**READING, STEADY . . .GO!**

BBS ready for Reading - Building Bridges to Better Bones — Mark II

This year’s annual gathering of the Brittle Bone Society will see us resurrect our theme of BUILDING BRIDGES TO BETTER BONES . . . that welcomes not only the OI community but cousins in the rare bone world, those with HPP and XLH — conditions we have learned more about since joining with the RUDY study.

This year’s Conference agenda is set to sizzle with the latest on the RUDY programme, Paediatric topics, a look at the landscape of current Adult OI Services nationwide and discussions which will help us add more layers of knowledge to our NHS bid proposal in calling for better services for adults living with OI. The agenda will also feature talks on the latest in specialist dentistry and a number of new research projects with an impressive line up of top NHS Healthcare Professionals.

Not to be missed is our fantastic Cool Bones Programme for 11-15 year olds where youngsters get a chance to hear a talk by Jack Binstead one of our first BBS Ambassadors. BBS will be launching our brand new Kids Club and providing updates on our new hospital packs. Also get set for our Annual Kids Talent show, our star studded Gala Awards Dinner Ceremony, some tasty food, good company, excellent information and facts about OI and of course plenty of fun.

**BBS MEDICAL ADVISORY BOARD MATTERS**

Trustees of the BBS want to formally welcome the appointment of Professor Nick Shaw as the new Chairman of our Medical Advisory Board. Professor Nick Bishop will remain in situ as past Chair of the MAB. Important items managed by the Board include finalising plans for speakers at Conference and other events, peer review and updates to our Medical Factsheets, guidance on new projects like our Adult OI proposal to NHS England and dialogue on matters like European Reference Networks (ERN). The MAB will also assist in completion of our plans to submit a proposal to join the Association of Medical Research Charities (AMRC). This will enable us to choose which research programmes we will endorse or support.

Professor Shaw has been employed at Birmingham Children’s Hospital for 20 years. He heads up a team that provides a comprehensive bone density assessment service for children & adolescents. His team also runs a dedicated multidisciplinary clinic for Osteogenesis Imperfecta and have other clinics for children with Metabolic Bone Disease. Professor Shaw undertakes outreach clinics in Worcester, Oxford and Southampton. He is also a member of The American Society for Bone & Mineral Research and British Paediatric & Adolescent Bone Group.

Trustees also wish to extend their congratulations to the new MAB Chair, who has been awarded a Professorship.

**OI AWARENESS FILM WOWS THE WORLD!**

This year for Wishbone Day (May 6th) the BBS premiered it’s brand new OI Awareness film to an audience in excess of 19,000 people!

The film which was shot the weekend before, at the Annual BBS Youth Event VOICE (in partnership with OIFE) features many of our younger members and others from across Europe explaining the different types of OI and the importance of continuing the UK’s well established OI child services into the adult world.

If you haven’t seen the film already or want to share it with your friends and family you can find it on our Facebook page, via the BBS YouTube channel or by scanning the QR Code.
STAFF PRAISE INDEED
BBS staff are already working hard on our new strategic plan. Coreen, Karl & Marthe are very busy working with Patricia handling frontline enquiries, planning new Patient Day events, fundraising and supporting fantastic events like Jenny Jones’ Gala Ball. Working with our fantastic NHS Healthcare Professionals updating BBS Factsheets, securing speakers and applying for grant funding so that we can keep providing the services you want from your Charity.

BETTER EVENTS & SUPPORT 2016
Your charity continue to look for essential funding for events like VOICE, Cool Bones, AGM Family Conference, Patient Days and projects like our Kids Club and new Hospital Packs.

COMMUNICATIONS
How we communicate with you is essential, on NHS policy developments e.g. specialised commissioning; keeping everybody up to date on the latest in exciting research projects that the BBS are becoming increasingly involved with.

MILLION DOLLAR WHEELS
We continue to fund essential wheelchairs and equipment and we are all set to reveal a fabulous update about how we are improving this important part of our work at Conference in August – you will just need to wait to find out what that is!
An interesting fact we reminded ourselves of is that we have raised around £1million for wheelchairs in the past 10 years!

