NEW YEAR, NEW PATIENT DAYS!

The BBS are delighted to be bringing back our Patient Day Events for a 3rd year running.

We are kicking off the 2017 Patient Days in London on February 25th by celebrating Rare Disease Day with renowned OI specialist Professor Francis Glorieux, along with a host of other OI Healthcare Professionals. Not stopping there we’ll then be heading to Bristol the very next day for our second Patient Day of the year with talks from Healthcare Professional from Bristol Royal Hospital for Children.

We also have Patient Days planned for Belfast and Dublin for Wishbone Day (see page 5) and then Scotland later in the year (More details to follow). To register or to find out more about any of these events visit: brittlebone.org/support/events/patients-days/

BBS JOINS AMRC

After months of detailed discussions and planning the BBS has been accepted into the AMRC (Association of Medical Research Charities). BBS were delighted to gain membership. Working with the expertise of our own BBS Medical Advisory Board and Research Committee the charity can now chart their own course to focus on those research areas that matter most to them. Your views and ideas on this will be sought in the weeks and months ahead.

INAUGURAL SCIENTIFIC SYMPOSIUM

Whilst we appreciate the BBS held a symposium many decades ago, we are thrilled to host our first in recent memory under the direction of the BBS Medical Advisory Board Chairman Prof Nick Shaw. Working with him, Trustees Prof Bishop and Prof Ahmed have devised a wonderful programme of speakers and topics attracting top OI specialists from across the world. The event will be hosted by our Vice Chairman John Phillip’s at his law firm Jones Day HQ in central London in February. The symposium will be a great opportunity for Healthcare Professionals to learn about OI.

MALTESER MAGIC FOR MS RENKE

Actress, disability rights activist and former BBS Trustee Samantha Renke recently starred in a new commercial for confectionary giant Mars. The ad for Maltesers first aired during the Channel 4 coverage of the Rio Paralympic Games.

The advertising campaign which aimed to put people with disabilities at the forefront of their marketing strategy sees Samantha tell an amusing story of a wedding she once attended. (Read more on page 11).
CEO & CHAIRMAN UPDATE

TRUSTEES
August saw us host yet another very successful Conference in Reading. We said thank you and farewell to Harry Venet and members unanimously re-elected our Treasurer Robert Gordon. In November we co-opted to our Board Angie Stewart and Gareth Cumming. The Board are constantly refreshing and reviewing how we operate and want to ensure we keep our governance procedures and the people who manage them - vibrant and impactful.

JONES DAY LAW FIRM
We are grateful, yet again to Jones Day law firm and to John Phillips who have worked incredibly hard in drafting policies and contracts that ensure the BBS works appropriately relating to all matters in our charitable activity.

CONFERENCE & EVENTS
Conference 2017 will likely be North East England but we haven’t yet agreed a venue. We are looking to scope a theme around ‘technology’ and will update members in our regular e-zines as soon as we have more details. Patient Days have now been planned up until May, with one planned in London in February, followed by an event in Bristol. We travel to Ireland in May visiting Belfast and Dublin. Information on all upcoming BBS Events is available at: brittlebone.org

SCIENTIFIC SYMPOSIUM
We are thrilled to be hosting our first Scientific Symposium in London early 2017, and the first in quite a few years. Boasting an impressive array of speakers and being held at our Vice-Chairman, John Phillip’s prestigious conference facilities at his law firm in London.

PROFESSIONAL NETWORK
BBS launched this after realising they had a growing list of fantastic Healthcare Professionals who are eager to work with and support the Society by attending events and participating in work around health. As BBS strive to work towards an Adult OI service, to continue to work towards achieving better, clearer universal care guidelines for people with OI – it makes sense that we register interest from those Healthcare Professionals who want to help the world of OI.

RESEARCH
BBS have been sharing updates on new and ongoing trials and you can find more details on our website. It looks like there will in the next few years be a real possibility of new treatments as a result of current projects and it’s a really exciting time for OI.

ADULT OI
We held our first members consultation meeting in October in Edinburgh, attended by Trustee Prof Faisal Ahmed and Chair of our Adult OI Forum Dr Richard Keen. We will be sending out further surveys to gain your input and hope to have a meeting with commissioners in the spring to talk of our hoped for service.

FUNDING APPLICATIONS
Staff have been working really hard on various funding applications. Securing grants to pay for our new Kids Hospital Packs helping children when they attend hospitals. We gained funding grants from Pharmaceutical companies to help cover the costs of our patient day events and conference and to cover outlays for a new website and associated materials.

