WHY AYE O.I. NEWCASTLE CONFERENCE 2017

A brighter future for Bones

Trustees and staff will descend on Newcastle August 11th for a sizzling weekend of BBS Healthcare talks, updates on Research, exciting plans for our 50th Anniversary Celebration and invitations for members to get involved in. Fridays family buffet meal and keynote talk will be delivered this year by chairman of our Medical Advisory Board Professor Nick Shaw. Get ready to hear about planned events that you can get involved in for the 50th, including our Medics Walk of the West Highland Way with Professor Ahmed and Dr Arundel to name just two. We will also have a walk n wheel section and ways you can start chalking up the miles on foot or by wheelchair to countdown with us to the 2018 Conference Anniversary Event. TV Celeb, BBS Ambassador and former Trustee Samantha Renke will lead off with our Cool Bones Kids, and we will have an array of super healthcare professionals talking about child health, surgery, services, treatments and new trials. Medical talks over the weekend will be chaired by Trustees Professor Nick Bishop of Sheffield and Professor Faisal Ahmed, Glasgow. We are delighted to have local support from Newcastle upon Tyne Hospital who will give members an update on bone services in the area with a series of talks led by Dr Terry Aspray. Member of our Medical Advisory Board, Dr Catherine DeVile from Great Ormond Street Hospital, also joins us for an exciting update on the very latest in Stem Cell Treatment - BOOSTB4.

STRICTLY MONIQUE AT BBS CONFERENCE

Monique Jarrett will be part of the entertainment segment in a fantastic wheelchair demonstration at our Gala Dinner and we have secured this through the wonderful Ray Bulpitt Dancentre who offer expert tuition in wheelchair dance. Ray’s company will also arrange a beginners class for BBS Delegates on Sunday of our event. What are you waiting for - register your interest today!

DAVID KING - STEM CELL STORY

BBS had the pleasure of meeting up with the King family at our recent Dublin patient day event and heard Dad David King’s interesting take on the journey he, his wife and children went on when they embarked on stem cell treatment. He spoke about their son Adam who was born with OI and how being a part of the new stem cell treatment had affected him.
TRUSTEES & GOVERNANCE UPDATE FROM ELAINE
As we head towards the AGM in August - I thank all my Trustees who work year long and want to inform you that Trustee Andy Mills has decided to step down. We all thank Andy for his contribution and wish him well. Trustees were pleased to invite two new co-opted members Gareth Cumming and Angie Stewart in November 2016 to give them a few months of trialling out the work agenda on the board and both have indicated their wish to go forward. You can read their supporting statements in the Calling Notice letter.

Our Secretary Mirrick Koh’s AGM calling notice is attached and is also on our website.

Trustees have agreed to support both the candidate’s nominations. Treasurer Robert Gordon’s full report and accounts will be available at the AGM.

SCIENTIFIC SYMPOSIUM 2017

BBS staff have been on a whirlwind of activity from January 2017. Hot on the heels of securing membership to the AMRC the Chair of the Medical Advisory Board, Prof Shaw welcomed leading UK based and international healthcare professionals including Professor Glorieux from Shriners Hospital, sponsored by the OIF to attend, at the first Scientific Symposium held by the BBS in over 25 years.

http://www.brittlebone.org/about-oi/research/

Feedback from 2017 was amazing and notably many said it would be hard to top it!!!

RESEARCH NEWS

BBS Research Chairman Prof Bishop held the first committee meeting in May and the research grants programme went live with a closing date for research proposals on 23rd June. We will report back at Conference on any new projects approved.

Pictured: Prof Bishop receiving his wishbone pin from Lay member of our Research Committee - Joanna Cannon - in London in February

EVENTS - ON THE ROAD

BBS staff visited Sheffield which played host to VOICE this year, led by Dr Jennie Walsh of Great Northern Hospital, in March, a really successful event you can read more about in this newsletter. (see page 9)

Our London roadshow Patient Day Events continued to a packed London event in February headed up by Dr DeVile of GOSH and headline talk from world renowned Professor Glorieux.