TRUSTEES BUSIER THAN EVER

ERN’S AND RARE DISEASES
CEO Patricia Osborne confirmed BBS were previously working closely with our NHS Healthcare Professionals and members of the Medical Advisory Board on supporting key applications to join this exciting new network in Europe. This project was one to share expertise across all European countries to seek better treatments, cures and learn the best methods of sharing expertise. The rare disease community is strong, and are wonderful at being collaborative and we are fully resolved to ensuring that we continue to work together in the field of metabolic bone health, research and therapies and treatments for the OI community now and in the future. Our wonderful Healthcare Professional speakers at Conference will provide the latest in Research happening in Britain and how we may still be able to pull ideas, data, results and remain active in important clinical trials that matter to our community.

WELCOMING COUSINS OF THE OI FAMILY
Building Bridges to Better Bones II – Conference 2016 will see us invite again our cousins of the OI Family. We extend a warm invitation to people with Hypophosphatosis (HPP), X-Linked Hypophosphatemia (XLH) and Fibrous Dysplasia; friends we met through our work with RUDY Study. Sharing many of the same NHS Healthcare Clinicians that the OI world work with, by forming close alliances with people sharing varying or even more rare bone disorders, we can grow our influence whilst helping others in the rare bone world enjoy the friendship and knowledge that we enjoy.

OIFE VISITS DUNDEE
Trustee Yvonne Grant, CEO Patricia Osborne and Staff at BBS HQ welcomed Ingunn Westerheim, President of OIFE and Inger-Margerite from OIF Norway. Local BBS members joined in the celebration lunch in Dundee. BBS staff also attended an ERCD event in Edinburgh to hear the latest in developments of surrounding access to medicines in rare disease (see page 6).

Elaine & Patricia
BELFAST

The BBS kick started the year by holding the first of our 2016 Patient Day Events in Belfast on January 22nd. The event played host to a variety of topics ranging from OI services and updates to therapeutics. Speakers included Professor Nick Bishop and Dr Paul Arundel from Sheffield Children’s Hospital, along with Liz Knowles and Claire Hill. From Musgrave Park Hospital Dr Madeleine Rooney, Dr Paul Jackson and Dr Catherine Duffy all gave talks. Ms Christine Collins, Chairman of the Northern Ireland Rare Disease Partnership gave an update on Policy.

DUBLIN

The Dublin Patient Day was held on January 23rd and was well attended by over 70 delegates. Topics of discussion ranged from local service provision to therapeutics. Guest Speakers included Professor Nick Bishop from Sheffield Children's Hospital, Dr Ciara McDonnell from the Children’s University Hospital Dublin and Dr Malachi McKenna from St Vincent’s Hospital Dublin.

GLASGOW

The Glasgow Patient Day was held on January 30th at the Beardsmore Hotel. The event played host to a variety of topics ranging from genetics to adult service provision, and research. Speakers at the event included Professor Faisal Ahmed, Dr Avril Mason, Dr Esther Kinning and Liz Dougan all from the Royal Hospital for Children Glasgow. We were also delighted to welcome Professor Stuart Ralston from Edinburgh University and his colleague Professor Bente Langdahl from the University of Aarhus in Denmark. Speaking on behalf of Rare Disease UK was Natalie Frankish.

BIRMINGHAM

As part of our BBS Wishbone Day celebration, the BBS held a Patient Day in Birmingham on Saturday 7th May at the Holiday Inn. At this event delegates were able to hear from a host of leading Healthcare Professionals from Birmingham Children’s Hospital. We were delighted to welcome Professor Nick Shaw, along with his team. Dr Trevor Cole from Queen Elizabeth Hospital gave a talk on genetics and the adult service in Birmingham. Our guest speaker was Britain’s most successful Wheelchair Tennis Player of all time and BBS Patron Jordanne Whiley, MBE.

YOUTH EVENT VOICE IN CONJUNCTION WITH OIFE

Voice 2016 was held in London at the Radisson Hotel at Stansted Airport. This year, for the first time, saw the BBS host the youth event in conjunction with OIFE (Osteogenesis Imperfecta Federation Europe). There were 50 participants from all over Europe; 9 different countries took part in total. NHS Healthcare Professionals from the UK were at the weekend and covered a range of OI topics in a series of talks and workshops. During the event we filmed an OI Awareness raising film which you can read more about on page 1. We also had fun activities such as a pub quiz, disco, photo booth and a sports session.

