BBS SUPERSTAR AMBASSADORS SHINE A LIGHT ON OI

Tyler and Dante raise the awareness stakes even higher and help us get OI on the map

Trustees and staff were delighted to see two of our youngsters dominate across the media in the past few months. With our congratulations to Dante winning a Pride of Britain Awards and our own OI CAN Champion Tyler Ridley as the Chronicle Champions Awards 2019 – Champion Child of Courage category.

WELLCOME TRUST RESEARCH RESOURCE WIN FOR HISTORY BONES PROJECT

Chairman of the Brittle Bone Society – Elaine Healey said “its fantastic news that The Wellcome Trust has approved a research resources award for our History Bones Project – which is being undertaken with such care by the University of Dundee. Staff and trustees are delighted that our precious historical archive will be thoroughly documented and archived and this is great news for improving understanding of OI, for the benefit of people with the condition and and recognising the work of our Charity. In years to come this will be an invaluable resource and we look forward to work beginning”.

BBS SUPERSTAR AMBASSADOR ALICE
BBC NORTHERN IRELAND

Just as this newsletter was going to press we caught a fantastic article from BBC NI highlighting young Alice Boyd all about her life living with OI. Alice talked about her visits to Sheffield Childrens Hospital and her mum Jacky, former Trustee of the BBS also spoke about how the family just get on with living and how they just take OI in their stride. BBS are spoiled with the number of young and confident ambassadors who are using various methods of media and raising awareness of OI.
Elaine says: I can’t believe that’s another year over and myself and my Trustee board couldn’t be happier with the progress we are making. We couldn’t do it without the fantastic support we get from you our OI family and supporters. I never cease to be amazed at the generosity of our friends and it was a pleasure to uplift yet another generous cheque from the Dragon Clay Club through the Siegler family. Presented by Victoria on behalf of so many kind people. Thanks for keeping OI high on the agenda and for raising valuable funds for our very important work.”

“XMAS NIBBLES FROM ELAINE AND PATRICIA
Festive wishes and seasons greetings from your Chairmain and CEO

ROYAL OSTEOPOROSIS SOCIETY
Patricia invited to attend Board Meeting
Exciting plans to work with ROS

CEO Patricia was thrilled and honoured to be invited to attend the recent Royal Osteoporosis Society Board Meeting in September. CEO of ROS Claire Svergnini explained to the Board how she and Patricia had been good friends and colleagues over the past 10 years. Trustees and staff at the meeting shared their operational updates and were keen to continue to grow positive relations with BBS. Patricia said she had a really interesting and helpful day and would report back to BBS Trustees. Our own Board were very pleased we were given this kind invitation and at the October board meeting it was agreed to reciprocate the favour very soon. We are already looking at some cross platform working with the ROS – so look out for our next E-zine with details.

CONFERENCE — DEVERE Wokefield —
THE GATHERING 2019
Thanks to all who helped make it a big success.
Trustees agreed this was a good event this year – it’s a mammoth task and well done to BBS staff for another successful event.

BBS The Gathering delivered with a strong and equal balance of healthcare professional speakers and other facilitators and experts from a wide range of professions. Huge thanks from us to volunteers who helped our CEO Patricia and Support Development Office Coreen throughout the weekend. Patricia Lewington, son Jack and Laura whom we couldn’t have managed without and also the Great Ormond Street team for helping with Cool Bones. Huge thanks to guest host for our awards, Steve Edney — and to the amazing Basingstoke Scout Gang Show Choir who sang beautifully for all the guests. Trustees voted unanimously to support a special award to young Max Edney. All winners as ever were worthy recipients and we were able to keep this one til last!
WELL BALANCED PROGRAMME

Talks over the Wokefield weekend included Collaboration with other rare bone groups, Access to medicine, European updates on studies about OI, managing pain and mental health. We also listened to updates on the latest Clinical trials on TOPAZ and Asteroid, and a talk on sleep and fatigue. Some of the talks from conference can now be viewed on our Youtube channel.

