BBS ON BBC COUNTRYFILE, CHILDREN IN NEED AND BOOTS MAGAZINE

Cameron Allen, Jill Nelis and Steven Aghanti helped raise the profile of the BBS taking to the screen, airwaves and pages of magazines to tell the world about Brittle Bones and the work of the Brittle Bone Society.

CAMERON RAMBLES FOR THE BBS

BBS were delighted to watch BBS Award Winner, Cameron Allen (age 13) appear on national television’s BBC Countryfile on the 20th of September. The show launched BBC Children in Need’s big idea for fundraising this year; a nationwide ramble that happened on the 10th and 11th October. Cameron and his family spoke about living with OI and the trials and tribulations that can bring. Cameron shone through as a determined and ambitious young boy taking part in sports at his local school, getting out and about in the beautiful picturesque village of Appin, Argyll and Bute. Mum Heather thoroughly enjoyed the family’s ramble with John Craven. Just before the walk Cameron experienced a bad break to his femur. Mum Heather mentioned how Cameron always wanted to experience being in a rescue helicopter but hadn’t quite wanted it that badly! Thankfully he recovered and took part in what was certainly a day to remember.

JILL HELPING CHANGE YOUNG LIVES

BBC Children in Need now in its 12th year featured an awareness campaign in national magazine Boots Health and Beauty. Northern Ireland’s Jill Nelis was featured and spoke highly of the BBS support she and her family had gained over the years. Jill is certainly a big fan of BBS events and catches every opportunity to join in the fun at our annual events. Jill noted all the encouragement she has grown up with and said being part of the BBS had made a huge difference to her life.

STEVEN SPURS ON MILLIONS OF NATIONAL BBC CIN VIEWERS

Well done Steven Aghanti – featuring on the big night TV programme BBC Children in Need, encouraging viewers to join in the fun.

BRIAN COX ACTOR

Proud to be a Patron of the BBS. Read more inside about our recent BBC Radio 4 Appeal. Netting over £6,600 and with cash still coming in.

Merry Christmas
BBS STAFF 2016

In November this year we welcomed new member Marthe Handling to join our team as Fundraising and Admin Officer and Jodie Whitham to take up the position of Fundraising Grants Officer. Karl Henry is continuing with the Communications role and Coreen Kelday is completing the final steps in her newly promoted role of Support Development Officer. Now we have a full compliment of staff we are set to undertake all the new milestones and ambitions for the BBS; as set out in the new Strategic Plan which will begin in earnest early 2016.

BBS EVENTS GET BETTER

Annual Conference in September, held this year in Manchester over the weekend of 11-13th September seen 152 members at the Radisson Blu Hotel for a wonderful weekend.

TRUSTEE MATTERS

Elaine Healey was re-elected unanimously as Chairman, as was John Phillips to Vice-chair. Merrick Koh steps up as the Charity’s new Secretary. From our Medical Advisory Board we welcome Professor Nick Bishop and Professor Faisal Ahmed to join the Trustee Board. Yvonne Grant and Helen Chappel were also back as Trustees. Thanks were offered to the work achieved from those Trustees standing down – Mrs Jacky Boyd, Ms Sam Renke and Mr Simon Mckeown.

The programme at conference involved leading NHS healthcare speakers specialising in Orthopedics, Genetics, Research, Psychology and current treatments. For the first time the Charity arranged to have their talks live streamed allowing those who were unable to attend the chance to catch the latest updates in OI. 104 viewers watched the talks over Friday and Saturday. Since then our collection of talks have gone on to be viewed more than 250 times. You can access them on our YouTube Channel.

During our AGM this year we had a passionate debate about the future planning of Conference and the costs associated. At the Trustee Meeting in November it was unanimously agreed to continue with the annual event. A more concerted effort to secure the funds needed was paramount, as this is the largest expenditure facing the charity each year. A comment from the conference floor said if each member raised a couple of hundred pounds each year we could cover this cost with ease. Since then my thanks to so many who have done just that!

During Conference we welcomed Rebecca Skarsberg from Oslo to speak with Professor Bishop about differing healthcare systems.