FEEDBACK FROM ATTENDEES:

“The Voice event for those with OI is a chance for us to network and we get to meet people who understand what we go through. Many people without OI don’t understand it isn’t just about fracturing there are a lot of secondary things we need to go through. We can get advice, learn from each other about medical staff, wheelchairs, adaptations. Great social event, educational and we get to voice our opinion about what we want whether that’s in the BBS or the medical environment. We get to talk to experts that we might not get to see. We get to be independent and learn about independence. We get to learn about the advances in OI and what treatments are available. It’s a chance for us to talk about sex, relationships, life and the things that we want and have but might access differently. That’s why we think that these events are really important.”

To read more about Voice, first time attendee Thines has written a blog which you can find at:

http://thinesganeshamoorthy.weebly.com/blog/finding-my-bbsvoice16
RICHARD TONER AND THE SOUTH AYRSHIRE TIGERS

In September of last year Richard Toner joined his local Wheelchair Football team the South Ayrshire Tigers. Speaking to the BBS Richard expressed his initial concern at partaking in the sport due to his condition. However he has acknowledged the opportunities the Wheelchair Football has allowed him.

Richard has so far played in the Scottish League and various other tournaments; a personal highlight being when he scored twice against one of Scotland’s most formidable teams. Richard is currently hard at work training and getting ready for the start of the next season. Telling the BBS that “scoring those two magnificent goals has made me want to stay with the team even more” – we all hope you do Richard, for many more seasons to come!

U15 BRITISH TITLE FOR MATTHEW HUNTER AND NORTHERN IRELAND WBC

Matthew Hunter and his U15 Basketball team Northern Ireland WBC played their way to gold on Saturday 16th April as they took on the UK’s best teams in the Lord’s Taverners Junior League Finals at the Worcester Arena.

The final took place in front of a packed crowd – where Northern Ireland WBC competed against CWSC Phoenix. The first half saw Northern Ireland push ahead, finishing 10-2. With everything still to play for in the second half, Northern Ireland WBC were able to find another level of play as they overcame a gritty comeback by CWSC Phoenix to close out a 24-19 victory and with it the U15 British title.

GRAND SLAMMING HER WAY TO RIO AND BEYOND

BBS Patron and all round wheelchair Tennis champ Jordanne Whiley secured her first title of the season after winning the doubles tournament at the Japan Open with partner Yui Kamiji. Jordanne then competed in France where she won both the singles and doubles tournaments, gaining further Grand Slam titles at Roland Garros.

Jordanne also secured her third singles title of 2016 at the Paribas French Open ahead of competing in Wimbledon in both the singles and doubles tournaments. Jordanne will also be representing Team GB in the Rio 2016 Paralympic games. Be sure to catch some of her games and why not try and spot the BBS logo on her kit when she’s playing at Wimbledon!

LIZZIE WILLIAMS – RACING AHEAD

Lizzie Williams is just back from her Senior International debut in Switzerland. Competing in the 100, 200 and 400 metres races. Lizzie finished 3rd in the 100, 4th in the 200 and 5th in the 400 finals. Lizzie has also been making great strides in beating her personal best times. Competing in the BWAA Grand Prix, Lizzie shaved a remarkable 10 seconds of her previous 800 metres time; leaving her just 1.9 seconds off the B qualifying standard for Rio 2016. We wish Lizzie all the best!

SEND YOUR NEWS STORIES TO:
admin@brittlebone.org

Find the BBS at:
CONFERENCE 2016

The not to be missed event of the year plays host to a variety of talks on subjects from research, adult services to dentistry. Cool Bones for 11 – 15 year olds, professionally staffed Kids Club for 0 to 10 year olds and of course the Awards Ceremony Gala Dinner and Disco. Registration form can be found on our website.