Off we went in May to Ireland to greet around 90 plus delegates and celebrate wishbone day in Belfast and Dublin. Professor Stuart Ralston of Edinburgh University travelled over to discuss his TOPaz trial in Northern Ireland and this was also shared with the Dublin audience by Dr Malachi McKenna of St Vincents Hospital.

Other speakers over the weekend were provided by our good friends at the NIRDP (http://www.nirdp.org.uk/). Chairman Fiona McLaughlin attended and gave a great update on their valuable and important work in Northern Ireland. They work closely with the Northern Ireland Department of Health, Health and Social Care Board, Public Health Agency and the Patient Client Council; and with Patient Representative Organisations in the UK (Genetic Alliance UK; Unique) Republic of Ireland (IPPOSI, MRCG and GRDO) and Europe (EURORDIS), as well as with a wide range of condition specific groups and organisations.

GET BEHIND THE BBS IN 2018

Trustee - Prof Faisal Ahmed getting ready and warmed up for his Medics on the March walk with Dr Arundel of Sheffield Childrens Hospital. They will be doing a walk of the West Highland Way to mark our 50th.

CAMPAIGNS GALORE

WOW what a successful wishbone campaign we enjoyed this year. We reached over 250,000 people with a series of powerful messages about living with OI.

Thank you to our new Comms Officer Natalie Eislle for devising such a unique and standout winning campaign, that was clearly loved by the entire OI community worldwide, and especially you our members who showed your support in your thousands, getting behind this and supporting the OI voice.

Thank you also to Birmingham Support Group and Newcastle for putting on some fantastic gatherings, a huge well done. You can see some pics in this newsletter on page 10.

ADULT OI CAMPAIGN

BBS Adult OI Committee Chairman Dr Richard Keen, Vice Chairman John Phillips and CEO Patricia Osborne held talks with NHS commissioners in March 2017 to further raise issues around lack of cohesive services for adults with OI. Relevant specialists healthcare professionals were then polled by the BBS about aspects of treatment to identify the biggest gaps in service and other information needed to help further and strengthen our case to ask for better treatment care and prospects for people’s quality of life.

Due to a legacy donation which created a surplus figure in our accounts it has been difficult securing grants. We encourage members to really get behind fundraising for the BBS in the coming months especially to help up commemorate and celebrate our 50th Event. See our wonderful new 50th Logo on page 9.

50 REASONS TO LOVE THE BBS

Already people are getting in touch to say they are doing 50 walks, sits, laughs, sleeps, eats, claps, jumps, skips, swims … you name it. You can do 50 of anything at all - and raise a few pounds, fill in our special 50th sheet online or post to us.

Don’t forget to send us in any memorabilia to help with our exhibition in 2018.

NEWCASTLE CONFERENCE

We promise another fantastic conference programme for you this August and we look forward to seeing as many of you as possible over what promises to be a fantastic weekend.

Elaine & Patricia
LONDON PATIENT DAY EVENT

BBS staff hosted a hugely successful patient day event Feb 25th in London fully supported by London hospitals with our thanks to all the medics involved – GOSH, Stanmore, Royal National Orthopedic and London North West hospitals. The packed room of 75 delegates were greeted by VIP guest Professor Glorieux whose visit to the UK was sponsored by our good friends at OIF in the USA. Topics covered by wonderful speakers spanned across children’s and adult services, dentistry, genetics and specialised surgery and there were also great talks by the Allied Healthcare teams on aspects of Occupational Therapy, Physio and Clinical Psychology.

BRISTOL PATIENT DAY EVENT

The BBS team then travelled to Bristol for Sunday Feb 26th to round up their whirlwind weekend of fabulous events with the Bristol Hospital teams from across local hospitals. This event covered many of the similar topics hosted in London – and there was a great debate about pain and pain management which the BBS would like to explore further with the Healthcare Professionals involved. We got a chance to discuss our plans at the BBS and gained some fantastic stories from members which we can use for our 50th Anniversary.