Feedback from this event has been great and concensus is it was one of the best BBS events in many years.

We are keen to commence with our super new hospital patient day events planned for 2016 across the British Isles. The events will begin in mid-January starting in Northern Ireland followed by the Republic of Ireland and Scotland for Burns Day. Various dates in England are in the process of being confirmed for early summer. We have a growth of activity in research matters on the horizon and will need your input, we will be hosting our VOICE event alongside the OIFE youth event in London in the Spring when we welcome delegates from across Europe to the nation’s capital.

Our BIGGEST problem is we could run out of days in the week to fill in all the activity planned for the next 12 months.

BBS TO CALL FOR SERVICES FOR ADULTS WITH OI

The BBS are also excited to work on a project to gather information we may be able to present in order to ask that a full service for Adults with OI is properly and fairly considered. We will keep you informed of the progress of this project. Doing all we can to continue to keep abreast of policy matters we respond to those we can and attend relevant UK Rare Disease meetings and collaborative events.

‘A’ LIST BBS PATRONAGE

Our thanks go to Jordanne Whalley MBE for support this year and our newest ambassador Mr Brian Cox – Actor who delivered a very successful BBC Radio 4 Appeal in September. We have brought in over £6k of funds from the 2 minute broadcast with money still coming in. The awareness raising has been a boost and we are set to capitalize on this as much as we can throughout 2016.

GREAT BBS MEDIA BUZZ

We had an unprecedented run of coverage beginning with our Radio 4 appeal, then with the launch of BBC Children in Need Ramble we watched Cameron Allen on Countryfile with John Craven, we also read with interest our young Northern Ireland Star Miss Jill Nelis in the Boots Health and Beauty Magazine, every single word and item raises the bar for greater understanding of OI. Thank you all for your support across all these successful and wide reaching campaigns.

As Lord Mayor of Manchester Cllr Paul Murphy said at Conference – LET’S MAKE SOME NOISE in 2016.

Elaine & Patricia

Have a wonderful Xmas and a great new year.
HOSPITAL VISITS
Support Development Officer Coreen Kelday took some time out to visit POINT colleagues in Sheffield, Birmingham and GOSH Children’s Hospitals in October and November. The visits centred around pre-planning for Xmas parties, plans and ideas for future patient days, talks and workshops for BBS events, special events planning for Rare Disease Day and Wishbone Day; not forgetting Annual Conference and updates on wheelchair applications for members. Coreen enjoyed hospitality from therapists at the hospitals — being shown round the departments and getting a chance to speak to Occupational Therapists and Physios in their own hospital/clinic settings. Coreen said it was invaluable to get the therapists views on how we can improve and develop BBS events and build on greater collaboration. Coreen is already planning a visit to our friends in Bristol and hoping to visit Liz Dougan in Scotland formerly of Yorkhill Childrens Hospital as they settle into their new building at the Queen Elizabeth Hospital in Glasgow.

THE POINT
Paediatric Osteogenesis Imperfecta National Team (POINT) meeting was held at Sheffield’s Children’s Hospital on 30th November and was attended by our Support Development Officer, Coreen. Topics covered were areas such as transition and adult services, multi-centre research potential, future BBS factsheets, wheelchairs and equipment to mention but a few.

OIFE AGM — OSLO, NORWAY
Patricia Osborne, Chief Executive and Coreen Kelday, Support Development Officer were delighted to attend the OIFE AGM hosted by the Norwegian OI Society in September. After 14 years of being President of the OIFE, Ute Wallentin stood down from this post and Ingunn Westerheim is now the OIFE President. The OIFE AGM gave both Patricia and Coreen the opportunity to make friends from around Europe, and also have the privilege of hearing a talk by Dr Francis Glorieux. On a practical note Coreen gave assistance in reviewing the OIFE annual accounts and minute taking, and Patricia prepared a press release which can be viewed on the BBS website.

