The 50th year of the Brittle Bone Society has been one for the history books. Two Parliamentary Receptions, our fabulous Family Conference and the usual mammoth fundraising achievements. We couldn’t have done all of this without you, our members and supporters. Special thanks for the funding of the Annual Conference go to Mereo Biopharma who continue to assist us with grants for this our most expensive event of the year. We also received funding from Alexion to help us once again.

Here’s to the next 50!

MAX EDNEY ON BBC

The BBS is tremendously grateful for the support received from BBC Children in Need year on year, and this year our young Max was the star of Radio 2’s Chris Evans Breakfast Show leading up to the appeal night, as well as an all-star presenter on the TV appeal! See page 6 for the full story »

SCOTTISH PARLIAMENT

On Wednesday 5th December, the Brittle Bone Society attended a Parliamentary Reception at Holyrood to round up a year of exciting events celebrating the charity’s 50th anniversary. The event, kindly hosted by Shona Robison MSP, featured a keynote address from First Minister Nicola Sturgeon, and allowed us to acknowledge the great work in healthcare and research throughout Scotland, demonstrate the importance of research projects and partnerships, and give a shout out to the Hypophosphatasia Softbones UK and X-Linked Hypophosphatemia communities. Events like this really help us raise awareness of OI, and allow us to highlight the need for a coordinated rare bone service in Scotland.

Thanks to Kyowa Kirin for their support in funding the event.

NIHR NON-COMMERCIAL PARTNERS

The BBS have recently been accepted as non-commercial partners with the National Institute for Health Research! This means that any appropriate research studies funded through our Research Grant Scheme are automatically eligible for NIHR Clinical Research Network (CRN) support. To find out more about the Research Grant Scheme, read more on page 10 »
CHAIRMAN AND VICE CHAIR SHARING THE LOAD

Chairman Elaine Healey and Vice chairman John Phillips were delighted with the success of our recent Conference event in Dundee.

All BBS Trustees wanted to thank Patricia and staff: Coreen, Nikki, Rosie and Lizzie for planning and producing an amazing Conference experience for delegates in Dundee.

The weekend celebration held at the Apex Hotel in Dundee was a truly fitting tribute to founder member Dr. Margaret Grant MBE, to the Grant family and to all the pioneers who helped build the BBS.

VIP GUEST

The weekend event was made all the more special by the guest appearance of both Margaret and David Grant. It was heartwarming to witness the outpouring of respect, love and admiration for what this woman started all those years ago. The specially commissioned film on the BBS was warmly received and thanks to Ben Wiles and his colleagues for producing a super time capsule of how the BBS was built!

MEDICS DINNER - UNICORN SHIP

Thursday night saw our Vice chairman John Phillips and Chairman of Medical Advisory Board Prof Nick Shaw welcome healthcare professionals from around the world to a celebration dinner aboard the Dundee berthed HMS Unicorn to herald the start of our exciting 2nd Scientific Symposium event.

INTERNATIONAL SCIENTIFIC SYMPOSIUM

Friday morning kicked off with Allied Healthcare professionals gathered from Great Ormond Street Hospital, Birmingham Childrens Hospital, Sheffield Childrens Hospital and Bristol Royal Hospital for children gathered to discuss what has been learned in the care of OI in the past 20 years. Mr Nicolaou Paediatric Orthopaedic surgeon gave a talk on limb deformities. Other topics included dental care, stem cell therapy, whole body vibration. There was focus on research and updates on fracture prevention study TOPAZ. Later in the family programme Dr Shane Clarke discussed both TOPAZ and the Asteroid programmes. At the Symposium we also heard from Dr Balasubramanian about her research project funded by the BBS and from Dr Alex Ireland on his study around physical function and soft tissue health. We were also honoured to have with us Dr Astrom from Stockholm and Prof Francis Glorieux from Canada.
FRIDAY NIGHT PREMIER LAUNCH

VIPs joined a packed dinner in the conference suite, and the weekend’s events were formally opened by Ian Borthwick, Dundee’s Right Honourable Lord Lieutenant and Lord Provost accompanied by the Lady Provost. Other guests included Jenny Hanley, the TV celebrity of Magpie fame, supporter and funder Mr Blair Thomson of Northwood Trust, local constituency MSP Joe Fitzpatrick and local Councillor Richard McCready to name just a few of our very special guests. John Phillips hosted the nights event along with Jenny Hanley and it was an emotionally charged room. The film of the history of the BBS was well received and if you missed it you can see it on our youtube channel.