BELFAST & DUBLIN WISHBONE DAY CELEBRATIONS

We celebrated Wishbone Day with free events in Belfast and Dublin this May. We had featured talks from: Professor Stuart Ralston - The University of Edinburgh; Fiona McLaughlin - Northern Ireland Rare Disease Partnership; David King – Parent of Adam; Professor Malachi Mckenna - St Vincent’s University Hospital; Dr Ciara McDonnell - Children’s University Hospital, Temple Street. Thanks to the speakers, and to all those who attended and made our Wishbone Weekend a great success!

SUPPORT GROUP WISHBONE DAY CELEBRATIONS

BIRMINGHAM SUPPORT GROUP

Members got together to celebrate Wishbone Day by holding competitions, stalls, cake sale and refreshments at the Bilston Peoples Centre in Woverhampton. They had a great turn out and much fun was had by all age groups.

NORTH EAST MEMBER MOMENTS

It's all going on up north! By Lisa - Area Support Co-ordinator

I’m still smiling after our amazing Wishbone Day party, which happened at the Ravensworth Arms near Gateshead. We filled the place with yellow, put on the tunes and had a brilliant afternoon getting together. I’m still amazed how many people there are affected by OI in the north of England and when we are together, there is an amazing buzz in the room. I know there are people out there who it would be wonderful to re-connect with and of course many new people and families.

There are plans afoot for all our support groups. If you would like to be put in touch with local organisers please contact us at bbs@brittlebone.org or on 01382 204446 we will be delighted to hear from you.
Congratulations to our member, Gem Turner, who has been nominated for the Diversity in Media Blogger of the Year Award!! Gem is an avid and talented blogger, with topics ranging from her life as a disabled woman living in an awkward and funny society to me talking about fashion and cosmetics.

Gem also joined our Communications Officer, Natalie, at a fundraising event in Leeds in May. Pharmaceutical company Kyowa Kirin teamed up with events company Bluehat, for a fundraising day. Gem & Natalie gave a joint introduction to the day – giving Kyowa Kirin more of an insight into Osteogenesis Imperfecta, before they headed out to raise funds for the BBS. They raised an incredible £8,433.44! Thanks Gem, for taking part in this superb fundraising event!

BLOG: STYLING SMART WHEN YOU’RE SMALL

Posted on June 25, 2017 by Gem Turner

When I was in Primary School teachers told me I didn’t have to wear school uniform due to my small size. Being my stubborn self, I obviously immediately declined and tried to conform as much as possible, because that’s just the way I roll. As I’ve grown up (age not height obvs), it’s really important to me to make sure I look smart. Not for vanity reasons but to make me feel extra confident. Now I have one particular job where I like to look relatively smart. It’s a tricky task trying to dress formal when clothes don’t naturally look the way they do on mannequins. Most smart clothes are super fitted which is a no go for me or long sleeved which doesn’t exactly work. So I thought I’d give some top tips for how I dress smart with this particular outfit.

First of all I go for more plain colours and simple styles – not too fussy. My wardrobe has a lot of white, black and grey now which I thought I would never have. But I always find that these colours look more office-y.

I make an extra effort with my make up. Depending on how much time I have on a morning but my two must have products are Eyebrows filled in and bronzer, anything else is a bonus. We all have our compulsory must do products don’t we?

Read more at: gemturner.com/2017/06/25/styling-smart-when-youre-small/

JULIAN FLYS HIGH

It had always been my dream for a few years to fly, and as a wheelchair user, I always doubted I could actually pilot a plane. Fortunately, a charity called Aerobility offered a fully adapted aircraft, with everything needed to ensure my comfort, and as a result, I am currently in the process of obtaining my Private Pilots Licence.

Over the last few years, developing my knowledge of flying and aviation has been all down to the support of Aerobility. They offered me two courses to try, the Aviation Education Programme and, the most recent; Aspiring Pilots Programme. Both courses were fun and inspiring, the team at Aerobility made sure that there were no obstacles on the way to achieving what I wanted in the world of aviation.