SUPPORT GROUPS
Our Northern Ireland and Birmingham Support Groups have both met up in December for pre-Christmas get-togethers. Northern Ireland are planning another meeting early January and Birmingham are looking at going bowling later in the year. Our North East, Scotland and Republic of Ireland Groups met in May for Wishbone Day. Support Group meetings are a great opportunity to meet up with old and new friends and discuss OI issues with each other.

For more information on any of the Support Groups please contact coreen@brittlebone.org

PENNY CLAPCOTT ATTENDS OIFE BERLIN
THANKS TO RAFFLE DONATIONS AT CONFERENCE 2014
BBS SENT PENNY CLAPCOTT TO THE OIFE YOUTH EVENT IN GERMANY.

Speaking about the event Penny Clapcott said how fortunate that this was her second OIFE youth event, the previous one being in Belgium 5 years ago. Penny said to be in Berlin, Germany; a place she’d never been to before, was exciting and it was great that she had been asked to attend as a formal delegate for the Brittle Bone Society.

Penny also attended an English Federation of Disability Sport (EFDS) event for us. The event focused on how best to encourage people to be active regardless of their disability; and to ensure they have the same opportunities to partake in activities and sport.
GOOD NEWS STORIES
CARER OF THE YEAR AWARD 2015

Congratulations go to BBS mum, Jennifer Carroll who won the overall Carer of the Year Award. Jennifer received the award from the Carers Association in recognition of the full-time care she provides for her two children Alex (age 8) and Ava (age 3). The ceremony which took place in Dublin was hosted by RTÉ Radio personality Marty Whelan and TV presenter Mary Kennedy. Speaking about the event Jennifer said “It was lovely to receive the award. It was such a big shock. The ceremony was lovely and there was so many carers who really deserved the award as well.”

MILLIE SIMPSON — CHESHIRE PHOENIX BASKETBALL TEAM

Millie Simpson has been making friends in high places as she has struck up an unlikely friendship with local Basketball star, Kinu Rochford. Rochford who is originally from New York and now plays for Cheshire Phoenix said “my little friend Millie, I just love her and she is my inspiration every time at the arena and she’s the reason why I want to win.” Speaking to their local paper, (The Chester Chronicle) Millie’s mum Stevie said that her daughter “can find some things hard to focus on but she loves going to the basketball and cheering on the Phoenix and she just adores Kinu.” BBS HQ staff can now un-officially confirm that Cheshire Phoenix is our new favourite Basketball Team!

POLICY TRAINING FOR BBS STAFF

CEO, Patricia Osborne and newly appointed Fundraising and Admin Officer, Marthe Handling attended a Charity Fundraising and Data Protection Seminar held at BBS Vice-chair, John Phillips’ Jones Day Office in November. The event was hosted by Partners Liz Robertson & Jonathon Little both experts in the field of Privacy & Data Protection.

A group discussion was held on the Etherington Report and what measures will be rolled out over the next 18 months in regards to regulating fundraising, the importance of compliance and good practice and a more actively engaged Trustee Board.

Other topics covered were Data Protection and Charity Fundraising “Dos” and “Don’ts”. Both Patricia and Marthe found this event extremely beneficial. It was not only a great induction for Marthe about the importance of data protection and consent when handling member’s information but it also gave BBS staff a good insight into the future fundraising landscape.

BBS would like to thank John Phillips, Liz Robertson & Jonathon for their hospitality.


Liz Robertson – Partner at Jones Day Law Firm, has considerable knowledge of data protection law and advises clients on compliance with the EU Data Protection Directive as they make transfers of personal data from Europe to the United States. Liz Robertson’s practice focuses on technology transactions, particularly software M&A deals, outsourcing (IT and BPO), and facilities management arrangements.

She has extensive experience with software licensing, particularly for the financial services industry. She advises on IT issues, including ownership issues, website hosting agreements, privacy policies, and data protection.

Jonathon Little – Partner at Jones Day Law Firm, has been assisting the BBS team for some years around contracts and other extensive advice. Jonathon’s practice focuses on technology, outsourcing, and other high-value commercial projects. He advises customers and suppliers on a full range of transactions, including IT, BPO and other types of outsourcing deals, telecoms transactions, network service arrangements, IT licensing, systems and software acquisitions, e-business, framework agreements and other procurement structures, agency and distribution agreements, and other commercial contracts.