SATURDAY NIGHT TALKS & WORKSHOPS

270 delegates attended throughout our 4 day event. Goody bags with a local slant of jute, jam and journalism were offered with a specially commissioned comic.

Lord Shinkwin and Penny Clapcott each offered a fabulous talk about their lives and the experience of living with OI. Medical talks were given by Prof Glorieux, Dr Ireland, Dr Clarke and Dr Balasubramanian. A talk on collaboration was held by Patricia for the BBS, alongside Tracy Hart of OIF and Ingunn Westerheim of the OIFE.

SATURDAY NIGHT GALA DINNER AND AWARDS

Delegates were not disappointed with the star studded banqueting room at the Apex Hotel. Our popular volunteer awards ceremony was hosted this year by long-time supporter Paul Connor. Presentations were given by Chairman Elaine Healey and Treasurer Robert Gordon, assisted by our Fundraising officer Nikki Stark.

BBS SUNDAY PROGRAMME

We had the most successful Sunday session in a long time. The room was packed out and we held a series of fantastic workshops covering the future BBS programme of activity and support. We also had discussions about research handled by Prof Bishop. This year our workshops were really interactive with members taking part and getting their views over. A real success which helped us shape our next research strategy and our all important strategic plan which you can read on page 7.
Max Edney charms thousands on Radio 2 with Chris Evans, makes new celebrity friends and features on the live TV Children in Need appeal!

Young BBS member Max Edney shot to stardom last month, with his various appearances on the Chris Evans Breakfast Show on BBC Radio 2! Max recorded a clip last year, for the 2017 BBC Children in Need appeal, in which he shared his experience of OI, with the whole of the UK. This clip has been replayed this year, and has won the hearts of radio listeners up and down the country.

Since its replay on 6th November this year, Max has been featured again, this time alongside his mum Leanne, where he shared an update with listeners and helped BBC Children in Need raise tremendous amounts of money through their auction of their ‘Ultimate Christmas Party at the O2’ tickets. We are so pleased that Max’s story has reached so many people, raising awareness of OI and the work of the Brittle Bone Society.

The BBC Radio 2 Team invited Max into the studio to surprise Chris Evans live on air, where he got to meet new celebrity friends Dr Ranj and Liam Payne (formerly of One Direction). What’s more, on Friday 15th November, Max appeared on BBC1 as a presenter during the Children in Need live appeal.

BBS staff and supporters tuned in wearing their Pudsey ears to watch Max shine on the big screen, and couldn’t be more proud!

If you want to listen to the clips of Max and family on the radio, head over to our website:

http://brittlebone.org/max-charms-thousands-on-bbc-radio-2/

Pudsey at conference

How lucky we were to get special permission for Pudsey to attend and meet our children at the BBS Kids Club and Cool Bones. They had a ball!! Thank you BBC Children in Need for this, and for the regular support we receive year on year.
We welcomed a team of popular writers to produce insightful blogs and comments for our website and social media over the past 12 months. Samantha Renke, Gem Turner, Abbi Brown and Shani Dhanda - all of whom have made a strong impression in their own fields of work - have given us thought provoking and informative blogs.

**STRATEGIC PLAN 2019-2021**

Trustees and staff are excited to share the highlights of our next strategic plan:

- **Continue to raise public awareness and increase understanding of OI** by continuing to attend outreach events and developing innovative campaigns. We will take our History Bones exhibition on tour, to teaching hospitals and other venues.

- **Remain as advocates for people with OI** by networking with policymakers and healthcare services and responding to consultations to review policies which affect people with OI.

- **Provide and improve on support services for people affected by OI** using online and offline media, and providing equipment and support grants where they are needed. We will continue with our Annual Family Conference but will bring in new activity events and develop programmes in conjunction with OIFE.

- **Further our work with the NHS and healthcare professionals**. We will be increasing the number of training events run online and in-person, and develop our connections with healthcare professionals (particularly within adult services).

- **Continue to provide opportunities and incentives to further research into OI**. We will continue to support research projects and widen our funding search to corporate and event-based revenues.

- **Maintain effective governance**, seek out ways to grow educational healthcare events, and develop the ways we manage membership/supporter subscriptions.

- **Implement our fundraising strategy and develop income avenues** with new campaigns and PR activities. Invest in effective information technology to achieve the objectives laid out in our strategic plan.

