Brittle Bone Society Trustees and staff are thrilled to host our Annual Family Conference and History Bones exhibition in 2018 in Dundee. We look forward to welcoming you to the city from the 17th to 19th August at the Apex City Quay Hotel and Spa to celebrate the 50th Anniversary of the Brittle Bone Society.

We will launch our History Bones exhibition which we are working on with the University of Dundee. We shall also host our 2nd Scientific Symposium with our Medical Advisory Board and will play host to the OIFE AGM. The conference will include all our usual wonderful topical talks on health, and we will host our Kids Club and special entertainment programme. Don’t miss out on your chance to be part of our special Patient and Public Involvement groups and consultation meetings.

We have been working with Dundee and Angus Convention Bureau to help get the most out of planning your visit to Dundee. See page 5 for more information.

RESEARCH GRANTS

Trustees of the Brittle Bone Society met on 18th November in London to consider the first ever funding proposal from the Research Committee on the results of the recent research grant awards. At this meeting Trustees also earmarked funding to the Research Grants Fund with thanks to a legacy donation.

Chair of the Research Committee Prof Nick Bishop passed the management of the inaugural process over to Prof Faisal Ahmed. After following a detailed and thorough process and having met all the peer review requirements the committee resolved to select two outstanding projects:

Dr Meena Balasubramanian of Sheffield Children’s NHS Foundation Trust for her project, Assessing the Balance of Cost and Determining the Experiences of Families in Paediatric Osteogenesis Imperfecta Healthcare (ABCD Study).

The second grant award was made to Dr Alex Ireland, a Lecturer in physiology at Manchester Metropolitan University for his project on physical function and soft-tissue health in individuals with OI.

Dr Ireland said “I am so thrilled to be one of the winning recipients in the BBS first ever Grants Research Round. Having this support will greatly benefit the study I’m working on with my colleague Prof Neil Reeves, and our clinical collaborator Prof Peter Selby from Manchester Royal Infirmary. We will research how the size and function of muscle and tendon in adults with OI are affected by the disease. This information could help us to understand health problems related to OI including tiredness, reduced mobility and dislocations. I look forward to reporting back on progress of my project to the BBS at their events in the coming months and years.”

Dr Balasubramanian said “I am delighted to be one of the winning recipients in the BBS first ever Grants Research Round. This generous funding will be of enormous help to the ABCD project that I am working on. 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. I look forward to reporting back on progress of my project to the BBS at their events in the coming months and years. I hope this is one of many innovative research studies funded by BBS to improve the health and wellbeing of children and families with OI.”

KIDS PACK

Our new hospital packs are proving really popular. If you have a little one who would like to receive a pack, please get in touch with our Support Development Officer by emailing coreen@brittlebone.org. Coreen would also love to receive your pictures with the packs.
TRUSTEES & GOVERNANCE UPDATE FROM ELAINE

It’s been a busy six months since we last updated you. Staff are full steam ahead in planning for our 50th event in Dundee. The Newcastle 2017 conference was a fantastic success and we have a great picture gallery inside this update.

STAFF

We said goodbye to Natalie as her partner had to re-locate due to work. We thank her and wish Natalie well for the future and are pleased that we have secured a new Communications and Marketing Officer called Karen who took over this important role in early December.

We have been without a Fundraising Officer since 2015 but are delighted to welcome new team member Nicky who will be working on our fundraising plans in earnest.

Our new Administration and Finance Officer Rosie is doing a great job and is being trained in all aspects of administration, fundraising and finance at BBS HQ.

INTERNSHIPS

We welcomed intern Jhon Bateman in the summer and he has been working hard behind the scenes finding out all we do in preparation for events, and generally learning the ropes of working in a busy national charity. Jhon has also focused on assisting with communication on the new Research Grants project and he has also attended various events on policy and communications and spent valuable time helping contribute to the finishing touches of our new soon to be launched website. We can’t of course forget his fantastic contribution to hosting the awards ceremony at our 2017 Annual Family Conference in Newcastle. Well done Jhon!!

TRUSTEES

We have been working with former Trustee Simon Mckeown on some creative aspects of planning for our 50th event and value his expertise immensely. At conference we officially welcomed our two new Trustees - Ms Angie Stewart and Mr Gareth Cumming. Both have been getting involved in charity business and both attended events on our behalf. Angie attended the Findacure Conference in Newcastle and Gareth went along to a patient day event at Bristol Children’s Hospital on our behalf.