KIDS HOSPITAL PACK
Thanks once again go to pro bono supporters Jones Day Law team for helping draft contracts that saw us solidify our partnership with Julia De Bres a mum with OI, who we have been working with on our new kids hospital pack. Julia De Bres has created a beautiful cartoon book and BBS have secured significant funding to begin sharing our new fun packs to our children in hospitals up and down the country.

DONATIONS AND LEGACIES
Fundraising remains vital and we hope as many of you as possible do whatever you can to support our work. We acknowledge and thank all those who have done so much in the past year but with grants so difficult to obtain we hope we can encourage people to think about doing their own project. Why not try a coffee morning or a can collection or consider thinking of the BBS in your will? We know it’s a sensitive and difficult topic but without legacies we couldn’t have achieved nearly as much as we have in the past few years.

(see page 8-9)

Elaine & Patricia
AFOSTASE ALFA CONSULTATION

The Brittle Bone Society and CLIMB (Children Living with Inherited Metabolic Diseases) have been patient organisation consultees in the NICE (The National Institute for Health and Care Excellence) process – for the drug Afostase alfa for people with HPP (Hypophosphatasia). The draft guidance recommends Afostase alfa for children with the condition as part of a managed access agreement and when the company provides the drug with the proposed cost cap which will limit the cost the NHS will have to pay per patient.

Brittle Bone Society whilst working with their own OI community and other rare bone groups are aware of hopes to establish access to new treatments and therapies as they become available. It is important for the BBS to be familiar and understand the processes involved in getting new drugs approved on the NHS. This may be something we need to consult on in the future when new treatments for OI become available.

INTERNATIONAL OSTEOPOROSIS FOUNDATION

BBS were invited to attend an ambitious initiative by the International Osteoporosis Foundation (IOF) to look at better ways to communicate best practice, talk about treatments and matters relating to treatment of rare bone disease and important steps being taken to help educate the wider healthcare community in better understanding the care needed for people with rare bone disorders. Also at the meeting were reps from Osteogenesis Imperfecta Foundation (OIF), OIFE and Care 4 Brittle Bones (C4BB). BBS MAB member Dr Kassim Javaid helped chair the meeting and Patricia is discussing with Trustees about next steps.

UNBREAKABLE ALLIANCE

Patricia Osborne (CEO) and Coreen Kelday (SDO) were invited to a series of important meetings and seminars with colleagues in the OI world from all over Europe and further afield.

Two days were spent attending the Scientific Congress hosted by the Unbreakable Alliance, a partnership created between APOI (the Portuguese OI Society) and Fundacion AHUCE (The Spanish OI Research Charity). Talks were heard from Healthcare Professionals around the globe: from America, India to the UK and beyond.

NATIONAL OSTEOPOROSIS SOCIETY CONFERENCE

BBS were invited to give an overview of their work at the national conference of the National Osteoporosis Society (NOS) held in Birmingham early in November. Patricia had a productive meeting with CEO Claire Severgnini who has indicated a willingness to work with and assist the BBS in a few projects. The conference event gave the BBS a chance to tell those primarily involved with Osteoporosis about the distinct differences facing people who live with OI. Joining Patricia at the presentation were Dr Kassim Javaid (University of Oxford) and Dr Jenny Walsh (Sheffield Northern General Hospital).

BRSOL CHILDERN’S HOSPITAL FAMILY DAY

Bristol Royal Hospital for Children, metabolic bone team hosted an OI family day in October. Coreen, BBS Support Development Officer was delighted to be able to attend and meet up with so many OI families and have important discussions with Head of Children’s Service and BBS MAB member Dr Christine Burren; as well as catching up in person with OT’s and Physios from the POINT team. Coreen met up with Dr Shane Clarke, Consultant Rheumatologist from Bristol Royal Infirmary whom the BBS hope to work more closely with in the future. The day consisted of a fun packed four hours of talks, play and team work and also a free visit around the Science Centre.

Whilst in Bristol, Coreen was keen to promote the BBS Patient Day Event to be held Sunday February 26th (register at brittlebone.org). Coreen also gave an update on our fantastic new literature for hospital staff to hand out at clinics.

OIFE AGM

Osteogenesis Imperfecta Federation Europe’s AGM was attended by representatives from 13 different countries. BBS delegates Patricia and Coreen were pleased to attend.

Patricia was able to share some management updates about good governance that they follow in the British Isles, and also offered to share some details on documents and policies adopted at the BBS which OIFE may also be able to use. These policies cover a myriad of topics.