- **Maintain effective human resources, facilities, and risk management functions**. We will continue to reward good work by both staff and volunteers, and monitor the operations of the charity to ensure best value is achieved.

**BIRMINGHAM SUPPORT GROUP**

BBS staff members Coreen and Nikki attended the Birmingham Support Group at Bilston Peoples Centre on Saturday 1st December. To find out about support groups happening near you, get in touch with us at the BBS office!

**IRELAND EVENTS**

The events featured a film charting the history and fascinating stories of the close knit community, showing the sheer resilience and hard work over many years that enabled the BBS to blossom and grow. Also featured were extracts from the BBS History Bones exhibition which charts the 50-year story about how the charity was formed, facts about developments in treatment of the condition and the fascinating stories of the people they have worked with over generations of families.

The gatherings brought together charity members and local supporters, including HSC healthcare professionals Dr Paul Jackson of Royal Belfast Hospital for Sick Children, Dr John Lindsay of Royal Victoria Hospital, Belfast, and HSE healthcare professionals Dr Ciara McDonnell of Temple Street Children’s University Hospital, and Dr Malachi McKenna of St Michael’s & St Vincent’s University Hospital.

**BBS BLOGGERS 2018**

We welcomed a team of popular writers to produce insightful blogs and comments for our website and social media over the past 12 months. Samantha Renke, Gem Turner, Abbi Brown and Shani Dhanda - all of whom have made a strong impression in their own fields of work – have given us thought provoking and informative blogs.
**CLAIRE’S FAMILY FUN DAY**

We were delighted to receive £350 from the fabulous Claire John, who has run an annual charity fun day in Bristol for the last 4 years. Each year Claire supports a different charity close to her heart and we were delighted that this year she chose the Brittle Bone Society.

Thank you Claire and everyone else involved.

**MISS MANSFIELD OUTSTANDING TEEN**

We are excited to update on the achievements of 16 year old, Layla Allsop as she continues her fantastic awareness and fundraising efforts for the BBS as Miss Mansfield’s Outstanding Teen.

Since being crowned in May this year, Layla has already hosted a large number of events including cake sales, football team presentations, summer fetes and has given many public talks about OI and the Brittle Bone Society to businesses, rotary clubs and Councillors.

Layla’s efforts have even caught the eye of a few famous faces too, meeting Emmerdale Actor Anthony Quinlan and being donated a signed photograph and boxing glove from boxer Carl Froch to auction as part of her fundraising efforts.

Most recently Layla held a ‘Battle of the Couples’ contest (based on the Mr and Mrs show) at the One Call Stadium, Mansfield Town Football Club. The event was a great success and included a disco, raffle, photo booth, food and a silent auction raising £500 for the BBS on the night.

The run up to Christmas will be an extremely busy time for Layla as she will be attending lots of Christmas fayres and light switch on events in her local area, continuing her awareness raising of OI and Brittle Bone Society.

With lots more planned for the coming months, including a fashion show, tombola and choir concert, Layla is so focused on making a difference for the BBS and has already raised over £1000 of her £4000 target.

**THE EDNEYS**

As the massive “12 events in 12 months” campaign by the amazing Edney family comes to end we just want to say a final thank you to Steve, Leanne, Max and Cove, their extended family and friends and everyone who got behind this amazing challenge. £20,000 was the target and we are delighted to announce that this was well and truly smashed with a total raised of £60,760.

And it didn’t stop there when young Max rocketed to stardom with his appearances on the Chris Evans Breakfast Show on BBC Radio 2 for the BBC Children in Need appeal, in which he shared his experience of OI with the whole of the UK. Max wowed so many people and even got to meet some famous faces along the way, before appearing as a presenter on BBC1 during the live Children in Need appeal show.

“We are so proud that Max’s story has reached so many people and raised awareness of OI alongside the funds for Children in Need and the BBS.”

**SARAH & ANDREW MARSHALL**

The lovely Sara and Andrew Marshall recently held their 16th annual coffee morning to raise funds for the Brittle Bone Society. Sara and Andrew first became involved with the BBS following the birth of their youngest daughter Alice who has OI.

Over the last 16 years, they have raised an exceptional amount of money. This year the event itself raised a huge £838 topped up by a £100 donation from the local Rotary Club and Inner Wheel.

**CHLOE GIFOLI**

When 7 year old Chloe applied to us for funding towards her much needed wheelchair she was determined that she would help raise some of the money herself. Chloe raised a massive £500 towards the cost of the equipment by sitting in a bath of jelly and having family and friends sponsor her. Well done Chloe.