I have now finished my 6th hour flying, it really is amazing, every flight is different, different weather, different route... I really believe that flying offers an amazing sense of freedom, independence and joy. This is what Aerobility is for, to offer people like me the opportunity to jump out of the wheelchair and into the cockpit. I would encourage anyone with a passion, or even a mere curiosity for flying to get in contact with the charity, as they have most certainly presented brilliant opportunities to me, and I am certain that they will continue to offer such amazing opportunities to others for years to come.
SUPPORT DEVELOPMENT

SERVICES

It’s been a busy few months, being out and about meeting up with members during patient day events in London, Bristol, Dublin and Belfast and also the Youth Event in Sheffield. It always a delight meeting up with old and new faces and I am looking forward to Conference in August. As well as meeting members I also meet up with Healthcare professionals.

I attend the POINT (Paediatric Osteogenesis Imperfecta Team) meeting twice a year and we continue to work on new literature and factsheets. We now have a factsheet called “Wheeled Mobility for children and young people” and will soon have a factsheet on advice for Nursery and Pre-Schools”. POINT are also busy working on other factsheets such as information for travelling, advice on exercise, and we hope to have a colouring story book available on our website soon.

I recently attended the ICCBH Conference (International Conference on Child Bone Health), which was held in Wurzburg in Germany. It was great to catch up with so many healthcare professionals from the Centres of Excellence, and some of our European Colleagues from OIFE. This event was a full 3 day programme of updates in areas of research, treatments and therapies from leading healthcare experts from around the globe.

In March I was asked to attend a workshop with the East Anglia (NHSE) Specialist (Metabolic Bone Diseases) Service looking at how to adopt a collaborative approach to delivering specialist services care/management of adults with rare metabolic bone disease and to give a presentation on “What patients want from a Specialised Service”.

VOICE

Voice 2017 was a huge success. The weekend commenced on Friday with an evening meal and pub quiz. Saturday was an early start with a presentation from Dr Jenny Walsh about current research for adults withOI including the Topaz study. Penny Clapcott spoke about her work with Rudy project including her trip to Switzerland. The OT Team from Sheffield Children’s Hospital held discussions about independent living with topics such as university, driving and PAS. And they also held a workshop about exercise and physical activity. Lizzie Williams talked about her sporting achievements. After Lunch the Brittle Bone Society held a workshop about the history of the BBS and held discussions around the 50th year celebration planning. The Day drew to a close with Prof Bishop talking about Research and Patient involvement.

On Sunday the Bluehat group facilitated a workshop session called “Making the News” where we were put into 2 groups to discuss the BBS 50th year celebrations and what Voice means to us. Many of us have been supporting the Brittle Bone Society in many ways, we have been doing this by raising awareness and fundraising for the charity. To help fund equipment, wheelchairs and weekend conferences held throughout the year. We have organised bake sales, sponsored walks, swims and marathon to raise this essential money that is needed to help what we estimated 5000 people in the UK with OI.

Many of use are also involved in research like the Rudy study which is a 5 year study monitoring what the lives of people with OI are living with and how we are doing like how pain levels are and how many fractures we have had throughout the course of the year.

Overall Voice 2017 was a weekend to remember and we can’t wait for the 50th anniversary next year.

RESEARCH

If you want to get involved or have your say into Research please see our website for more information. Here is a summary of what is currently ongoing:

James Lind Alliance (JLA) Priority Setting Partnership

Help set the research agenda for rare musculoskeletal diseases in adulthood

Created to identify unanswered questions about Osteogenesis Imperfecta and other rare conditions which affect the bones in adults, the JLA is bringing together patients, carers and social care professionals in Priority Setting Partnerships (PSPs) to agree what research matters most to patients and health care professionals.

What questions do you think need answering in the area of Osteogenesis Imperfecta?

Have your say; participate in the survey and help set the priorities for research in OI: https://www.surveymonkey.co.uk/r/fjZ9RDFK

BOOSTB4: Research study exploring views and attitudes to stem cell therapy for Osteogenesis Imperfecta

A new research study called Boost Brittle Bones Before Birth (BOOSTB4) is investigating the possibility of using stem cell therapy as treatment for severe OI. The study is being undertaken by researchers at Great Ormond Street Hospital and the UCL Institute of Child Health.