You can see more info on our glittering awards and see pics on our Sunday activity programme on pages 8 and 9

GOVERNANCE TRAINING

Our October Trustee board meeting involved a Governance training day run by Liz Oberle Robertson who is Head of Pro Bono at Jones Day. This covered the Governance frameworks in legal, financial, operational and much more and as expected by the Charity Commission. Trustees rolled up their sleeves and powered through the day. Liz received a BBS award at Conference for all the legal support she and her colleagues provides year round – with advice on contracts and other important legal duties connected with running our UK Charity.

TRUSTEE ELECTIONS 2019

Trustees were delighted to see the re-election of Robert Gordon as Treasurer at our AGM and formally welcome new trustee Prof Margaret Smith who was former chairman of the REVIVE MS Charity in Scotland.

BBS RESEARCH GRANT AWARD PRESENTATION

Vice Chairman John Phillips helped host the Gala Awards event and awarded Dr Judith Bubbear with her research grant award cheque of £10,000 – part of the BBS research grants round for 2019.
BLOGGERS VALUED CONTRIBUTION

Blogging for the BBS enters the 2nd year. Shani Dhanda, Abbi Brown, Samantha Renke and Gem Turner handing over the reigns to Andy Mills, Elaine Rush, Dom Hyams and Elaine Corkery – you can catch up on their current offerings in the news and blogs section of our website https://brittlebone.org/newsandblog/>

We have been delighted with the series of articles from all writers. Topics for 2020 are all agreed.

BBS Trustees are delighted that we have formalised our BBS Bloggers Project by ensuring last year's and this years bloggers are offered a small payment in recognition of their valuable contribution and their time. We have issued our editorial team with contracts to ensure we abide by appropriate guidelines as set out by the charity commission. We appreciate people often want to share their stories for free, however CEO Patricia and our Trustee Board think it is very important that we place a fair and reasonable value on people's contributions.

Gem Turner also attended the Genetic Alliance AGM for us and you can read her report here https://brittlebone.org/event/genetic-alliance-uk-annual-conference-2019/"}

BBS COLLABORATION – RARE TOGETHER
@ BBS CONFERENCE 2019
FRIENDS FROM OTHER RARE BONE GROUPS COME TOGETHER TO CONFIRM CLOSE CO-OPERATION

BBS CEO Patricia Osborne and Trustee Angie Stewart facilitated a collaboration forum. They welcomed leaders from the following groups to Conference. Oliver Gardiner from XLX UK, Heather Wall of Fibrous Dysplasia Support UK, Gillian Willendorf of RGA (Restricted Growth Association, Alexandra Ockenden of Softbones UK with President of OIFE – Ingunn Westerheim. Patricia updated members on the work over the past few years on trying to establish a health service for rare bone conditions within the NHS and how all of those groups coming together in one voice will help push this project further. Chairman of our medical advisory board (Adult Consultant) Dr Kassim Javaid of the RUDY project chaired the session. All the leaders are planning to meet up again in Amsterdam at the Quality of Life Conference. Their next informal meeting is to be held at the offices of Jones Day in London in January 2020.

MEMBERS ACTIVITY
THE BIG CHAT
MEMBER STEVEN HASTINGS HAS BEEN BUSY ORGANISING A LOCAL EVENT AND SHARED THE UPDATE WITH US HERE AT THE BBS.

Steven said:

“I have been getting support from Stepping Stones, a Local Mental Health Service near me in Clydebank for a few years now and I attend one of their social Groups in Alexandria called Reflect & Connect once a week.
A few months ago, myself and other Stepping Stones members and staff went to a meeting about having some sort of Conversation Café but we were not exactly sure what to expect.”

You can read the full article on our website with in our news and blogs section.

RARE BONE DISCUSSION MEETING

Brittle Bone Society will be hosting a rare bone discussion meeting in January in London with leaders from a number of rare bone groups – Softbones (HPP), XLH-UK, RGA (Achondroplasia) and FDDSUK (Fibrous Dysplasia). The meeting will be chaired by our CEO Patricia Osborne and our Vice chair John Phillips. Trustee Angie Stewart will be speaking up for OI at the forum meeting.