He also has extensive experience in data protection and privacy, cyber security, and e-commerce rules. Jonathon has a particular focus on large outsourcing, including IT, network, telecoms, BPO, and other arrangements, as well as strategic IT procurements. He has led outsourcing projects in the insurance, technology, aerospace, banking, and manufacturing sectors.

Patricia Osborne – CEO of the BBS said to have the help and guidance from legal experts at Jones Day, is invaluable, and thanks to our Trustee and Vice-chair John Phillips – the legal team has given us advice and help on very important matters, and such extensive knowledge ensures that the charity is able to operate with confidence. We wouldn’t be in a position to be able to afford these services and our thanks go to the professionals for giving the BBS their time and expertise.

BBS Survey calling for Adult OI Services — Remember This is for Your Children’s Future Too!

Please fill this in for OI Children and Adults, who need you today, tomorrow and in the future. Youngsters like Daniel have dreams and ambitions, they should be able to look forward to life knowing there is a good healthcare system ready to support them. Please complete the survey online to help us scope out our case to the NHS.

(See insert)
At the jet setting location of the Manchester Airport Radisson Blu, 152 BBS members from across the UK and Republic of Ireland gathered for a weekend of talks, AGM, networking and our award show and Gala dinner, all in the name of #BBS2015.

The event – featured presentations from leading healthcare professionals and guest speakers from around the world. The BBS were proud to welcome Rebecca Skarberg OIFE Representative and Member of the Norwegian OI Society, who shared a platform with Professor Nick Bishop and Gerald Brandt, who joined from the HPP community in Germany. To officially open the proceedings CEO Patricia Osborne welcomed the Lord Mayor of Manchester Cllr Paul Murphy who gave a fantastic speech on the need for communities to pull together to achieve their goals and make some NOISE. Not only was it a weekend for adults and parents – the younger generation got to join in with cloak and dagger Spy Games that tested our youngsters in mind games, agility and problem solving. A chance for Cool Bones Kids to discover if they were cut out for a life of espionage – watch out for the next James Bond 007. BBS were also pleased to welcome to the Gala Awards Dinner VIP guests Mr Blair Thomson of the Northwood Trust and Mrs Baljinder Boparan of the Boparan Trust. The Northwood Trust has been supporting the charity for 18 years donating a staggering £250,000 over that time and recently the Boparan Trust supporting us in purchasing Childrens wheelchairs amounting to over £14,500. The talent show was amazing as ever and our thanks to former Trustee Mr Mark Ross who was our compere for the evening.

<table>
<thead>
<tr>
<th>Date</th>
<th>Item</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 22</td>
<td>Patient Day Event</td>
<td>Belfast</td>
</tr>
<tr>
<td>January 23</td>
<td>Patient Day Event</td>
<td>Dublin</td>
</tr>
<tr>
<td>January 30</td>
<td>Patient Day Event</td>
<td>Glasgow</td>
</tr>
<tr>
<td>February/March</td>
<td>Patient Day Event</td>
<td>Dundee</td>
</tr>
<tr>
<td>March/April</td>
<td>Youth Event VOICE</td>
<td>London</td>
</tr>
<tr>
<td>(Rare Disease Day Event – Genetics Collaboration)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>May 7</td>
<td>Wishbone Day Patient Event</td>
<td>Birmingham</td>
</tr>
<tr>
<td>May 8</td>
<td>Patient Day Event</td>
<td>Bristol</td>
</tr>
<tr>
<td>Date TBC</td>
<td>Medical symposium</td>
<td>London</td>
</tr>
<tr>
<td>Aug/Sept</td>
<td>Annual Conference</td>
<td>TBC (3 x day event)</td>
</tr>
</tbody>
</table>

If you would like more details on any of our events see www.brittlebone.org or contact the office on 01382 204446
**FUNDRAISING**

**CONTACT** bbs@brittlebone.org

TO GET YOUR FUNDRAISING PACK

---

**ROBIN HOOD HALF MARATHON**

Back in September, our terrific supporters, Annette Corrall and Claire Hall ran for the Brittle Bone Society in the Robin Hood Half Marathon. Claire and Annette completed the marathon in 02:38:55 and 03:10:50 respectively. So far they raised an incredible £1021.25. Thank you ladies!