CONFERENCE PRICE SCHEDULE

<table>
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<tr>
<th>COSTS</th>
<th>Rates</th>
<th>All prices include VAT at current rate of 20%</th>
<th>BBS Members</th>
<th>Non-Members</th>
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<tr>
<td></td>
<td></td>
<td>Full payment must be received by 29th July 2016</td>
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<tr>
<td></td>
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<td>Cost per person</td>
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<tr>
<td>Full weekend package per person (single occupancy)</td>
<td>£198.00</td>
<td>£218.00</td>
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<td>This rate also applies if sharing with a child</td>
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<td>Full weekend package per person (double/twin occupancy, based on two sharing)</td>
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<td>Children age 2 to 12</td>
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<td>full weekend rate. For families of 4, 2 rooms will be required with adults paying single occupancy rate</td>
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<td>2 days (Saturday &amp; Sunday) with Saturday night accommodation (single occupancy)</td>
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<td>Includes celebration dinner on Saturday evening</td>
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<tr>
<td>2 days (Saturday &amp; Sunday) with Saturday night accommodation (double/twin occupancy, based on 2 adults sharing)</td>
<td>£109.50</td>
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<td>1 day (Saturday) with Friday night accommodation (single occupancy)</td>
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<td>Day delegate rates for Children (not inclusive of evening meal – please add an additional £12.50 if evening meal required)</td>
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NB. To gain access to the assisted conference fund we recommend you apply as soon as possible to BBS HQ. Please complete the application form provided on our website www.brittlebone.org. Funding is allocated in accordance with a fair process including helping those who haven’t previously attended, however all circumstances are given due consideration. Alternatively you can call the office and ask for a form to be posted.
POLICY PROGRESS

EURORDIS RARE DISEASES & ORPHAN PRODUCTS

As members of EURORDIS the BBS attended the European Conference on Rare Diseases in Edinburgh in May and took the opportunity to meet with delegates from OIFE who also travelled to Scotland to attend the event. The conference focus in 2016 was on Game Changers in Rare Diseases: diagnosis, drug development and authorisation, social policy and care provision. To find out more about the conference you can visit their website at: http://www.rare-diseases.eu/

At the exhibition BBS snapped a pic of the BOOSTB4 trial Poster. ‘A clinical study on pre- and / or postnatal stem cell transplantation for treatment of Osteogenesis Imperfecta’.

RARE DISEASE EVENTS

This year Rare Disease Day fell fittingly on the rarest day of the year - 29th February. BBS Members attended events up and down the country to celebrate this International Awareness Day.

29th February - Ambassador Lesley Ann and John Starrett attended the Northern Ireland Rare Disease Partnership (NIRDIP) Reception in the Long Gallery at Stormont in Northern Ireland and heard Health Minister Simon Hamilton MLA talk about his vision for the NI Rare Disease Plan.

1st March - Theresa and Aiden Connor attended a Rare Disease UK (RDUK) Reception held at the Scottish Parliament in Edinburgh. The central theme was the importance of patient voice in creating change. Jamie Hepburn MSP, Minister for Sport, Health Improvement and Mental Health announced a £6 million investment in the Scottish Genomes Partnership.

2nd March - Birmingham Support Group Coordinator Gursharan Kaur represented the BBS at RDUK’s Westminster Reception at the House of Commons and listened to talks from various MPs and Healthcare Professionals. Fiona Marley from NHS England stressed the importance of an early diagnosis to prevent a potentially damaging and life threatening progression and endorsed the UK Strategy for Rare Diseases commitment to “work to achieve reduced times for diagnosis of rare diseases”.

BBS RESPONDS TO NHS CONSULTATION ON NUMBERS OF CLINICAL REFERENCE GROUPS

An overall reduction in CRG numbers was proposed and after discussion and consultation with our Healthcare Professionals and others, we submitted a thoughtful response to ask this be carefully reviewed in favour of the OI patient.

BBS can report there was a good outcome, as the concern was that rheumatology was going to merge with dermatology. This would have affected our membership.

NHS England published its response to the recent consultation on reforming CRG, see link below.

You can find the BBS response on our website at - www.brittlebone.org/index.php/get-involved/consultations/

You can find the final NHS outcome decision at - www.england.nhs.uk/commissioning/spec-services

EUPATI AND ABPI JOINT EVENT

Patricia writes it was good to meet up with Nicola Bedlington the European Patient Forum Secretary General, an expert for the European Commission on disability policy and NGO cooperation and to hear Nicola speak about pan-European progress for rare disease patient groups. Also speaking at the event was Simon Denegri of INVOLVE whose clear message was that we should all keep talking, keep in touch, share good ideas and work together for the best outcomes possible in healthcare. We were reminded by all that our country is producing some of the best research anywhere in the world and the BBS are keen to be as involved as we can be.

Delegates also heard from various individuals about their own personal journeys living with a rare disease and how that crossed over into collaboration with patient groups, Healthcare Professionals, and associations like the ALLIANCE (BBS are members). We also learnt of the role pharmaceutical companies play in this.

It was interesting to hear the many ways people and patient groups like the BBS can bring about real change in research and what type of research is undertaken.