We held our Medical Advisory Board meeting in the summer in London and the key deliverable sought at that meeting was agreement on some more factsheets and the frequency of review of our factsheets. We also held important discussions on clinical care guidelines and the BBS is driving ahead in the hopes our medics will produce a set.

Our friends at the OIF in the USA have already published a set of clinical care guidelines, and we are reviewing the data to ensure we don’t re-invent the wheel.

Vice-Chair John Phillips accompanied Patricia to an important trip to the House of Lords to meet up with Lord Shinkwin and we will share updates on progress of that meeting in the next e-zine.

TOP TALENT SECURED FOR NEW BBS WEBSITE LAUNCH

BBS are delighted to announce their very talented feature line up of writers and columnist partnerships - commencing with the launch of their new website in January 2018!

BBS feature writers for 2018 will be Samantha Renke, Abbi Brown, Gem Turner and Shani Dhanda.

Trustees and staff at BBS are thrilled they have firm commitment for a body of work throughout the year from these very talented writers for a series of editorial articles, blogs and comment throughout our milestone anniversary year in 2018.

All of the young women invited to take part in our year long programme are outstanding, outspoken, humorous, edgy and very talented individuals whom we hope you will enjoy hearing updates from.

One of the outcomes of this project we hope will be to help influence the direction of the charity’s content and programme of events; help us with our dialogue in policy on news and current affairs - but also taking a look into fashion, style and last but not least to encourage other hopefuls out there to get in touch and provide their views on what matters to them.

Wishing everyone a Merry Christmas

Elaine & Patricia
BBS COLLABORATION

GETTING THE RIGHT MEDICINES THAT PEOPLE NEED!

Our CEO Patricia Osborne was invited to speak at the Royal College of Physicians in London recently, where the Faculty of Pharmaceutical Medicine held their AGM. It was an invitation to discuss the work of the BBS, and address the important topic of how we can ensure people with rare conditions are not neglected in research and development programmes. Also sharing the platform was Simon Denegri of INVOLVE and Jonathan Van-Tam, Deputy Chief Medical Officer for England at the Department of Health.

HOUSE OF LORDS

The Brittle Bone Society accepted a kind invitation to meet up with Lord Kevin Shinkwin. Patricia and Vice-Chair John Phillips were pleased to discuss potential collaboration and also held additional talks with Lord McAvoy about our hopes to raise the profile of OI and raise awareness about our campaign for focus on transitional health services and a much needed Adult OI service.

AMRC - WESTMINSTER DAY

Patricia was honoured to get the chance to spend a day with 25 other leading UK charity CEO’s in the Houses of Parliament to meet with senior politicians to discuss important topics that will affect the UK charity research sector. Patricia had specific meetings with Norman Lamb MP and Dr Phillips Whitford MP.

Medical research charities invested £1.6 billion of research funding in the UK, funded the salaries of over 17,000 researchers and recruited 170,000 patients into clinical trials funded by charities.

The meetings on the day covered; protecting patients and medical research, Data Protection Bill, GDPR and regulations in clinical trials; (CTR - clinical trials regulation) EU funding and collaborative programmes, charity research support fund, and taking forward the Life Sciences Industrial Strategy.

It may be early days for the BBS to be involved in such big topics but in line with our mission of supporting people with OI and our newest research strategy, we feel it is important to have our say in research. In a survey in 2011, 72% people told the AMRC they would like to be offered opportunities to be involved in trials of new medicines of treatments. The NHS Constitution includes a pledge that the NHS will inform you of research studies which you may be eligible to participate in.

CORRA FOUNDATION

On the 9th October, Patricia and Jhon attended the launch event of the Corra Foundation, the new name for the charity previously called Lloyds TSB Foundation for Scotland. The event was attended by many charities from across Scotland and many important issues were discussed, such as how civil society can respond in the climate of uncertainty, using digital media as a force for good, and there were opportunities to speak to various funders about chances for collaboration. Both Patricia and Jhon found the event very useful to attend, and they were inspired to hear from charities right across Scotland who are creating substantial change in their communities in these uncertain times.