TRANSITION & ADULT CARE CONFERENCE NEWS

Saturday 8th October 2016 – The Studio, Birmingham

On Saturday 8th October BBS Communications Officer Karl Henry attended the CLIMB Conference: Transition and Adult Care. The one day event saw a variety of speakers discussing a wide range of topics.

- The UK strategy for rare diseases and transition
- The differences between paediatric and adult care
- Bridging the gap to independent living

While the event was aimed at those living with a rare condition, it also provided the charity the opportunity to form a stronger alliance with those working within the rare disease community. The event also gave the BBS the opportunity to network with other Healthcare Professionals working with similar rare bone conditions.
Rhona Lang

After leaving the world of welfare rights behind and deciding to travel the path less travelled, BBS member Rhona Lang, or McKenzie as she is otherwise known, took her first professional acting role in Ramps on the Moon’s production of The Government Inspector as the Locksmith’s Wife.

The company was integrated in that approximately 80% off the cast were deaf or disabled and the roles given were not specifically for a disabled cast. The Gogol play is the piece that Fawlty Towers: The Hotel Inspector episode was based upon so as you can probably guess there were laughs and high farce to be had.

The set was amazing and had a fully functioning lift, revolving door and 3 floors, some of the costumes were very elaborate. Rhona’s however came straight from her own wardrobe. “I never even knew I was rocking the Russian peasant look” says Rhona.

The play is the start of a five year project to bring fully integrated work to mainstream venues with British Sign Language, subtitles, audio description and plenty of wheelchair spaces for the audience, but also allowing access for all cast too.

Rhona’s role was very demanding and despite her OI, she was hurled out of a prop wheelchair night after night. Thankfully, due to a good stage dive, no bones were harmed. This is the first time she has been asked to break a leg without taking it literally.

Thanks to Birds of Paradise Theatre Company, Rhona is currently on a course for emerging producers called The Optimists with the China Plate Theatre Company in London. She is also working on her solo stand up debut hour and a theatre piece looking at disability, love and sex called The Disability Sex Archive.

Penny Clapcott

Penny Clapcott is off to Bern in January to attend the Swiss National Science Foundation, a forum to discuss e-consent and dynamic consent. Penny will be attending with the Rudy Study and will discuss her experience being on the patient forum, talking about how the Rudy study uses dynamic consent, how she and the patient forum feel about this and how they were involved in the process.

Research is now becoming more and more digital and with the large amounts of data being shared its use has grown significantly. Sometimes the methods for involving research participants have not kept pace with the changes in research capability. E-consent and Dynamic consent (DC) may be a new way to address this. There are wider concepts offering a new approach to consent.

Central to the concept of DC is a personalised, digital communication interface that connects researchers and participants, placing participants at the heart of decision making. Switzerland is now in the process of implementing a national template and process for broad consent.

Monique Jarrett

Check out brittlebone.org to read about our new dancing star Monique.

Dates for your Diary

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

Jhon Bateman

On Wednesday 12th October BBS Members Jhon Bateman and Gareth Cumming attended the National Institute for Health Research (NIHR) ‘Think Research’ Patient Day as representatives of the Brittle Bone Society.

The event provided practical advice and information on the changing role of patient organisations within research. Highlighting the need for such organisations to assist in the creation of research information leaflets; as it is important to view these from the patient’s perspective and to remember that potential research participants may not be familiar with all of the medical terminology.

One of the other key points stressed by the meeting is that many Patient Information Leaflets will say that the researchers may require access to medical records in the future, but they do not provide a reason why; and for this reason it is important to give potential participants as much up front information as possible.
SUPPORT FOR YOU
by Coreen Kelday

Please get in touch with me on any of the topics below to let me know your ideas and suggestions. I look forward to hearing from you (and you can always ring the office on 01382 204446 if you prefer) coreen@brittlebone.org

COMMUNICATIONS UPDATE
by Karl Henry

AWARENESS Raising GOODIES
Over the coming year there will be many opportunities for you to help the BBS raise awareness of Osteogenesis Imperfecta and support the work of our Charity. This is why we’ve been revamping an exciting range of BBS posters, fliers and merchandise, (see page 10) because we want to make it as easy as possible for you to be able to tell the world all about OI.