**AMAZING RUNS**

BBS fundraisers really are an active bunch - Theresa Connor & Conor McArdle ran the Great Scottish Run Half Marathon. While her son Aiden and friend Eoghan McArdle ran the Great Scottish Junior Run. Our incredible Irish supporters, Niamh Lehan and Mick Murphy took on the Dublin marathon. Céad mile maith agat guys! Cate Coffey, Abi Anness, Beth Watson and Anne Wilmott also ran the Leicester Marathon, which means all these runs added to a tremendous £2578.16. We salute you all and hope you’re not still recovering!

**A CUT ABOVE**

Thanks to one of our youngest BBS supporters, Clare Murphy who had her beautiful hair cut off and donated the hair-raising amount of £115 to the BBS. We think your new hairdo is a cut above the rest Clare!

---

**CONFERENCE FUNDRAISING**

Enormous THANKS to Ashby De la Zouch & Coalville Lions Club who were inspired by the Bateman family to give to BBS. They gave a kind and generous donation of £500 acknowledging support gained from the BBS. This will help us to continue to fund our Annual Conference.

**COFFEE MORNING**

Looks like it was a fantastic turnout for the coffee morning organised by Sara Marshall and family, which raised £960. The Marshall family have been supporting the BBS with Coffee Mornings for the past 13 years and have raised an amazing £8854 to date.

**POOLING TOGETHER**

Thanks go to BBS member Paul Lewis, Laura Rose Thornton, Zoe Jarrett, Sam Sprackman, Chris Eldred and everyone at the Martock Snooker Centre for hosting a charity pool match in aid of the BBS. The final figure isn’t in yet but so far they have raised £600.
Halloween Party

Tracy McAnena and family supported the BBS by getting into the mood for Halloween. From being dressed as film characters and spooky vampires to witches, it was a night not to be missed! Thank you for raising £500 for BBS in the process!

Quilt Raffle

Well done to S Darrington and Jill Marsh who won the large and small quilt in the raffle. Massive thanks goes to everyone involved in the social stitch and Bee Crafty for raising a fantastic £510 for the BBS.

Jones Day – Office Quiz

The team working behind BBS Vice-chairman, John Phillips held an office Quiz Night in October. From what we hear it was a fantastic turn-out for Jones Day who are only more than happy to support the work of the BBS and its members. All in all they raised a great £705.00 with John saying “This was absolutely nothing to do with me and entirely down to the efforts of Naomi Miles who has run for the Society in the past and does a lot on the pro bono side in addition to her day job as a litigator”

Skies Above

Christopher Lynch took the skies and raised a sky-high £773.98. Thank you Chris – the sky is no longer the limit!

This is Spartan… 5K

A massive thank you to Oliver Ralph, who took part in the Spartan 5K race and raised a great £328.75. We’re loving how you remained enthusiastic throughout, and how it’s not put you off taking on Toughest Challenge in April next year!

BBS Total Warriors

A huge thank you and congratulations to our amazing team of BBS supporters headed by Kimberly Black, who all took part in Total Warrior; a gruelling and muddy course and raised an astounding £4,042.83!

Longridge

Thank you our amazing supporters from Longridge Branch! John & Gertie Farmery and Jacqueline Quinn have been making huge leaps in fundraising over the years. This year they have a raised an amazing £10,800. What a great way to end the year!

Holmfirth High School

BBS Support Development Officer Coreen & Jodie our new Fundraising Officer accept a fantastic donation of £453.96 from Martina and her classmate - proceeds of a yummy cake bake sale at Holmfirth High School. Thanks also go to the Caudwell Trust allowing BBS to purchase a specialised power wheelchair for Martina.

Huge thanks and well done all!