RARE DISEASE SHOWCASE

By Angie Stewart

In October I attended a Rare Disease Showcase, representing the Brittle Bone Society in Newcastle upon Tyne. Hosted by a charity called ‘Findacure’, the events are about promoting collaboration between people affected by rare conditions, clinicians, pharmaceutical companies, biotech industries and charities. It was great to find out about projects and initiatives happening in the North East and other parts of the country. I was fascinated that Findacure say there are 7000 rare diseases, which affect 350 million people worldwide. Osteogenesis Imperfecta is just one of these conditions and it was great to hear Charlotte Proud on the stage, giving her experience of living with type 1 OI.

A focus of the event was to consider how treatments can be researched and developed for some of these rare diseases. When the small numbers of people affected make it difficult to attract research and pharmaceutical funding, drug re-purposing is a possible opportunity. They investigate new uses for existing medicines.

There was a buzz in the room about future possibilities, with all partners working together on new and exciting ideas.

There are plans afoot for all our support groups.
If you would like to be put in touch with local organisers please contact us at bbs@brittlebone.org or on 01382 204446 we will be delighted to hear from you.
BBS CALL OUT! YOUR PART IN THE OI STORY

Win a PRIZE for the best historic story “pre 2000”

In preparation for our 50th anniversary exhibition, History Bones, we are appealing for you to play your part in the OI story. The History Bones collection will show the local significance of Dundee in the formation of our charity, the influence of the charity across the UK, and on other rare bone disease organisations around the world. We are working with the University of Dundee (who host our existing archive of materials) and renowned artist Simon McKeown, to produce an exciting exhibition for display at the Apex Hotel during our 2018 anniversary celebrations, a longer-term exhibition at Dundee Central Library, and an online collection.

However, there are gaps in what is currently held, and this is where you can help! Contact bbs@brittlebone.org to tell us what treasured items and stories you can send in to us to make History Bones even better. We’d love to hear your stories. The particular topics that we are interested in are:

**QUESTIONS WE NEED YOU TO ANSWER!**

- How has the BBS influenced you? (ie did you receive a typewriter from the Magpie Appeal, do you remember having a spacesuit, do you still have one in your attic?)
- Pre-NHS stories, treatments, hospital stays in the “olden days”!
- Work – attitudes in the work place and how they have changed over the years.
- School – eg: did you go to main stream school or not, what education did you receive?
- Relationships – with family, friends, partners, work or school colleagues and the BBS and attitudes which you faced.
- Social welfare and benefits – how have things changed since 1968?
- Holidays and travel, sports and other hobbies.

Please do write in or email us with your contribution, it really matters. Thank you!

bbs@brittlebone.org

SEND YOUR NEWS STORIES TO:
admin@brittlebone.org

Find the BBS at:
2018 is a special year for the BBS as it sees us celebrate our 50th year of supporting people living with Osteogenesis Imperfecta, so where better to host our celebrations than in the town where it all started – Dundee in 1968.

Registration this year is to be done online, please see our website for more information and links to registration, accommodation bookings and travel information: http://brittlebone.org/support/events/conference-and-agm/. We have been working closely with Dundee and Angus Convention Bureau to help you plan your trip and make your visit to Dundee and Angus as easy as possible.

The weekend will consist of:

**Friday 17th August** shall herald the beginning of the weekend of events with a welcome event and international Scientific Symposium for healthcare professionals, followed by a fun-filled entertainment programme launching our historical exhibition bringing families and medics together at the Apex Hotel.

**Saturday 18th August** will play host to our conference talks, workshops and consultation events and features our annual Gala Dinner and Awards Ceremony with special entertainment.

Plans for speakers and content of this year’s special conference programme are almost complete which will include delegates from across UK, Europe and USA to exchange the latest developments in the care and management of OI.

Patient and Public Involvement workshops canvassing the input of people with OI will feature strongly in the weekend’s activity across a wide range of topics, helping us shape our future plans in events activity, policy and research.

**Sunday 19th August** we will welcome OIFE delegates for business meetings and their formal presentation dinner. Throughout the day our charity will be hosting consultation meetings with our own members.

Expect some special Scottish hospitality with a little bit of tartan thrown in! The Trustees want to welcome friends to Scotland for the first time in 10 years. So get saving the pennies!