For this first meeting we have also invited along a guest speaker from the NHS, Specialist Nurse Ian Tucker, from Bristol Childrens Hospital. Ian was recently appointed co-chair of a new group called the ‘Rare Bone Nurses Network’ (RBNNUKI) which is of interest to this new forum being launched by the BBS.

The Rare Bone Nurses Network (RBNNUKI) for United Kingdom and Ireland (RBNNUKI) is designed for the small group of paediatric nurses who work within the rare bone disease field. The intention of the group is to share practice to increase knowledge, work collaboratively to produce patient information and resources, and to enhance the quality of care patients receive.

The RBNNUKI are in their infancy but are looking at affiliating with national charities to use as a platform to launch their important work. Brittle Bone Society are delighted to welcome Ian to hear more about the plans and how we can all continue to work together for better care for people with OI and other rare conditions.

Ian Tucker said

“We are excited to be invited to this meeting hosted by the BBS in January to explore the extent of our work further. Exciting developments in paediatric bone health make it a very special time for us as nurses to be involved, and the group will help facilitate our learning to help care for our patients”.

4
FUNDRAISING

FITNESS FUNDRAISING FUN

Fitness instructor and good friend of the Edney family, Ali Allaston held a fundraising fitness drive recently to raise funds for the Brittle Bone Society. Around 40 people turned up for the 2-hour exercise class finished off with a cake sale to replenish those calories burned, and raised over £1000.

1 WEEK, 2 HALF MARATHONS

David recently ran not one but two half marathons in 1 week to raise money for the Brittle Bone Society. Running in memory of his dear friend Paul Scanlan who had OI.

His first race was the Colchester Zoo Stampede which he completed in 1hr 46 minutes then the Royal Parks half marathon in 1hr 55mins. David raised over £500 and looks forward to fundraising again in 2020.

LIZA’S ROBIN HOOD HALF MARATHON

Thank you to Liza who ran the Robin Hood Half Marathon recently for the Brittle Bone Society. Liza chose to support the Brittle Bone Society and raise awareness of OI following her younger cousin, 3-year-old Connie’s recent diagnosis. Liza raised an amazing £900.

LAURA TAKES ON THE GREAT SCOTTISH RUN

Well done to Laura Pilkington in completing the Great Scottish Run in Glasgow recently, propelling herself round the grueling 10km course in her wheelchair and completing the course in a fantastic 1hour 41 minutes.

Laura, who has OI herself was excited for the challenge and explained “I hope that I can raise funds to help people with OI especially for the kids of the future”. Laura certainly did that raising a huge £1500 for the Brittle Bone Society.

STEVE EDNEY GETS THE RUNNING BUG

Steve Edney needs no introduction to our fundraising hall of fame having raised over £80,000 in the last couple of years. His recent efforts saw him run his first ever half marathon in Basingstoke recently. Never one to shy away from the challenge Steve has now set his sights on the 2020 London marathon in aid of the Brittle Bone Society and we can’t wait to follow his journey as he starts his training.

5KM INFLATABLE OBSTACLE FUN

Well done to Kim Gittens and her nephew, 10 year old Oliver, who completed a 5km inflatable obstacle course to raise funds for the Brittle Bone Society back in the summer, raising over £230.
GREEN TOKEN DONATION FROM ASDA BASINGSTOKE

Asda Foundation give thousands of pounds to charities across the UK each year through their green token scheme and we were delighted to receive £200 from Asda Basingstoke after being nominated by Steven Edney. It is so simple to nominate the Brittle Bone Society at your local store and we would love it if you would too next time your in store.

INNER WHEEL CLUB OF LEIGHTON ON SEA

Thank you to the Inner Wheel Club of Leigh on Sea who donated £700 after selecting the Brittle Bone Society as their chosen charity. Inner Wheel Club member Kim Gentry’s grandson Nolan was diagnosed with OI in March 2018 at 3 weeks old. Nolan’s big sister Amberley accepted the cheque on behalf of the Brittle Bone Society, and is pictured with club president, Sue Stepney.