Don’t forget, to check out www.brittlebone.org/get-involved for tips and advice on how you can fundraise for the BBS in 2016!
GROUNDBREAKING RESEARCH
GIVEN HOPE THANKS TO AMAZING BBS COMMUNITY RESPONSE TO SURVEY!

With the prospect of BBS being involved in as much meaningful research as we can, Chairman Elaine Healey, CEO Patricia Osborne and Professor Nick Bishop wanted to extend fulsome thanks for the outstanding uptake to complete a recent survey. Collaboration on this scale will assure Researchers that there is optimum chances of groundbreaking work getting off the ground.

In July of this year the BBS received a request from Professor Stuart Ralston asking for members to assist with a study in new medicines in adults with OI by completing an online survey. Since circulating the survey with its members the BBS has learnt that an amazing 169 of you responded - a response rate which far exceeded the expectations of both Professor Ralston and the BBS. A massive thank you goes out to everyone who took part.

The trial which was scheduled for review by the EME this October past, has been withdrawn and Professor Ralston and his team are currently exploring a number of options and remain hopeful that it will continue at a later date.

We promise we will keep you posted.

YOUR RUDY UPDATE!

RUDY has 350 rare disease patients recruited (when last checked) and the BBS have been told the first paper on quality of life in adults with rare disease has demonstrated fascinating results. RUDY have also made it even easier for participants to record their fracture dates and added a step by step guide on how to get involved.

RUDY are still hoping for 200 OI patients (adults and children) so spread the word! With bigger numbers across all the rare bone groups, RUDY can write more competitive grants to answer the key questions from patients and researchers.

The team are also hoping to create a short animation explaining RUDY for their website, so if you or someone you know has any animation skills get in touch with - Alison.turner@ndorms.ox.ac.uk

1000,000 GENOMES PROJECT

Researchers at Oxford University are looking to interview people who have been invited to take part in the Genome 100,000 Project. If you are interested and would like further information or have questions get in touch with Melissa.stepney@phc.ox.ac.uk or Sara Ryan sara.ryan@phc.ox.ac.uk

BBS CONSULTATION RESPONSE TO GOVERNMENT MANDATE TO NHS ENGLAND 2020

Prior to completion and submission we spoke to our Occupational Therapists across the country. (Please note this paper refers to NHS England.)

The BBS response asked for consideration relating to NHS specialised healthcare and also we call for greater focus on wheelchair provision within this response.

We asked to see more detail referencing commissioning of specialised healthcare and more information on direct commissioning responsibilities.

It would be our hope to see a reduction of future health inequalities covering all patient populations and with respect of rare conditions as this often equates to smallest numbers in society.

Wheelchair services must be specifically mentioned as an improvement area.

Taking a lead from the Wheelchair Alliance we asked for wheelchair services to be specifically mentioned within the mandate.

With the evidence that the Wheelchair Leadership Alliance, has been able to collate from listing various sources, (you can see our full response on the website) it is clear that positive change in wheelchair services is essential if the aims of the mandate are to be achieved: You can read the entire paper on www.brittlebone.org

UPDATE - ALL PARTY PARLIAMENTARY GROUP RARE DISEASE

In July we asked you to write to your local MP, asking them to join a new All Party Parliamentary Group (APPG) on rare, genetic and undiagnosed conditions for the House of Commons. Since then over 30 MPs and Peers have joined the group - a number which would not have been possible without the support and action of BBS members. So for that we congratulate you in helping ensure that there will be a strong BBS presence within the group. We now have an improved opportunity to raise awareness, influence change, and work together to improve the lives of individuals affected by rare and genetic conditions like OI.
TOP TRUSTEE MIX

A GREAT BALANCE OF SKILL, PROFESSIONALISM AND VITAL PRO BONO SUPPORT

BBS Chairman Elaine Healey and BBS Trustees welcomed newest board members Professor Nick Bishop (Sheffield) and Professor Faisal Ahmed (Glasgow) to the November Meeting in London. It was held at Mirrick Koh our new Secretary’s offices (law firm Linklaters) in London, the meeting had to be re-arranged from the usual venue of Jones Day Law Firm due to traffic restrictions caused by the Lord Mayor Show. Elaine said “to have such a wide and knowledgeable breadth of talent at our Trustee Meeting is wonderful, and that the Charity is offered such modern meeting space and facilities without any cost to the Society is not only very kind but incredibly beneficial. We wouldn’t be able to meet the costs of meeting at such prestigious and updated offices – especially in the centre of London which is ideal for us all to meet up”. BBS Treasurer Robert Gordon said “it’s no surprise how fast costs can mount up, when you appreciate the thousands of pounds that are saved each year to the BBS coffers in pro bono support, especially due to Vice-chair John Phillips”.