### CONFERENCE PRICE SCHEDULE

<table>
<thead>
<tr>
<th>Package Description</th>
<th>Cost per person</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACCOMMODATION</strong></td>
<td></td>
</tr>
<tr>
<td>Accommodation costs at the Apex Hotel single occupancy</td>
<td>£95.00</td>
</tr>
<tr>
<td>Accommodation costs at the Apex Hotel double occupancy</td>
<td>£105</td>
</tr>
<tr>
<td>Accommodation costs at the Apex Hotel for a family room (extra £10 per child over 12 years old)</td>
<td>£140</td>
</tr>
<tr>
<td><strong>CONFERENCE ATTENDANCE</strong></td>
<td></td>
</tr>
<tr>
<td>Full weekend package per adult (Friday 17th to Sunday 19th)</td>
<td>£116.50</td>
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<tr>
<td>Full weekend package per child age 12 to 15</td>
<td>£64.85</td>
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<tr>
<td>Full weekend package per child under 12 staying at the Apex</td>
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</tr>
</tbody>
</table>

If you require financial assistance to attend the conference, please complete the online grant application form [https://form.jotformeu.com/73162215560348](https://form.jotformeu.com/73162215560348). We have limited grant funding available for UK & Republic of Ireland members.

You must apply for a grant prior to registering.

For more information or to book by phone please contact the office on 01382 204446 or email admin@brittlebone.org
**Support for You**

By Coreen Kelday

We have had another busy year at the Brittle Bone Society with planning and hosting events. We kick-started 2017 with a Scientific Symposium and two Patient Days in Feb in London and Bristol. In April we held another successful youth event in Sheffield and we visited both Dublin and Belfast in May to host two further Patient Days. We also ran a very successful Wishbone Day campaign on social media which saw us reach 250,000 people throughout the month. In June I attended the ICCBH Conference (International Conference on Child Bone Health) where I met up with many of our healthcare experts from the UK and gained lots of knowledge on latest developments. August saw us host our annual family conference and now it’s onto planning the next big celebrations. We would like to say a big thank you to everyone who came along and supported the events. It’s always a pleasure to get our and about and meet so many of you.

2018 – SPECIAL YEAR

2018 is going to be an extra special year and I am really looking forward to finding out and learning more about the history of the charity and hearing everyone’s memories and stories of year’s gone by so please get in touch.

We have also been working hard on developing our new website which will have lots of useful up to date information and resources available. I continue to work closely with POINT (Paediatric Osteogenesis Imperfecta National Team) who have created another two new factsheets this year; Wheeled Mobility for Children and Advice for Nursery and Pre-Schools which are both available for download on our website. POINT would also like to hear suggestions from members of what other topics families would find useful. The Kids Pack was also been launched in November and children going to hospital for treatments have now started receiving packs and we have been delighted to receive photos of lots of smiling faces.

Please get in touch with me on any of the topics above. You can ring the office on 01382 204446 or email me at coreen@brittlebone.org

**OI Family Day, Bristol Children’s Hospital**

By Gareth Cumming

On Saturday 7th October, Trustee Gareth Cumming, attended the OI Family Day held at the Watershed in Bristol. It was an event run by the Bristol Children’s Hospital for families of children with OI. The event was well attended with about 30 children between the ages of 3-11 and their families attending. The day began with a Q&A session for children and adults who came up with a variety of challenging questions for the Children’s Hospital staff. In the next session adults and children split up; the adults carried on another Q&A session whilst the children went off to see a selection of exotic animals brought in by Animal Zone UK. The animals included tarantulas, a huge tortoise and a massive albino python which, those brave enough, were allowed to touch and even hold on their shoulders. Once the adults’ Q&A session had finished they joined the children before the last of the animals were put away giving the adults a chance to brave the python.

After a break for lunch everyone came together for an exciting boat building competition, everyone was given a selection of craft supplies and they were tasked to build the prettiest boat which was capable of floating and holding 50 baking beans. There was a huge variety of boat designs and styles, some were more seaworthy than others. As a representative of the BBS, I was given the job of being the judge of the prettiest boat which I chose a very multi-coloured boat with a Welsh flag on top (no bias, honest). It was a great day with all the children and parents making great friends and trading helpful advice and stories.