Patricia was impressed with the segment by young people and what type of research is undertaken.

BBS prepare to launch our own Research Strategy and begin work on a number of new trials – all of this information helps us develop skills to collaborate with everybody involved.

As we all strive to achieve common objectives, such as improving patient information and access to medicines. Already Generation R have composed a document calling for a range of changes to issues that affect clinical trials, and as the BBS embark on exciting new trials and studies we hope BBS members will enjoy learning more about this important topic. We hope that our Cool Bones Kids will get switched on to what Generation R are getting involved with.
HEARTFELT THANKS, HARRY

HARRY VENET TRUSTEE

Harry Venet Trustee of the BBS, has decided it is time to take a much deserved rest from the cut and thrust of the BBS Trustee Board.

Harry is a Chartered Accountant by profession, taking retirement from full time employment in 2000. Harry's former post was as a senior manager in the audit department of Price Waterhouse Coopers in Leeds. Harry's connection with the Society began in 1976 when he and wife Rosemerry's middle daughter Joanna was diagnosed with OI.

Over the years Harry's involvement and support with the BBS was consistent, and in 2007 Harry was invited to stand for election as a Trustee. We have benefited from his support since that time. Harry has also been treading the boards and has been involved in acting and theatre work since his retirement.

Throughout his dedicated service to the Brittle Bone Society he has been a member of the our finance sub-committee and his outstanding professional skills background meant he was in a position to take responsibility for the preparation of the Society's annual accounts when the Treasurer unexpectedly resigned, in 2010.

During his successful term as Trustee, his daughter Joanna gave birth to Jacob, who has also been diagnosed with OI, so his then attachment to the Society was assured for a further few terms, during which time Joanna and husband Richard had a beautiful little girl Molly. The family are all rightly proud of Harry who has been a key part in the Charity's progress over the past period.

Harry has been involved in BBS working committees which have drafted the past two successful strategic plans and the current new set of documents include a fundraising strategy, communication strategy and the early beginnings of the Society's first research strategy.

Harry's attention to detail has been remarkable. His reliability in supporting the Society take bold new steps in setting up our Medical Advisory Board and a number of new projects – all under his careful and measured guidance.

On behalf of the entire Trustee Board and all the staff at BBS HQ, whom Harry also supported – Patricia also wanted to say a huge thank you for all that Harry has helped us achieve over the past few years.

We shall miss you Harry – but you will always be part of the BBS family.

Mereo is a UK-based biopharmaceutical company focussed on the rapid development of innovative medicines in rare and specialty disease areas that have the potential to transform patient quality of life and improve human health.

www.mereobiopharma.com
THANKS TO OUR FUNDRAISERS

BBS CHARITY OF THE YEAR 2015
Throughout 2015 Gary Tarling, Captain of Worldham Golf Club, organised various fundraising events to raise money for the Brittle Bone Society. At final count the Club had managed to raise a staggering £3,282.00.

PENNY VS MOUNT MONTSERRAT
This February we saw a more adventurous method of fundraising. Penny Clapcott travelled to Barcelona, Spain to climb Mount Montserrat with Norwegian balancing artist Eskil Rønningsbakken. The pair performed a balancing act on the edge of the mountain and managed to raise £752.64. Talk about living life on the edge!

BRIGHTON ½ MARATHON
Martin trained through rain, hail and shine to prepare himself for Brighton’s ½ Marathon back in February. On the day Martin managed to finish the run in 2 hours and 19mins, having this to say about the experience - “I’m not going to lie… the last three miles were agony, but worth it!” Worth it indeed – Martin supported by friends and family raised the fantastic amount of £1,265. Well done.

THE JONES FAMILY RAISE THOUSANDS!
In March Jenny Jones organised a Great Gatsby themed Ball to help Johnny & Lewis, who ran in this year’s London Marathon, reach their fundraising target for the BBS. Here is what Johnny had to say about the experience - “The Brittle Bone Society is a charity that I have been aware of for most of my life; the Society has been positively supporting my sister Abbie Jones ever since she was diagnosed with Osteogenesis Imperfecta. Lewis, Abbie’s fiancé, and I wanted to show our gratitude to the Society by running the London Marathon and fundraising along the way. With the help of my mother, Jenny Jones, our family and friends, I’m very happy to say we were able to achieve this goal!” The total amount collected so far is an amazing £3,245.25!