They would like to hear from;

• Young people (ages 16 -18) affected with OI
• Adults affected with OI
• Parents and carers of children affected with OI
• Health professionals and patient advocates who work with people affected with OI

If you are interested in taking part in an interview and would like to find out more about the study, please contact Dr Melissa Hill at Great Ormond Street Hospital by:

email: melissa.hill@ucl.ac.uk or phone: 020 7762 6871.

TOPaZ Trial

If you have a diagnosis of Osteogenesis Imperfecta and are aged 18 years or over, you may be eligible for the Treatment of Osteogenesis Imperfecta with Parathyroid hormone and Zoledronic Acid (TOPaZ) Trial across the UK and Ireland. The study aims to determine whether treatment with another drug called Zoledronic Acid (ZA) reduces the risk of broken bones occurring in people with Osteogenesis Imperfecta (brittle bone disease) as compared to standard care.

If you would like to find out more information, please contact the research team: TOPaZ Trial Office - Holly Ennis 0131 537 2573 or topaz.trial@ed.ac.uk

Alternatively, please take a look at the website: edin.ac/topaz-trial or download the flyer.
CONFERENCE 2017

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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<th>COSTS</th>
<th>Rates</th>
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<tr>
<td>All prices include VAT at current rate of 20%</td>
<td>BBS Members</td>
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<tr>
<td></td>
<td>Cost per person</td>
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<tr>
<td>Full weekend package per person (single occupancy)</td>
<td>£ 270</td>
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<tr>
<td>Full weekend package per person (double/twin occupancy based on two adults sharing)</td>
<td>£ 189</td>
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<tr>
<td>Full weekend package for 1 Adult and 1 Child (double/twin room)</td>
<td>£ 340</td>
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<tr>
<td>Full weekend package for 2 Adults and 1 Child (family room)</td>
<td>£ 448</td>
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<tr>
<td>Full weekend package for 2 Adults and 2 Children (family room)</td>
<td>£ 518</td>
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<tr>
<td>1 night only including meal (either Friday or Saturday) single occupancy</td>
<td>£ 135</td>
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<tr>
<td>1 night only including meal (either Friday or Saturday) per person, double occupancy</td>
<td>£ 94.50</td>
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<tr>
<td>Day Delegate only for 1 day (Friday) – includes evening meal (per person)</td>
<td>£ 30.00</td>
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<tr>
<td>Day delegate only for 1 day (Saturday) – includes access to exhibition area, conference &amp; workshop sessions plus a buffet lunch, and Dinner (per person)</td>
<td>£ 70.00</td>
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<tr>
<td>Day delegate only for 1 day (Sunday) – includes access to exhibition area, conference &amp; workshop sessions plus a buffet lunch (per person)</td>
<td>£ 40.00</td>
</tr>
<tr>
<td>Day delegate rates for Children (not inclusive of evening meal – please add an additional £12.50 if evening meal required)</td>
<td>£ 25.00</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.
RARE DISEASE DAY FEB

BBS attended Scottish Parliament 1 March to celebrate Rare Disease Day. Professor Stuart Ralston showcased the work involved in the TOPAZ Trial and you can find out more here http://www.ed.ac.uk/usher/edinburgh-clinical-trials/our-studies/ukcrc-studies/topaz/the-topaz-trial/get-involved and his collaboration with the BBS in this work.

NHS officers spoke about work in the new Scottish Genomes Study just launched (to work with 100,000 genomes partnership https://www.genomicsengland.co.uk/#)

Professor Jonathon Berg from Dundee University talked about great strides forwards in diagnosis and research. Finally we listened to moving testimony from patient groups and from a lady with Ehlers-Danlos syndrome about her struggle to be diagnosed, we heard from others with rare conditions of their journey to gain better treatment and care. The BBS is pleased we have some projects on our horizon giving some hope for the future. Patricia and Coreen met with colleagues Liz Dougan and friend Paul Conor who was there representing Kyowa Kirin.

