course meal of Minestrone Soup and Chicken stuffed with bacon and cheese, followed by profiteroles. We were treated to a One Man Band who sang both old classics and some modern songs as well. Towards the end of the evening, I was asked by the manager of the hotel if I would sing a song as I had said I was a singer, and everyone loved it. What I enjoyed about the first night was that for me, with being blind, I could still follow what was happening, even though I couldn't see what was happening, I still felt like I was involved in the acting part of the weekend.

The following morning, after breakfast, 'Jamie Lamont' came into the dining-room and announced that, through the day, there would be a mystery trail to look for clues to solve his secret. We then met up with our sighted guides in the hotel lobby and left the hotel in a group of five to go out and find the clues. It was really good, as at least half the clues were accessible for a blind person as they involved touching signs or memorials that had either raised letters or indented letters, so you could find out the clue for yourself. We found twelve of the clues before stopping for a drink and a bite to eat in a lovely little cafe. Afterwards, we did some shopping and continued looking for the clues as well. We called in at the Dunoon Tourist Information Centre and the lady was so helpful with all of the information we required. She also told us lots of interesting facts and history about Dunoon and was brilliant at describing all of the different gifts I could buy. When we got back to the hotel, my guide sorted out the items I had bought and helped me attach some elastic onto a bow tie to go with my costume for the evening.

In the evening, I got changed into my Scotsman's costume, comprising a kilt, shirt, jacket, hat, boots, and a belt. I also wore a sporran and bow tie which I had bought in Dunoon. We went downstairs into the bar where I had a cocktail, which got me into 'dinner party' mood. We then met in the hotel lobby to discuss where we would be going on the Sunday and who our sighted guides would be for the day. We then went back into the bar where Father Simon introduced Lady Isabel and we got back into the swing of the Murder Mystery, before going through into the dining-room for dinner. This was done in the same way as the Friday evening but we had the actress who was playing Lady Mary on our table. It was amazing how professional she was at going in and out of character. It was so nice to be able to interact with her and talk to her as 'Lady Mary', but also, whilst we were eating, we were able to talk to her as an actor to find out who she was and how she became an actor. We had a four-course meal of Lentil and Noodle soup, Haggis, Silverside of Angus Beef with apple crumble and custard for pudding.

As the evening went on, we learnt more about the characters and we had two deaths, Lord Campbell and Jamie Lamont and we were put into teams to discuss who we thought had done it. It turned out in the end that Lady Isabel had murdered Jamie Lamont because he had stopped her from marrying her true love. After they had told us, they read out everyone's guesses and the winner was drawn out of the correct guesses. I was then chosen as the

best fancy dress for the evening which was really nice. The evening finished with a disco and I stayed to dance for an hour before deciding to go to bed; it was going to be an early start and was going to be a long day.

The following day, we visited Inveraray which was the next village up from Dunoon. We first went to have a look around the Inveraray Jail museum which was amazing; the sighted guide was excellent, describing everything for me and reading out the plaques explaining the history of the jail. We then went into the old court room where there were life-sized mannequins dressed in clothes from the 1800s. There was also an audio recording of people being tried for various different offences. We then proceeded to the cells where we met a retired jail warden who was there to tell us about the history of the prison. This was amazing, as all of the cells had things that you could touch so it was very accessible for a blind person.

After we had bought some gifts from the Jail shop, we went for lunch at a lovely hotel called The George. It was lovely as, when you walked in, you could feel the heat coming from the open log fires. After lunch, we had half an hour to have a quick look around Inveraray and do some shopping, before returning to the hotel. We got back at about 5.30pm and had a group coffee and tea in the bar before going upstairs to freshen up for the last evening of the holiday.

We had a drink in the bar before going into the dining-room for dinner, which was another three-course meal. I had Garlic Mushrooms to start, a really nice pasta dish for the main course called a Penny Godfather and for pudding, I couldn't decide, so I had a little bit of both tiramisu and sticky toffee pudding. I enjoyed the food on all three evenings; it always tasted delicious and the staff who waited on us were amazing. After tea, we all gathered in the bar for the evening and had a few drinks and had an evening of light entertainment with the group singing, telling jokes and tales. I sang three songs and everyone loved it.

The following morning, it was time to go home. We booked out and I thanked the staff for how well they had looked after me whilst staying at their hotel. So over all, I would say that my experience with Vitalise was a brilliant one and I had an amazing time. I was looked after the entire time from when I got to Gourrock until I got the train from Glasgow home. We had a guide the entire time we were on the holiday to help us get around and to get to and from the room in the hotel and I never felt uneasy about anything.

I would also like to say that, if anyone is thinking of going on holiday with Vitalise, it is definitely a good idea to try one in the UK first to see what you think, but for me, I would definitely go on another holiday with them as I felt safe the entire time.

Information about Vitalise and the holidays they offer, can be found on their website: www.vitalise.org.uk

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.