INVERNESS ½ MARATHON
Inspired by one of our younger BBS fundraisers, (Jack Lewington who you might remember took part in the Meadows 5km Fun run last year) Nina Roberts decided to sign up for the Inverness ½ Marathon which took place in March. Motivated by thinking of Jack’s strength and determination Nina finished the run in 2 hours and 32 seconds (a new personal best!) and managed to raise £615.29 in the process.

GREEN PARK CHALLENGE
The Reading 3km Green Park Challenge that took place in April was no challenge for Joseph Errington! Joseph who ran with his dad David had this to say - “I did it!! I ran all the way and finished in 21 minutes and 3 seconds. I have a great medal!” Not only did Joseph finish with a brilliant time but he also managed to raise £648.75, for which we are so thankful.

TOUGH MUDDER MAY MADNESS!
The month of May saw 2 BBS fundraisers enter into Tough Mudder Challenges. James Freshwater and his team of 7 strong took part in the London West event. Motivated by James’ son Evan who was born with Type 3 Osteogenesis Imperfecta, the team aptly named “For Evans Sake” - managed to raise an amazing £3,047.61. What a great team effort – well done guys!

Tough Mudder isn’t just a lads’ challenge though… we also had Sarah Beaumont take part in the Midlands Challenge. Sarah took part on behalf of the BBS because like many others OI is a condition close to her heart. Although she is still collecting in sponsorship money Sarah has so far managed to raise £149.54! Thanks!
ANNUAL SPONSORED WALK
Every year Cameron and his classmates take part in a sponsored walk to raise money for the BBS. This year they walked from Benderloch to Barcaldine in Argyll and Bute... AND back again raising a total of £530.70.

GALWAY GREATS
The MacConnell family have been busy this May. Not only did they host a Wishbone Day Tea Party to raise awareness of OI but later in the month Niamh also organised a Teddy Hospital Fundraiser where teddies and dolls received treatment for their complex medical conditions. Lucy’s primary school even got involved and held a non-uniform day on Friday 13th of May, overall raising a fantastic €579.00.

FARMERIES IN FULL FORCE
Longridge Branch Fundraising superstars John & Gertie Farmery have been busy organising their annual fundraising events. Not only did the BBS send out 12 MORE collection cans to the Longridge Branch but 2016 saw the return of the June Baker Concert which is now in its 9th year and hosted a Comedy Night. The Brittle Bone Society are happy to announce during the last financial year the Longridge Branch raised a total £5,500.00.

RAFFLES AND RACES
At the beginning of the year the BBS received a cheque for £1,715.31 from the Labour Ward at the Royal Infirmary of Edinburgh. This donation was the result of their annual staff raffle. Proceeds were given to the BBS because staff were so inspired by Kirsty Perry (who works on the Labour ward) and her daughter Mila who has OI.

BBS would also like to wish good luck to Andrew Perry (Mila's dad) who is running the Scottish 1/2 Marathon with his friend, Jack for the Brittle Bone Society in September because “this is the backbone of my new family”. Andrew and Jack are training hard and between them have already managed to raise £1,347.13. We are all rooting for you!

COLLEGE FUNDRAISER
Our thanks go to Lizzie Williams who organised a fundraising event at Worthing College and donated the £100.00 proceeds to the BBS.

CHRISTMAS CARDS AND COFFEE MORNINGS
BBS Member David Queen spoke at his local church – Claremont Parish Church – about the impact having Brittle Bones has on his life and the work of the Brittle Bone Society. The congregation were so touched by David’s presentation they decided to raise money as a result. The BBS has received 2 donations totalling £1,325. They raised the money over the Christmas period and also through a coffee morning. Thank you to Claremont Parish Church and thank you to David for helping spread awareness of OI and the support we offer as a charity.

ETAPE LOCH NESS
After months of training in the freezing Scottish weather David Brown completed the ETAPE Loch Ness Challenge – a gruelling 66 mile cycle! He managed to power through and complete the route in 04:12:56 raising £1,100 in the process. Fantastic!

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LARNE ½ MARATHON
Ruth Lipsett ran the Larne ½ Marathon back in March for the BBS and although she is still collecting in sponsorship money, Ruth has managed to raise £978.15 on her Just Giving page alone!