GENETICS DISORDERS LEADERS SYMPOSIUM

CEO Patricia was invited to speak at Genetic Disorders UK event in London. Patricia said it was a terrific event and that many congratulated the BBS on their membership to the AMRC. Patricia also took the opportunity to congratulate Meryl Chambers (formerly Ockenden) on her tireless work to help set up a UK support group for people with HPP. You can see more about the meeting here https://tinyurl.com/ydcn6azd

COLLABORATION

ARTHRITIS RESEARCH UK CONFERENCE

BBS was invited to a rare musculoskeletal disease workshop run by Arthritis UK by member of our MAB Dr Kassim Javaid. You can see more about the event here.

https://tinyurl.com/y7ed528e
ROUSING RUNNERS RAISE MORE THAN £7000 FOR THE BBS!

Iain Lawrie £3,455.75 • Sally Humphrey £446.50
Caroline Nicholls - £3535.00

Our London Marathon runners raised in excess of an excellent £7,000 for the BBS! Thank you to Iain Lawrie, Sally Humphrey, and Caroline Nicholls. Iain was inspired to run by his Auntie Wilma, and Caroline by her friend Joanna Cannon. Read their fundraising stories below:

“The Brittle Bone Society were looking for a volunteer to run the London Marathon for them. When I saw the request being made I assumed lots of people would jump at the chance, however when my Auntie shared the request again I took it as a call to action. My Auntie suffers from Osteogenesis Imperfecta (Brittle Bones) and has given a great deal of her time to help our local primary school. I thought running the London marathon to raise money for a charity that has done so much for her was a great way of saying thanks. I am pushing 40 years old so did not take on this challenge lightly.

So I will be running the London marathon next month! (Time flies when you are running). As much as the nights are getting longer, most of my runs are still in the dark at night and it is still pretty cold out there! Other than a blip at the start of the week I have been managing the training runs, on occasion I have been getting a little tired of the constantly strained leg muscles. Then I remind myself that those with Brittle Bones can’t just take a week off and recover, they face a daily challenge. The support that the BBS give to those with OI is irreplaceable and at times is what gives people the strength to stay positive despite daily pain and challenge.

I have had an amazing amount of support so far both verbal and financial. Every single donation will make a huge difference to the Brittle Bone Society and it would mean a great deal to myself and the Brittle Bone Society if you would consider sponsoring me. You can use the link below to donate or message my Auntie and I can add your name to my paper list! The training schedule is getting more demanding and time consuming but I am determined so see this through properly and help those with OI. If you are not able to sponsor me then please take the time to share this message to your friends” –

Iain Lawrie, London Marathon Runner 2017

“Caroline Nicholls, who has never run a marathon before, is running the London Marathon on 23rd April 2017 to raise money for the Brittle Bone Society. Joanna Cannon and family are helping her raise money towards her fundraising total.

When I, Joanna, was unexpectedly born with OI in 1975, my family, who knew nothing of the condition, relied heavily on the support of the Brittle Bone Society for practical and emotional support. My Mum has said in the past that she does not know how she would have managed without them.

Growing up, I also relied on the fundraising efforts of the Brittle Bone Society, receiving funding for powered wheelchairs which enabled me to study, work, live and parent independently. Without the Society’s funding for this specialist equipment, I know my life would not be as it is now.

Since my son Jacob was born with OI eight years ago, the Brittle Bone Society has provided advice, guidance, and funding for a specialist wheelchair for him. I have also grown to recognise the importance for all our family to become part of the OI community which the Brittle Bone Society helps to create; updating our OI knowledge and sharing experiences and fun times with friends at annual family conferences.

Providing equipment, advice, and events to meet others with OI is costly, but incredibly important, in fact life changing for many including three generations of my family. It is for this reason that I am helping Caroline fund raise for the Brittle Bone Society.” –

Joanna Cannon, friend of Caroline Nicholls – London Marathon Runner 2017

CHARITY CONCERT - GLASGOW UNI

3RD YEAR STUDENTS Royal Conservatoire of Scotland and the University of Glasgow CHARITY CONCERT for BBS and MacMillan Cancer Support - a massive £1,232

Gregor Keachie who helped organise the fundraiser for the BBS with a donation of £616.36. Patricia was pleased to attend the fantastic concert at Glasgow University and said the talent on display was outstanding. The musicianship, singers and talent was truly fantastic. Thanks so much for your support. We cant wait to attend the next one!!!