24 HOUR CYCLE LANDS’ END TO JOHN O’GROATS

Another group who took on a huge challenge recently were the team of Thames Valley finance directors, who joined forces with a 24 hour charity cycle covering the 976 miles from Lands’ End to John O’Groats. The team, inspired by our very own Max Edney raised well over £6000.

A huge shout out to Ann and Ian Robb who recently celebrated their Ruby Wedding Anniversary

A huge shout out to Ann and Ian Robb who recently celebrated their Ruby Wedding Anniversary. A big thanks to all their friends and family who donated an amazing £1650 instead of giving gifts. We were delighted Trustee Yvonne Grant could accept the cheque on behalf of the BBS.
FACEBOOK FUNDRAISERS

Another big thank you to everyone who has supported us with a Facebook fundraiser. In the last 12 months we have raised well over £15,000 just through Facebook. It is such a simple yet effective way to ask for donations to a cause that means a lot and we hope you all continue to support us in this way. To find out how you can get involved, head over to our Facebook page @BrittleBone Society.

THANK YOU ......

Thank you to everyone who has fundraised for the Brittle Bone Society during 2019. We love to hear all about the challenges you set yourself and see the amazing photographs.

If you would like to get involved in fundraising for the Brittle Bone Society or have a fundraising story you would like us to share, then please contact fundraising@brittlebone.org and we will be sure to feature them in our next newsletter.

Back in June we were delighted to announce our exciting new partnership with the Nexus Group (Nexus) which has chosen the Brittle Bone Society as its ‘Charity of the Year’.

Since then, staff at Nexus have been busy organising various fundraising events for the charity from their central London Offices. Events so far have included: “Nexus Wimbledon Tournament”, an in-house table tennis competition where employees battled to win the trophy and be crowned table tennis champion. The Great Nexus Bake-off, Rugby World Cup screening with raffles where prizes included an England rugby shirt signed by Phil Vickery MBE, and World Cup rugby ball signed by Sir Clive Woodward OB.

Tim Coles, COO of the Nexus Group said: “We are delighted and excited to be supporting the Brittle Bone Society as our Charity of the Year. At Nexus, we are committed to fundraising for charities where we feel we can make a real difference. We are very much looking forward to supporting the Brittle Bone Society and the families and individuals they work with who are affected by OI.”

The team have many more fundraising events planned for 2020 and we look forward to keeping you all updated.

So far they have raised £1520.16. Patricia will meet with Nexus in January to agree more events for 2020.
SCIENIFIC ADVISORY BOARD (SAB)

We still have a couple of vacancies to fill on this board to take over from Prof Nick Shaw who retired last year and Prof Faisal Ahmed who stepped down as chairman after Conference – although both are still in touch with BBS and will gladly assist if we need them. Trustees are duly grateful to the Professors for all they have done for the BBS. Current board members are: Prof Nick Bishop, Prof Stuart Ralston, Dr Vrinda Saraff, Dr Christine Burren and Ms Penny Clapcott.

Medical Advisory Board (MAB) update 2019

BBS Trustee Angie Stewart has agreed to serve as layperson on this committee. Other new additions to the board include Dr Susan Parekh – Dentist. The next meeting will be held in London in spring 2020. Topics to be discussed will include updates on; adult specialist centres and highly specialised centres, updates on ERNs and PIP, BBS event planning for 2020 as well as regional, national, international and parliamentary activity.

PIP – WELFARE BENEFITS – BBS MAKING OUR VIEWS KNOWN!

Further to BBS survey on members experiences – Trustees were delighted that Lord Shinkwin was able to assist with suggestions for meetings that lead to some positive outcomes.