COMMUNICATIONS

Thanks to increased activity on our Facebook, Twitter pages and successful campaigns over the past few years the reach of the Brittle Bone Society is on the rise; with more people than ever knowing of the condition and the work we do. For this we thank our members for liking, sharing and retweeting our posts; and we ask you to continue. Every time you click like or share it has the potential for a new person to learn about OI and the work we do. It’s my role to communicate items of interest – but I need your help – so please get busy sending me what you would like to share. If you plan on taking part in a sporting event, have been nominated for an award, are appearing in your local newspaper or anything else of interest then please let us know beforehand. Contact karl@brittlebone.org and share your achievements today!

Find the BBS at:
**FUNDRAISING & ADMIN**

Let’s give a warm welcome to newcomer Marthe Handling to the post of Fundraising and Admin Officer. Marthe joins us after spending time in telecoms and having graduated from the University of Dundee with a degree in Politics and International Relations. Assisting the BBS operation with donor requirements, events planning and admin and getting up to speed on policy matters around the rare disease area. Marthe will be a key team member and addition to the BBS squad. If you would like to contact Marthe – send an email to bbs@brittlebone.org (new email addresses being confirmed as we go to press).

**FUNDRAISING & GRANTS**

Joining us, ‘Maggies Cancer Centre’ in Aberdeen – Jodie Whitham will take over our grants application and fundraising campaign activity. Jodie gained a degree in Public Relations at Robert Gordon University and is passionate about working in the third sector. Starting out for the BBS on a three month probationary period, giving Jodie time to learn about our work and our wider community and the vital fundraising we do. Expect great campaign ideas rolling out over the year in core areas and in restricted fundraising. We look forward to hearing new ideas for fundraising for the BBS from Jodie. If you would like any information on fundraising or have plans you would like to discuss with Jodie, then don’t hesitate to get in touch with Jodie on bbs@brittlebone.org (new email addresses being confirmed as we go to press).

**GIFT AID**

Please don’t forget for every £1 donated, the BBS receives £1.25 if Gift Aid is added.

You can give your donations a big boost by using Gift Aid. If UK taxpayers Gift Aid their donations, membership or supporters fees the BBS get an extra 25% 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://www.brittlebone.org/get-involved/fundraising/gift-aid/.

**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 bbs@brittlebone.org or phone 01382 204446 if you would like a pack full of ideas on how to fundraise. Remember to let us know about your fundraising events and we will promote them on the BBS website www.brittlebone.org Facebook and Twitter.

**BBS STANDING ORDER ADJUSTMENTS PLEASE!**

Please don’t forget to register the new subscription rate of £20 annual fee with your local bank. We are appealing to members to adjust their payment arrangements and regular standing orders to contact their bank or update their PayPal records to enable them to receive membership benefits.

The society continues to respect signed up life members, but hopes they will consider becoming regular supporters.

If you choose not to contact your bank or PayPal you will automatically become a Supporter, but will no longer qualify to vote at AGM meetings.

**CREDITS**

**Editor**
Patricia Osborne | patricia.osborne@brittlebone.org

**Sub Editor**
Harry Venet, Trustee

**Editorial Assistant**
Karl Henry | karl@brittlebone.org

**General Enquiries**
Tel: 01382 204446 | bbs@brittlebone.org

**Print & Design**
Winter & Simpson Print | sales@wintersimpson.co.uk

Brittle Bone Society, Grant Paterson House, 30 Guthrie Street, Dundee DD1 5BS

Registered Charity Nos. England & Wales 272100, Scotland SC010951