CHARITY SHOOT - £1,600

DRAGON CLAY CLUB CHARITY SHOOT - do it again for the BBS

Member and supporter Mr Phillip Seigler pictured far right accepting yet another cheque for the BBS. WOW!!!

The generosity of this club knows no bounds . . . another incredible donation of £1,600 for the BBS from the terrific team at Dragon Clay Club. We received a welcome cheque from supporters who have been giving to the BBS for 12 years. We never forget how many wonderful causes there are - and that they continue to think of us is truly humbling. THANKS!!!!!

FUNDRAISING FUN AT KYOWA KIRIN - £8K+

Kyowa Kirin raised an amazing £8,433.44 at their charity event in Leeds in May. Natalie, our Communications Officer, attended the event with member, Gem Turner, and it was truly remarkable to have raised this amount in one day!

The pharmaceutical company choose a charity to raise funds for at this one day event each year. Paul Connor works for Kyowa Kirin, and was the inspiration behind the company choosing the BBS as the charity of the day, as Paul’s son has OI.

A huge thanks to Paul, Gem, and everyone involved!

MARK IT WITH MARK!

We’re turning 50 . . . and so is Mark. Help us celebrate our golden anniversary in 2018 by organising a sponsored walk.

Whether you walk, wheel, or wander, let’s take a jubilee jaunt, and go the extra mile for Osteogenesis Imperfecta. Here are just a couple of our ardent amblers already lined up:

- Celebrating 50 years of the society her mother created, Yvonne Grant is doing ‘50 Golden Wheels Walks’. The walks that Yvonne has chosen are suitable for wheelchair use. Yvonne is doing 25 wheels between now and September and the others from March 18 to September 18 making a grand total of 50! https://www.justgiving.com/fundraising/yvonne-m-grant5
- Bone Rattler – BBS Wishbone Walk West Highland Way 2018
- OI Bone Service Professionals are joining forces over the Wishbone Day Weekend next year to walk part of the West Highland Way.

Email: fundraising@brittlebone.org for more information
THANKS TO OUR FUNDRAISERS

The BBS are so thankful to all our fundraisers who put in the effort all year round to raise money. There are too many of you to mention individually, but here is a selection of some of the activities which have taken part over the last few months. If you feel inspired please get in touch by sending an email to fundraising@brittlebone.org

Scottish Support Group members arranged a can collection at Silverburn Tesco, Glasgow:
TOTAL RAISED £485.72

Pub Quiz – Betty Nicholls in memory of Alistair Bruce. CEO Patricia Osborne, SDO Coreen Kelday and Trustee Yvonne Grant went along to offer support and met up with member Paul Noble and friends.
TOTAL RAISED £518.55

Jason Tittley and Emma held a Charity Auction and Raffle
TOTAL RAISED £1750

Lily aged 7, held a sponsored walk in a wheelchair outside her school
TOTAL RAISED £1323.75

Lauren & Ashley Wells raised money by running the Snowdonia Half Marathon
TOTAL RAISED £655

Mill Hill School SEN Ladies
TOTAL RAISED £63.40

Orla and Lucy raised money at their schools by holding a non-uniform day
TOTAL RAISED £345.04 (405 euros)

Birmingham and Newcastle Support Groups Wishbone Day raised funds by holding a cake sale, raffles, and stalls
TOTALS RAISED: £200 (Birmingham) • £210.60 (Newcastle)

THANK YOU

And to all the other amazing fundraisers who have supported the BBS we send a BIG THANK YOU
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 become 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.

**GIFT AID**

UK Taxpayers can give their donations a big boost by using Gift Aid – for every £1 donated, the BBS receives £1.25 if Gift Aid is added 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://brittlebone.org/get-involved/fundraising/gift-aid/

Please remember: if you are fundraising and using a BBS sponsorship form, please make sure your sponsors give their full name, address (including postcode) and amount donated, to ensure that we can successfully claim the money back.

**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.

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