**OIFE Youth Conference**

On November 1st to 5th I attended the youth conference in the Netherlands for people aged between 16 and 35 hosted by VOl and financial support from the OIFE. I already knew some of the people going as a few of them had attended VOICE 2016 in London, however I was a little apprehensive how we were all going to communicate with so many different languages being spoken, luckily my fears were put aside as everyone could speak English. Over 40 people with OI, plus helpers, attended from all over Europe and instantly people began to get along with each other as if we had known each other for years. We stayed in a huge adapted self-catering complex just outside of Zwolle, which was perfectly set up for so many wheelchairs, with an outside decking area, 2 huge kitchens and a self-service bar. The week was full of fun activities which included a challenge/scavenger hunt in the city of Zwolle, a boys vs girls gameshow style quiz, and a day trip to Amsterdam where we visited the Van Gogh museum and a boat trip around the canals. Unfortunately the cities of Zwolle and Amsterdam are not very wheelchair friendly so most of our time during our free time was spent walking around trying to find a bar/coffee shop that was accessible and had disabled toilets, but this did not deter us having a great time. The organisers created a fantastic week and everyone had a fantastic time and at the end of the week we were all making plans to see each other in Dundee for the BBS Conference and at the next OIFE youth event in Denmark in 2018.
ASTEROID STUDY INVESTIGATING THE EFFECTS OF ANTI-SCLEROSTIN THERAPY IN OSTEOGENESIS IMPERFECTA

Mereo BioPharma is sponsoring a multicentre international clinical trial to study the effects of anti-sclerostin therapy drug setrusumab (previously called BPS804) on bone in OI. The study has now started recruiting patients in the UK, and at multiple sites across Europe United States and Canada. Adults between 18 and 75 years old who have a diagnosis of OI Types I, III, or IV are eligible for this 1 year clinical research study, which aims to enrol up to 140 patients.

Visit the study website (www.asteroidstudy.com) to learn more, find your nearest study location, and register your interest in participation. If you have any additional questions, please email AsteroidStudy@mereobiopharma.com. Their study contacts will be able to tell you more about the clinical research study, review eligibility criteria, and find a site near you.

RESEARCH STUDY EXPLORING VIEWS AND ATTITUDES TO STEM CELL THERAPY FOR OSTEOGENESIS IMPERFECTA

A new research study called Boost Brittle Bones Before Birth (BOOSTB4) is investigating the possibility of using stem cell therapy as a treatment for severe OI. The study is being undertaken by researchers at Great Ormond Street Hospital and the UCL Institute of Child Health. The treatment involves transplanting stem cells into the baby affected with OI during pregnancy or soon after birth. The stem cells will make healthy collagen that will support damaged bones and help with the development of new normal bone. The BOOSTB4 clinical trial aims to test whether the treatment is safe and effective.

Great Ormond Street Hospital & UCL Institute of Child Health feel it is important to find out what people think of this new treatment and would like to invite people to give their views in an interview (phone or face-to-face) or focus group. They would like to hear from:

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

If you are interested in taking part in an interview or focus group and would like to find out more about the study, please contact Dr Melissa Hill at Great Ormond Street Hospital by email melissa.hill@ucl.ac.uk or phone 020 7762 6871.

TREATMENT OF OSTEOGENESIS IMPERFECTA WITH PARATHYROID HORMONE AND ZOLEDRONIC ACID (TOPAZ) TRIAL

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

Sites are opening across the UK and currently recruiting patients. Edinburgh and Aberdeen are both open now for recruitment, with Dundee, Glasgow and Newcastle all due to open soon. Further sites will be opening in the new year.

If you would like to find out more information, please contact the TOPaZ Trial Office - Holly Ennis 0131 537 2573 or topaz.trial@edin.ac.uk Alternatively, please take a look at the website: edin.ac/topaz-trial

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).

PPI GROUP

Our Patient and Public Involvement group has been working hard on its first task surrounding clinical trials and how to involve patients and their families in these studies. Secondly, they have been considering what topics they would like researchers to focus on in the future – particularly relevant now that the BBS has its own Research Grants Fund. Thank you to everyone for their commitment, and if you would like to join then please contact the office.
THANKS TO OUR FUNDRAISERS

MEDICS ON THE MARCH!
The Brittle Bone Society has a team of medics and others walking the West Highland Way as part of our 50th anniversary celebrations. The walk will take place over four days, 4th – 7th May 2018 and follow a challenging route from Fort William to Milngavie.