We were invited by CAPITA to help feed into a process to devise and design an information booklet about the condition of OI. We would like to thank all the members, trustees and NHS healthcare professionals who were involved. CAPITA reps kindly attended Conference at Wokelfeld. Unfortunately we didn’t get enough time to fully discuss the explanation booklet which we had emailed out to conference delegates prior to conference however, after Conference passed we were then invited to attend a special scoping group in London which included reps from other leading charities including: Aspire, BRAME, British Deaf Association, Blesma Crohn’s and Colitis UK, Citizens Advice, Derbyshire Mental Health Services, Disabled Motoring UK, Epilepsy Action, Headway, MS Society, Muscular Dystrophy UK, National Deaf Children’s Society, RNIB, Sense, Sickle Cell Society, Spinal Injuries Association. This meeting also involved representatives from the Department for Work and Pensions. BBS Trustee Yvonne Grant and a legal representative Peter Henshall providing pro bono support for us from Jones Day attended as observer and Yvonne acted as our spokesperson at the session.

A ‘conditions insight’ book has now been devised – Their Medical Director is now happy to go live with the document. Comments from Dr Richard Keen

“ It is a very good document, and hopefully will improve the knowledge of the PIP assessors. Please thank all your staff and the patients for their hard work in pulling this together”.

Members of our MAB all believe it’s a great document and everyone from both organisations now seem really happy with the content so we don’t want to delay getting this live any further as it’s important that the Assessors can start to access all of this information.

We have been told it’s worth bearing in mind that we can still make changes once the document is live if necessary: if for example we realise that something really important has been missed.

Joe FitzPatrick MSP visits BBS HQ in Dundee

Patricia was delighted to welcome local Constituency MSP Joe FitzPatrick to Guthrie Street with an update of the work going on at our head office.

Mr Fitzpatrick was delighted he got the chance to join us at our 50th Celebration event in 2018 and was keen to hear that our 2019 event was also a big success for the OI community. He looks forward to learning more about our BBS calendar of events and activity we will be pursuing going into 2020 and we will keep him up to date on our work.

LATEST IN CLINICAL TRIALS NEWS

ASTEROID

Mereo Biopharma announced bone building activity & trend in fracture reduction for strusumab in adults with OI.

Prof Bishop Trustee and member of our Scientific Board said “this is indeed an exciting time for folk with rare bone diseases and we hope that the emerging therapies will improve their lives and experiences. These results are promising and we hope will translate into benefit for affected individuals.”

Chair of our Medical Advisory Board – Dr Kassim Javaid said “Key findings is the results may suggest a benefit on improving the outer shell of the bone that was associated with a potential difference in fracture rate.”

TOPAZ Trials

TOPAZ is a non-commercial trial sponsored by a partnership of the University of Edinburgh and NHS Lothian called ACCORD and funded by the UK National Institute for Health Research (NIHR).

A randomised trial of Teriparatide followed by Zolendronic acid vs standard care to prevent fractures in adult with OI. It was reported recently that the researchers announced in October they have now reached their halfway point recruiting 190 people. However they still need many more patients, for further information contact coreen@brittlebone.org
**HOSPITAL FAMILY DAYS**

It was with great pleasure that Coreen, Support Development Officer was able to attend both Great Ormond Street and Bristol Children’s Hospital family days. It is always a delight to be able to catch up with members and meet new families, and she was even roped into judging the best dressed mummy! Some of the History Bones Banners were also on display at both events for people to see.

Coreen will be in Birmingham at the Children’s Hospital Christmas party in December and looks forward to catching up with members then.

**EVENTS FOR 2020**

We are delighted to have received funding to run a series of 4 Healthy Living Workshops. We will run these throughout the UK so keep your eye open for dates and venues which will be announced in the New Year. We also plan to run another OI CAN outdoor event after the success of last year. If you want to receive updates then either follow us on facebook or sign up to our online newsletter.

**BBS HEALTHY LIVING WORKSHOPS 2020**

Ol Can and you can too in 2020

Building on the success of our OI Can Event at Keilder in 2019 we are planning to host events in the new year. Watch out for our next e-zine so that you can sign up for our next event. Demand is set to be high – so don’t delay. If you would like to reserve a place, then drop us a line now.