Not only have we developed and improved our existing range of awareness raising goodies, we’ve also created a specific Wishbone Day poster for May 6th. So if you’re having a Wishbone Day or any other kind of event, get in touch to see how we can best help you! (email karl@brittlebone.org)

Early 2017 will see the BBS introduce our new Kids Packs to hospitals around the country. These exciting new packs funded by the Barbara Ward Children’s foundation will not only help keep OI kids entertained when receiving treatment, they’re also going to be a fantastic resource to educate - as we’ll be including a very special colouring book that tells the story of SUPER BONES! We really can’t wait for you to see it!

2017 will also see the launch of the new BBS website. We’ve been working hard with web designers to completely redevelop the current site - everything from the look and feel, right down to content. All the best bits of the current site will still be there, we’re just refining them. The new site will see the introduction of new features and sections that are going to make it easier than ever for you to keep up-to-date in the world of OI and the work the BBS are carrying out.

For monthly updates on BBS activity sign up to our E-zine at brittlebone.org

VOICE AND CONFERENCE 2017

We are currently working hard surveying a few hotels in England and our fabulous members are helping with these reconnaissance missions to ensure the venues are exactly what we are looking for. It’s never easy finding venues that meet all our accessibility requirements, have family rooms and enough breakout rooms to also host a Kids Club and Cool Bones. We appreciate your patience whilst we negotiate the best prices on your behalf, and hope to have these venues advertised early in the New Year.

ADULT OI SERVICES CONSULTATION MEETING

The BBS held our first consultation meeting with OI members. There was a good mixture of ages represented from England, Scotland and Wales representing all sections of the OI family. This group will continue to work with us in evaluating the data needed on this project and we hope they can deliver a workshop at our next conference and AGM.

Dr Richard Keen from Royal National Orthopaedic Hospital is Chairman of the Adult OI Project Group and Professor Faisal Ahmed from Royal Hospital of Sick Children Glasgow, Trustee of the BBS, attended this meeting. We had apologies from allied Healthcare Professionals who had travel issues and unfortunately our friends from Northern Ireland and Republic of Ireland weren’t able to make this first meeting.

We will need your help by getting involved in further consultation events, completing surveys and assisting us to gather relevant information to form a suitable service for the needs of the OI community.

SEND YOUR NEWS STORIES TO:
admin@brittlebone.org

Find the BBS at:
Fiona’s Fight to the Finish Line

“Nearly 6 years ago when my Son Oliver was born with 9 broken ribs, genetic testing revealed that Oliver, myself and a number of my family members have Osteogenesis Imperfecta. Over the years I have broken various things and during my pregnancy I broke my spine in 2 places and somebody told me “You’ll never run a half marathon!” In the past 6 years the Brittle Bone Society has always been a support and has introduced us to some great friends in the same position as my family and who don’t judge. I wanted to run the Glasgow Half Marathon in aid of the BBS, to try to raise awareness, give back a little and to say thank you. I also wanted to prove that having Osteogenesis Imperfecta doesn’t mean I can’t achieve the things in life that I want to.”

Terrific Triathlon

After Erin watched the CBBC programme ‘My Life’ about Star, who you may remember climbed the Eiffel Tower back in 2012; she was motivated to raise money for people like Star with brittle bones. Erin and her friend Neve came up with the idea for a triathlon involving running, scooting and cycling. Cheered on by neighbours and Erin’s little sister Nicole they whizzed by. After almost an hour of hard work, they had completed their challenge. Despite feeling tired and ravenous, they were proud of their achievement and between them they raised £150 for the Brittle Bone Society!

Tribute to Jordan

RIP Jordan McCabe

The OI Community are only too aware of the wonderful support we gained from Andrew Perry and his good friend Jack McCabe who ran the Scottish Half Marathon for our charity. Amongst the many fans, supporters and well wishers at the finishing line was Jack’s younger brother Jordan.

Jordan was extremely proud of Jack’s fundraising efforts and had contributed towards his sponsorship. The McCabe family are close friends of the Perry family and made the overwhelmingly generous decision to nominate the BBS as their charity of choice for memorial fundraising at the funeral. This resulted in £930 being raised.

Jordan is survived by his 6 year old Daughter Honey and the family have asked that the funds are used towards the Brittle Bone Society’s work with children as such was Jordan’s fondness for little Mila.

Unfortunately since the funeral Jack’s Mother Donna has taken very ill, and all our thoughts are with the family at these extremely difficult times.
FUNDRAISING WALL OF FAME by Marthe Handling

The BBS are so thankful to all our Fundraisers who put in the effort all year round to raise money! Whether you strapped on your running shoes, jumped out of a plane, or baked a cake – thank you so much. If you are looking for inspiration and want to read a bit more about our amazing fundraisers then head over to http://www.brittlebone.org/index.php/get-involved/fundraising/

Don’t forget to contact me if you need any tips or advice on running your own fundraising event. Also please don’t forget to gift aid it (see back page for more details).