50 WALKS, WHEELS, WANDERS... AND ANYTHING IN BETWEEN!
We are looking for fantastic fundraisers to join the Brittle Bone Society in celebrating our 50th anniversary by going on a sponsored walk, wheel or wander... or anything in between!
Some members have already joined in and are completing 50 walks leading up to our 50th celebrations. Yvonne Grant, Wilma Lawrie and Cameron Allen have all started their walks in so many places including Scotland and even London! We can’t wait for some updates on new walks next year and more fantastic pictures!
If you have any ideas for fundraising events to help us celebrate, whether it is 50 walks or 500 steps, please get in touch and let us know by either calling the office on 01382 204446 or contacting fundraising@brittlebone.org.

BRITTLE WARRIORS - KILT WALK
On the 20th August 2017, the Brittle Warriors team of BBS staff and friends took on the Dundee Kiltwalk Wee Wander. Some members of the team even put on their kilts for the occasion! The seven mile walk from HMS Unicorn (right beside the Apex Hotel, our fantastic conference venue for 2018!) to Monifieth was enjoyed by all even if the team were very pleased to see the finish line! It was a beautifully sunny day that helped to keep spirits high, and a quick pit stop for ice cream helped too. Thanks to a fabulous top up of 40% by The Hunter Foundation, the total funds raised by the Brittle Warriors were £917.80! Congratulations and thank you to everyone who completed The Kiltwalk to fundraise for the Brittle Bone Society.

STEVE EDNEY’S 12 EVENTS OVER 12 MONTHS
Steve Edney and friends are taking part in numerous events to raise awareness of OI and raise funds to help the BBS with much needed research and support. There have been a number of different events which have already taken place including a seven hour cycle and a 10k muddy obstacle challenge. Steve’s efforts will be finishing up with the 3 peaks challenge in June 2018. So far almost £9,000 has been raised and even little Max has been getting involved by making an appearance in the BBC studies and raising awareness of OI on BBC Radio 2!
THANKS TO OUR FUNDRAISERS

The BBS are so thankful to all of our fundraisers and 2017 has been another fantastic year! There are too many of you to mention individually, but here is a selection of some of the activities and events which have taken place over the last few months. If you feel inspired please get in touch by sending an email to fundraising@brittlebone.org

BIKE TOUR IN MEMORY OF VICKY HARTLEY
Over six days Alex Hartley cycled a total of 520 kilometres around France and powered through all kinds of weather to raise over £700 in memory of his late aunt Vicky.

CLIMBING MOUNT SNOWDON
Kirsty Snowdon and a group of others climbed Mount Snowdon and raised over £2,700. A huge well done and thank you to everyone involved.

SKYDIVE SUCCESS
Tracey Portlock wanted to raise as much money as possible for the BBS and jumping out of a plane is a sure way to do that! The Portlock family raised a fantastic amount of over £1,700 from their Mexico skydive.

CHARITY BOXING
It was no surprise to us here in the BBS office when a member of the Kealey family decided to fundraise for us. Matt Kealey took part in a charity boxing match and managed to raise over £1,200. This was great and very brave idea and the punches really paid off to raise such a fantastic amount!

TOGGLE WALK
Charlotte France organised the ‘Oi Can Toddle Walk’ in Worthing. A great day out for all involved and a fantastic £485 was raised.

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CARDIFF HALF MARATHON
BBS member Elanor Goodden and her friend Joanne Dunscombe ran the Cardiff Half Marathon to raise money for our charity. Thanks to these ladies efforts they have raised over £1000!

QUEENSFERRY CROSSING
Three year old Lucy and her troops including mum Julie Brown and uncle Jim who have both been involved in the BBS since the 1980s received the once in a lifetime chance to take part in the Queensferry walk for the opening of the new crossing. This was a fantastic effort for little Lucy and over £500 was raised for the BBS. Congratulations everyone that took part.

Yvonne and Wilma also had the chance to walk across the fantastic new bridge as part of their 50 walks being completed for the Brittle Bone Society's 50th anniversary celebrations. Both are trying to raise as much as possible for the charity over the course of a year. Well done both for another great walk!

THANK YOU
And to all the other amazing fundraisers who have supported the BBS we send a BIG THANK YOU
**GIFT AID**

UK Taxpayers can give their donations a big boost by using Gift Aid – for every £1 donated, the BBS receives £1.25 if Gift Aid is added at no extra cost to the donor. You can download a Gift Aid form from our website or request one by contacting the office. Alternatively, you can fill out the online version of the Gift Aid form at: http://brittlebone.org/get-involved/fundraising/gift-aid/

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

**IMPORTANT NOTICE**

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

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

**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 become a Supporter and will no longer qualify to vote at our 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.

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