**KIDS PACKS**

If your little one is going into hospital for treatments or check-ups then remember to get in touch with Coreen at coreen@brittlebone.org to be sent a BBS Kids Pack. Each pack includes Olly the OI Owl, a handy drinks bottle, some wet wipes, a colouring book and pencils all enclosed in a lovely BBS drawstring bag.

Coreen loves receiving your pictures with the packs! Here are a selection from the last couple of months.

**WHEELCHAIRS & EQUIPMENT GRANTS**

We have been busy as ever raising funds for much needed wheelchairs and equipment. Below are some pictures of happy recipients.

If you or your child have been diagnosed with OI and are in need of specialised equipment you can apply to us for grant (see details on our website: https://brittlebone.org/support/support-grants/).

Applications must be received with supporting documents from a healthcare professional and a quote from the supplier.

**RUDY**

Rudy is a study in rare diseases of the bones, joints and blood vessels. Headed up by a research team at the University of Oxford, Rudy aims to transform clinical care for participants through patient-driven research.

What is the purpose of the study?

The Researchers are interested in understanding more about all aspects of rare diseases. Some of this new understanding will be used to develop new tests and treatments for patients with rare diseases. A first step in doing this is to gather information in order to describe in more detail the different types of rare diseases and what it is like to live with them.

This is done through questionnaires over a period of five years.

In the future, the hope is to introduce some sub-studies such as a physical assessment, blood and urine and a skin biopsy (for certain rare diseases).

If you are interested in finding out more and how to get involved go to www.rudystudy.org
On October 23rd – 27th I attended the annual OIFE youth event, an opportunity for one of the OIFE’s member organisations to host an informal meeting for young people with OI between the ages of 18-35 years old to meet up somewhere in Europe for a range of organised activities and socialising, previous years have been in London (UK) in 2016, Zwolle (Netherlands) in 2017 and Aarhus (Denmark) in 2018.

This year’s event was held in Bilbao, Spain and was organised by AHUCE, which poetically translates as the Association for Crystal Bones in Spain, their equivalent of the BBS. The event was also partially subsidised by the OIFE.

The youth event was attended by 49 people (which included 21 people in manual chairs and 4 people in electric chairs) from 10 different European countries, I was the only attendee from the UK.

This was my first time visiting Bilbao, and due to limited flights, I had to fly up the day before giving me the opportunity scope out the city before the others arrived.

I was a bit apprehensive at first due to the fact that Bilbao is situated on a very mountainous area meaning that it was very hilly and difficult to get around by manual wheelchair. The weather also didn’t help as Bilbao is located in the very north of Spain and combined with the time of year meant that the first few days was torrential rain – worse than British weather!

Day 1
On the first day of the youth event I arrived at the BBK Bilbao Good Hostel. It was chosen as it is a hostel which has been designed to cater for many disabled guests, and it was the perfect venue to cope with all 25 wheelchairs that attended. Due to everyone arriving at different times from different countries there was only time for socialising and getting to know each other through ice-breaker activities.

Day 2
On the second day the rain had eased off a little, so we all made our way to the city centre. To get there we all had to get the metro train which was a short walk from the hostel and was fully accessible however it did involve going in several lifts which was only big enough for 2 wheelchairs at a time, so with 25 wheelchairs this did take a while! Once we all arrived at the city centre the rain was too heavy for the free city tour that was organised so this gave us all free time to explore the city’s shops and bars and sample the local Pintxos - the region’s version of Tapas, very tasty!! When we returned to the hostel the group collected for the first organised activity, a very in-depth talk about relationships and sex.