Jack Lewington and class mates Hayden Rumgay and Ruaraidh Haaris recently took part in a school enterprise project. The team were tasked with making and selling cakes. Their hard work paid off and they ended with a profit of £100.84! The boys had a choice whether to keep their profit or donate it to charity. Jack and his friends chose to donate all their profit to the Brittle Bone Society. Thanks for your hard work.

BETTY NICOLS PUB QUIZ
A pub quiz and raffle was held in June in memory of the late Alastair Bruce, Life Member of the BBS and dear friend to organisers Wendy and Rob Brown. After the event Wendy reported – “We had a wonderful day and it was a huge success - we raised £1,260.00 for the Brittle Bone Society. I still can’t believe it but have to say that it is a true reflection of how loved and respected Alastair was.”

RUNNING INDEPENDENTLY
Our thanks also go to Tania Hamilton who managed to secure herself a place in the 2016 London Marathon and raised £696.25 in total.
STAFF UPDATES

BBS Staff have lots of new and exciting projects they’ve been working hard on. Here are a few of the Staff’s top picks on what they are most excited to work on in the next 6 months.

Coreen Kelday: Support & Development

Coreen: For me it’s having the hands-on opportunity to work closely with members as we scope out and submit our application for an improved Adult OI Service.

Karl Henry: Communications

Karl: I’m always excited when we get to expand our online presence, which is why I’m excited to be working on our new social media corner at this year’s Conference along with live streaming talks on Saturday. Though, still some way off, we’re also working on a complete revamp of the BBS website, to make it an even better resource for people with OI.

Marthe Handling: Fundraising & Admin

Marthe: As someone who is relatively new to the Charity, what I’m most looking forward to is getting to meet members at this year’s Conference and try to recruit some new fundraisers! I’m also keen to show you all the new information leaflets and posters we have produced along with our brilliant new t-shirts.

IMPORTANT NOTICE

As this copy goes to press we would like to say thanks to all BBS fundraisers. If we have omitted any of our fundraising stars from this issue, or their items have not yet been finalised or sent into us, we will be delighted to feature them in our next newsletter.

Please contact BBS at fundraising@brittlebone.org or phone 01382 204446 if you would like us to send you out a booklet full of ideas on how to fundraise. Please remember to let us know about your fundraising events and we will promote them on the BBS website (www.brittlebone.org), Facebook and Twitter.

DATES FOR YOUR DIARY

If you need further info on any event below please contact BBS – 01382 204446 or email bbs@brittlebone.org

25th June    BBS Trustee Meeting, London
10 July      British 10k
30 July      Manvers Dusk till Dawn Run
12 - 14 August  BBS Annual Conference - Reading, including Cool Bones
10 September Thames Path Challenge
18 September Scottish Half Marathon
6 - 8 October  Congress OI in 2016 - Lisbon
9 - 10 October OIFE AGM - Lisbon
7-9th Nov    NOS Conference Event, Birmingham

BBS Patient Day Events Bristol and London tba

GIFT AID

Please don’t forget for every £1 donated, the BBS receives £1.25 if Gift Aid is added.

You can give your donations a big boost by using Gift Aid. If UK taxpayers Gift Aid their donations, membership or supporters fees the BBS get an extra 25% at no extra cost to the donor.

You can download a Gift Aid form from our website or request one by contacting the office.

Alternatively you can fill out the online version of the Gift Aid form at http://www.brittlebone.org/get-involved/fundraising/gift-aid/

SCOLIOSIS RESEARCH PRIORITY SETTING PARTNERSHIP

The James Lind Alliance have been in touch with the BBS to ask if our membership would like to help them in an important study that has been set up to identify unanswered questions about the diagnosis and management of scoliosis. The survey is available at: https://www.surveymonkey.co.uk/r/SSJZ28R or contact the James Lind Alliance Project Manager at the Oxford Biomedical Research Centre to request a paper version (voicemail 01865 223298) e: sandra.regan@ouh.nhs.uk

KEEP UP TO DATE

Please remember that the rate for full BBS membership is an annual fee of £20. We appeal to our readership to amend their payment arrangements to enable them to receive membership benefits. If you haven’t adjusted this payment with your bank or PayPal account you will have automatically became a Supporter and will no longer qualify to vote at AGMs.

The BBS continues to respect signed up Life Members, but hopes they will consider becoming regular Supporters.

Make sure you let the BBS know if you change address to ensure you don’t miss out on any news and events updates – email any changes to admin@brittlebone.org.

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