**FUNDRAISING HALL OF FAME**

**KARL HOOD**

Karl, who has OI, recently ran the Bournemouth marathon raising money and awareness for the Brittle Bone Society. Completing what he describes as a “killer course” in 4hrs 7 mins and finishing with a calf injury hasn’t deterred Karl who is already planning to run the Brighton Marathon in April next year again raising funds and awareness for the BBS.

Because of his OI, Karl was only able to train once a week for the marathon and found it difficult to find a tailored training schedule. This really got him thinking about challenges people face with all sorts of “invisible” conditions and the struggle just to get to the start line, never mind the finish line with the additional training, rest, recovery and physio burden.

Karl has been very active in raising awareness of OI on social media and plans to write a blog on marathon training with the condition so watch this space. Well done Karl, a well-deserved medal indeed.
CLASSIC CAR & HOT ROD SHOW

The Coach and Horses Pub in Stotfold, Bedfordshire host an annual Classic Car and Hot Rod show at the pub and on the village green to raise funds for charity. This year they selected the Brittle Bone Society as their chosen charity for the event.

Attracting around 2000 visitors, we are delighted to announce that they raised £1045.76 for the BBS. A huge thank you to Leah, and the rest of the team at the Coach and Horses.

The fun filled day included an auction, raffle, games, face painting and a bouncy castle, with plenty food and drink.

GEORGE & DAVID CHURCHOUSE

George and David Churchouse organised a charity football match to raise funds for the Brittle Bone Society. The football match was in memory of their late brother Steven who had OI and was sadly born asleep in 1993. Both George and David captained their teams in BBS tshirts and even had a trophy made for the winning team. Raising £530, the brothers are so pleased with how the match went they plan to make it an annual event.

DRAGON CLAY CLUB

Thank you to the amazing Dragon Clay Club who sent us a cheque recently for £1,100.00 from their Annual Charity Shoot. We have received thousands of pounds over the years from this fabulous group. With special thanks to Reg Smallwood who does all the organising.

SAM WALKER & STEVE REYNOLDS

Thank you once again to top golf professional Sam Walker and Steve Reynolds who donated a whopping £10,000.00 to the BBS! We were so proud to see you sporting our fabulous BBS hats during recent golf tournaments!

FACEBOOK FUNDRAISERS

Huge shout out to all our fabulous supporters who have fundraised for us on Facebook since we launched this great fundraising tool in September. To date we have had 20 people supporting us raising a massive £2247.

To set up your own Facebook fundraiser simply head over to our Facebook page.

Thank you to everyone who has fundraised over the last few months for the Brittle Bone Society. We absolutely love hearing your stories and seeing all the amazing pictures. If you are looking to fundraise for us or have a story you’d like to share then please contact our fundraising officer Nikki at fundraising@brittlebone.org.
POLICY, HEALTHCARE & RESEARCH NEWS

ALL CHANGE ON MEDICAL COMMITTEES

We held our Medical Advisory Board meeting in the summer in London and the key deliverable sought at that meeting was agreement on two new fact sheets and the frequency of review of existing BBS factsheets.

We are also pleased to announce that Professor Faisal Ahmed has been appointed as Chairman of the Scientific Committee, taking over from Professor Nick Bishop who has adeptly steered the committee since September 2016. Further to this, Dr Kassim Javaid will now sit as Chairman of the Medical Advisory Board, succeeding Professor Nick Shaw who has stepped down after two successful years.

ADULT OI SERVICE

Patricia has been involved in a series of meetings representing the BBS with comments and input towards the creation of a new NHS rare bone service. There will be a meeting in December in London attended by Patricia and members of the Medical Advisory Board, we will keep member updated on the progress of this project.

RESEARCH GRANTS SCHEME 2018

We continue to chart our own course in research, as applications are now invited for our 2018 Research Grants Scheme from investigators conducting research that will advance knowledge and application in the field of Osteogenesis Imperfecta. The BBS Research Grant Scheme is open to clinicians, scientists, nurses, allied health professionals and anyone else involved in academic research and/or health care of OI.

PIP EXPERIENCE CONSULTATION

People affected by Osteogenesis Imperfecta may deal with the Government welfare system to assist with the extra costs associated with the condition. Before 2014, this assistance was received through a Disability Living Allowance (DLA), but since then a new welfare programme of Personal Independence Payments (PIP) has been introduced.