Day 3
On the 3rd day the sun had started to come out and we went on our next activity, a visit to the world famous Guggenheim Museum. To get there we all boarded a large wheelchair accessible coach – which again took forever to load 25 wheelchair on and get strapped in. Once at the museum we split up in to 3 groups for a guided tour around the museum and talk about some of the museum’s most famous pieces of art. The works ranged from very traditional paintings from artists such as Van Gogh and Monet to a giant metal spider sculpture and a giant puppy made out of flowers. Once the museum visit was over most of us decided to make our own way back to the hostel loading the bus took too long, so groups of us made our way to the metro station with several stops at the local bars to get some more Pintxos (Tapas) and Cervezas (beer), the evening was finished off by more “socialising” on the hostel’s roof balcony.

Day 4
On the 4th day the Spanish sun had finally come out to play so we all made our way to a nearby park where we all took part in the “Gymkana”; we all split out into teams and took part in team activities such as quizzes, riddles and physical challenges, ending with a picnic on the grass where it was warm enough to strip off and top up our tans.

In the afternoon the majority of us went back into the city centre where we were able to go on the free city tour that had been rearranged from earlier in the week. We were able to take in the amazing views of the city and hear about its fascinating history. The evening culminated in the main party night where the organisers had reserved a local night club where we partied until the small hours. It may not have been wise to hold the main party on the last night as many people had early flights the next day and we all had to check out of the hotel by 10:30am!

The last day was just enough time for early morning goodbyes through teary eyes and painful hangovers, which was an encouraging sign that everyone thoroughly enjoyed the week and that it was really well arranged and executed by the organisers and their volunteer helpers. The whole trip was fantastic, even with the dodgy weather, and there was only one OI related injury.

Unfortunately, being 35, this was the last year that I was young enough to qualify to attend, which is a shame as 2020 will be somewhere in Poland, therefore I would encourage anyone reading this with OI between the age of 18 – 35 to sign up as soon as....

If you have a story you would like to share please contact us at admin@brittlebone.org
QUALITY OF LIFE CONFERENCE AMSTERDAM

Trustees and staff go Dutch

BBS attended QoL conference in Amsterdam

This was a 4 day International conference hosted by a coalition of OI organisation and medical professional coordinated by the Research Charity Care4BrittleBones.

Our Research

The BBS were invited to speak about our journey into Research, we also had the opportunity to find out all the latest updates on treatments and care for OI.

MOI Study

We learned of a study called the “MOI study” being run by Prof Nick Bishop for children (aged 8-17) with OI who have not yet received any drug treatment; the study will look at what the response to an existing medicine, losartan, is like in terms of increasing bone density, improving muscle strength, and any effect on quality of life. Losartan has been used for many years in children for the treatment of high blood pressure; the laboratory studies suggest it could be an effective treatment for OI as well. They hope to recruit 6 children from the UK to the study and possibly another 3 from Ireland.

BoostB4

Whilst there Patricia attended an update on the BoostB4 programme held by Dr Cecilia Gotherstrom and Dr Eva Astrom of the Karolinska Institute and we learned the trial is underway in both Sweden and in the UK.

Diagnosis

Coreen attend the Workshop on Diagnosis of OI, led by Dr Meena Balasubramanian from Sheffield and Dr Cormier from France. There were updates given on the ERN Whitepaper, a talk given on the patient perspective of issues in relation to Diagnosis, as well as covering topics such as non-accidental injury and other conditions which can mimic OI.

Medical Advisory Board

Dr Kassim Javaid Chair of our MAB delivered an excellent talk about how the people who are ‘expert’ in their own condition should be more involved in informing and educating the healthcare professionals as opposed to the current trend where people with the ‘condition’ are being encouraged to learn more about systems and processes. The talk was well received. Continued on page 15.
Scientists in Manchester are still looking for adults aged 18-35 with osteogenesis imperfecta type I to take part in our BBS-funded study on musculoskeletal health. They will take pictures of your muscles, tendons and bones, and measure your strength and balance. This visit lasts around 2 hours, and they will refund travel expenses from anywhere in the UK. The study aims to help understand health problems related to OI including tiredness, reduced mobility and dislocations. For further details please contact Dr Alex Ireland: a.ireland@mmu.ac.uk or Tel: 0161 247 1987.