Alastair & Richard ran The Great West Run – RAISED £751.25 at last count

Bradley Skydived – RAISED £1030.50

Franck took part in Race to the Stones – RAISED £1009.65

Mark ran 8 laps of the Dusk till Dawn Run – RAISED £101.25

The Marshall family’s 14th Coffee Morning – RAISED £750

British 10k runners Dr Meena Balasubramanian, Jake & his team of Emma, Gina, Joe, Mark, Sian, Alan, Kat, & Matt – RAISED £2056.59

Andrew & Jack ran the Scottish Half Marathon – RAISED £4146

The Sieglers & the Dragon Clay Club Charity Shoot – RAISED £1600

Geoff walked 100km of the Thames Path Challenge – RAISED £2866.82
BBS MERCHANDISE

Get your hands on some snazzy BBS merchandise and to support your favourite charity! Please email admin@brittlebone.org or call the office on 01382 204446 to order.

Please note delivery charges may apply

Limited stock - order quick!
Available in Small, Medium and Large
FREE UK Delivery

New t-shirts also available to purchase online
http://www.brittlebone.org/index.php/get-involved/merchandise1/

Ol Bear £12
Ol Bear T-shirt £5
Ol Bear Crutches £10
Ol Bear Wheelchair £20

Please note delivery charges may apply
“I often have to pinch myself when I look at how my life has changed since moving to London 4 years ago and how my career as an actress has blossomed. Not one to be told I can’t, I have many fingers in many pies and love all the work I do. My main passion is acting and having already worked in feature films, music videos and earlier this summer landed my first national commercial for malteser’s. I also have a passion for writing and have a regular column in Pos’Ability Magazine and am a regular blogger for the Huffington Post. Promoting diversity is at the heart of what I do and working with charities such as Scope and launching my production company Born This Way Media, ensures I highlight the importance of inclusion. Future projects include teaming up with a burlesque group and becoming a producer on a Channel 4 project. All in all exciting times ahead.”

By Samantha Renke

WIMBLEDON & RIO — BBS PATRON KEEPS ON WINNING

The BBS extends our warmest congratulations to our patron Jordanne Wiley on her latest strike of victories. For a third consecutive year Jordanne along with partner Yui Kamiji are grand slam Wimbledon wheelchair doubles champions defeating second seeds Jiske Griffioen and Aniek van Koot 6-2 6-2 in one hour and nine minutes.

Jordanne also took home Bronze for Team GB at this year’s Summer Paralympics in Rio despite suffering a wrist injury earlier in the games. Playing against her regular doubles partner Yui Kamiji, was able to overcome the injury that hampered her performance in the matches before. She said: “In London I was young and quite fit and now, not that I’m not young, but I had this injury 48 hours ago and I did think that it was over for me.” Luckily is wasn’t and Jordanne and partner Lucy Shuker took home Bronze.

USED STAMPS APPEAL FROM MILDRED

It doesn’t matter if they are new, used, overseas, first or second class stamps - Mildred can turn them into cash! With Christmas fast approaching we would like to kindly remind everyone to save all the used stamps from your Christmas cards. Leave your stamps on their original envelopes but trim them to leave about 1cm of paper around each one. Whether you’ve managed to save up a little or a lot please make sure you do send them to Mildred - every little helps. Please note that postcards and old coins can also be sold on.

CAN YOU CAN COLLECT FOR THE BBS?

Look after the pennies and the pounds will take care of themselves! Each year the BBS receives thousands of pounds from collection cans alone. As well as raising much needed funds, they also help spread awareness of the BBS and OI to local communities across the UK. Whether you keep a can next to the till or fill a bucket at a supermarket collection - it all adds up! Please help the BBS get a team together and organise a can collection in your local area.

Please contact the BBS for your own can today and help us make it a can collecting bonanza year in 2017.
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 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 for at: http://www.brittlebone.org/get-involved/fundraising/gift-aid/ Please remember that if you are fundraising and using a BBS sponsorship form that your sponsors give their full name, address (including post code) and amount donated to ensure that we can successfully claim the money back.

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 AGM meetings.

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.

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.

GIFT AID

Please consider leaving the gift of a legacy for the Brittle Bone Society

To find out more
bbs@brittlebone.org with LEGACY (in subject line)

Help the Brittle Bone Society build a better future

www.brittlebone.org - Tel: 01382 204446