The process involves rigorous assessments that have been controversial, and as your patient support group, we began a consultation on the matter. We have the opportunity to bring forward feedback about Personal Independence Payments (PIP) to a minister, and have been collecting feedback from BBS members and supporters through our PIP Experience Survey (published on our website) since early autumn.

We will be sure to keep members informed of any outcomes from these meetings, and will continue to take responses from you so that we can present a clear picture of those with OI negotiating PIP.

BBS FUNDED RESEARCH

As many members and supporters are aware, both Dr Meena Balasubramanian and Dr Alex Ireland are conducting research projects funded by the BBS.

Both studies are now in a position to start recruiting patients.

THE ABCD STUDY

This study is conducted by Dr M Balasubramanian from Sheffield Children’s NHS Foundation. Researchers are looking to speak to families with a genetically confirmed diagnosis of Osteogenesis Imperfecta. They are looking at the most cost-effective methods of diagnosis and the experience of families in achieving a diagnosis. This would involve an interview with a researcher and completion of a short questionnaire.

For more information or if you would like to get involved you can find out more on our website or contact david.walker@sch.nhs.uk or meena.balasubramanian@sch.nhs.uk or call Sheffield Clinical Genetics Service on 0114 271 7034.

PHYSICAL FUNCTION AND SOFT-TISSUE HEALTH IN OI

Scientists in Manchester are recruiting adults aged 18-35 with Osteogenesis Imperfecta type 1. This study will examine how OI affects the size and strength of muscles and tendons. This may explain why people with OI are also prone to other injuries and problems with their movement. You will be invited to the General Manchester Laboratory, where researchers will take pictures of your muscles, tendons and bones. They will measure your strength and how well you can balance and jump. The visit will last around 2 hours.

For more information or if you would like to take part you can contact Dr Alex Ireland via email at a.ireland@mmu.ac.uk or by phone on 0161 247 1987.

For information on all ongoing Research Studies and Clinical Trials or to find our more on above please visit the Research Section of our website.
OUT & ABOUT

FINDACURE RARE DISEASE SHOWCASE

The BBS team attended the Findacure Rare Disease Showcase in Glasgow on Wednesday 10th October, 2018. Patient groups, healthcare professionals, pharmaceutical companies, and the life sciences industry came together to network and discuss rare conditions, sharing their experiences and promoting collaborative working. CEO Patricia Osborne delivered a presentation to the delegates, providing insight into how the BBS has charted its own course in research. BBS staff also held an information stand where we were able to raise awareness.

PATRICIA VISITS CENTRE FOR RARE DISEASE BIRMINGHAM

Patricia met with Professor Nick Shaw on 19th September at the new Centre for Rare Disease in Birmingham where she was shown around the new state-of-the-art facilities which will now be used in the treatment of Osteogenesis Imperfecta.

NATIONAL OSTEOPOROSIS CONFERENCE

The Brittle Bone Society staff set up a stand at the National Osteoporosis Society conference in Birmingham. They were able to network with a number of people interested in bone health, and raise awareness of the similarities between Osteogenesis Imperfecta and Osteoporosis with which OI is commonly confused.

SOCIETY FOR ENDOCRINOLOGY

BBS staff attended the Society for Endocrinology conference in Glasgow from 19th to 21st November where they were able to network with healthcare professionals from around the UK and raise awareness of Osteogenesis Imperfecta at their stand in the main conference hall.

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NICK OLIVER: A TRIBUTE
Brittle Bone Society received a request to pay tribute to a much loved and dearly missed son.
Nicholas Vincent Oliver was born in 1973 and grew up with older brother Justin and their mum and dad, Vince & Kathy, in West Norwood.

Nick was born with brittle bones which meant that he had to face a mountain of disabilities. If things weren’t bad enough, during his teenage years he lost his hearing but learnt to lip-read very quickly. The hearing loss was an extreme blow to him because of his love of music and he realised that being deaf was more of a disability than being in a wheelchair. However, he wasn’t one to let disabilities get in his way and was determined to live life to the full and that is exactly what he did.

Thanks go to the family for donations received in memory of Nick.
To read the full obituary please go to the news and blogs section of our website

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.

KEEPU P 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 become a Supporter and will no longer qualify to vote at AGM meetings.

The BBS continue to honour life memberships, but hopes that life members 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.

Think of us in your will
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