The study aims to quantify and describe the types of soft-tissue problems adults with OI suffer with and what adults perceive the problems to be. People with OI are more likely to have musculoskeletal issues than the general population; issues such as dislocated joints, tendon and ligament injuries have been raised as a key concern, however there is no evidence on prevalence of musculoskeletal complaints and how therapy might best be organised. This study aims to address these needs.

The care for adults with OI is fragmented, and most do not receive the quality of care they need. To address this, NHS England is developing a specification for expert rare bone disease centres. A central concept is that better-coordinated care leads to better outcomes for people with rare diseases, their family and the wider NHS. It is therefore crucial for the NHS to understand the healthcare services used by people with OI and their costs. This research application directly addresses these questions by describing how adults with Osteogenesis Imperfecta use NHS services in hospitals as well as in the community. This information will be useful for people with OI, their families, clinicians and policymakers.

In the last decade, it became clear that the skeletal deformity and fragility associated to reduce bone mineral density, typical features of the OI, are not only due to the abnormal type I collagen in the bone matrix. The compromised function of bone forming cells, caused by intracellular retention of the mutant protein also contributes to OI severity. Thus, targeting simultaneously the cellular compartments and the bone matrix seems promising. Researchers aim to develop and in vivo test a new drug that will combine the stimulation of osteoblasts protein secretion to the bone resorption reduction by conjugating the chaperone 4-phenylbutyrate to the alendronate.

Most patients with Osteogenesis imperfecta go through a prolonged patient journey before diagnosis of OI is confirmed and appropriate treatment is instituted. The ABCD study is designed to assess the healthcare needs for children with OI and how early diagnosis impacts their patient journey and healthcare costs. We look forward to hearing the results of this study in due course.
Continued from page 13.

Biopharma Companies

There was also a talk at conference by Wills Hughes-Wilson of Mereo Biopharma. Wills is head of Patient Access.

OIFE, Bond and OIF

President of OIFE Ingunn Westerheim delivered a summary update on the session about ‘empowerment’ which Tracy Hart of the OIF and Patricia Osborne of BBS took part in. We also heard a passionate account from Dr Laura Tosi about her amazing work in the USA, and Epag Member of the Bond ERN group, Rebecca Tvedt-Skarsberg gave a joint talk and update about European Reference Networks.

BBS Member

Member Member Penny Clapcott attended the workshop on psychosocial aspects of living with OI.

Penny said:

“Something that we all agreed on is that this topic is often overlooked and only recently started being researched. For me this topic is really important, we’re always told we have unbreakable spirit, our quality of life (QoL) is determined originally by other people’s perception of what they think, how they’d cope in same situation or more commonly fracture rate with the opinion that less fractures equals better quality of life.”

Whilst elements of this does impact on our QoL it was refreshing to discuss this on a more holistic approach.

Mental health, anxiety, dealing with repeated trauma all have an impact of QoL. Some intertwined with OI, some relating to just having a disability and not forgetting some of it could be from being a human and that anyone can face these issues. Put into the mix other factors such as bone pain, fatigue, internal and external ableism can have the biggest effect on our QoL. It’s clear it’s a very emotive and complex topic.

We were in agreement the need to be able to statistically research QoL however with the acknowledgement it is very subjective and a fluid feeling. What one person may feel to them being high QoL will be very different to someone else. It’s a very broad topic and Saturday’s session was a whistle stop tour of some of the key challenges there are into researching into QoL but it’s refreshing to discuss and acknowledge these factors when talking about QoL.”

There were also talks given around Multi Disciplinary Care, Patient Data, Registries and outcome measures and there were workshops held on Medical Treatment Options and Roadmap to Surgery.

Copies of talks will be available in due course on the Quality of Life 4 OI website.
MERCHANDISE

Thank you to everyone who gave their input into the design of our new car stickers. We are excited to announce that these are now available to buy for £3 each, with two different designs available. To order these or any of our other merchandise, please head to our website!

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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.

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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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