CONFERENCE HEADS TO THE HOME OF CORRIE

CONFERENCE PLANNING WELL UNDERWAY – AMAZING TOPICS PLANNED!

BBS CONFERENCE MANCHESTER

BBS Trustees and staff cannot wait to unveil this year’s conference agenda. A cracking line up of top NHS healthcare professionals including Professor Nick Bishop, Professor Peter Selby, Dr Meena Balasubramanian, Dr Julia Twynholm, Dr Raja Padidela, Claire Wagstaff, Physiotherapist – and more yet to be confirmed. Some of the confirmed topics will cover Adults with OI, Pain Management, Psychology, aspirations of new services for NHS, updates on OI treatments, Paediatric Issues and we hope to secure a talk on Surgery.

We will have a pleasant start to the day’s proceedings that involves smiling! The rising superstar actress of ‘Games of Thrones’ fame - Miss Kerry Ingram will host our Talent Show.

This year’s Cool Bones for 11 – 15 year olds will involve some top level interactive workshops kids will absolutely love, including a SPY workshop (will it be Mission Impossible? – we shall see!) We will be polling ideas on a new Cool Bones Newsletter along with a Cool Bones member only t-shirt and relaunch our education packs for school kids. 2015’s theme of Pain Management and Mental Health features strongly due to the number of comments and enquiries the BBS has taken over the past year. We will feature talks for adults and we are delighted the presentation about psychology which was cancelled in 2014 will take place this year presented by Dr Julia Twynholm from Birmingham Children’s Hospital.

Our prestigious Gala Dinner will be as sparkling and glamorous as ever – with some tear jerking awards we hope you will approve of. Please send in any suggestions of people you would like to see honoured. What are you waiting for – get your registration completed. Subsidies are available as Trustees agree it is an expensive package this year and will do all they can to assist – BBS staff have done their best to negotiate the best deal possible.

AU REVOIR ANNETTE

Long serving staff member Annette McIntyre retired in April after 29 years with the BBS. Trustees and staff paid tribute to Annette’s long service and she was treated to a farewell dinner attended by all staff and by Trustee Yvonne Grant. BBS Chairman Elaine Healey and the Trustee Board sent a beautiful bouquet of flowers and we presented Annette with a lovely pearl necklace as we know how much she enjoys her jewellery. So many good wishes have been sent in and we all wish Annette a long and happy retirement.

More Breaking news about staff on our back page…

BBS PATRON JORDANNE WHILEY MBE

Brittle Bone Society Patron and wheelchair tennis champion Jordanne Whiley has been made an MBE for services to sport.

The Wheelchair Tennis star from Halesowen has been recognised for her incredible form over the past couple of years. Jordanne, aged 23, was born with Osteogenesis Imperfecta, and was announced recently as the Charity’s Patron – having already supported events for the BBS VOICE group and helped raise awareness for OI with the wider public. Jordanne won bronze in the London 2012 Paralympics and has also won five consecutive Grand Slam doubles titles alongside partner Yui Kamiji.

You can read some more about Jordanne inside (Page 6).
JOINT CEO & CHAIRMAN’S UPDATE

COMMUNICATING, MEETING MEMBERS AT OUR NEW PATIENTS DAY EVENTS – PATRICIA AND ELAINE WISHING EVERYBODY A RELAXED ENJOYABLE SUMMER

BBS STAFF

On the staff front having bid a fond farewell to Annette McIntyre (29 years service) on her retirement, we were saddened to learn Christine Hope (of 16 years service) had sadly decided to move on to another opportunity with another Charitable organisation in Dundee. Both ladies have been a part of the BBS for such a long time and will be much missed.

We are delighted that Coreen Kelday has been appointed as our new Support Development Officer and will continue to offer front line support and manage and steer our outreach activity including events, and continue to develop the volunteer groups. We will keep members posted on any further staff developments.

WISHBONE DAY, NEW PATIENT EVENTS & ALL IRELAND FORUM

Chairman Elaine Healey, Patricia and Coreen visited Sheffield on Wishbone day in May along with the new probationary staff Karl Henry and Lucian Wilson. We were joined by Professor Nick Bishop and Dr Meena Balasubramanian. On the day we heard from NHS Yellow Card Pharmacist Karamjit Khangura – who discussed issues patients need to know when taking medicines. The day also included a presentation on therapeutics from Davina Ford and Liz Knowles from the local Sheffield Hospital. We also met up with families on Rare Disease Day in February in Dundee where we launched our new patient days funded by Awards for All. That was a busy weekend: we also held our first All-Ireland Forum – which covered lots of issues for the OI family in Ireland and made agreements to meet up later in the year to chart progress.

VOICE – OUTDOOR FUN

We were thrilled to showcase and premiere our BBS VOICE Movie by Ben Wiles and team – shot at a fun packed youth event held in March at the Calvert Trust Centre in Kielder and funded by the Bruce Wake Charitable Trust and St James Place Foundation. The movie went down really well – and since then we have had many BBS members asking when the BBS will be hosting another outdoor adventure and how they can book a place. Watch this space!!!

MEDICAL ADVISORY BOARD

The Medical Board has now completed its first three year cycle and Chairman Professor Bishop has submitted an operational plan to assess the work and the impact of the group, to ensure that it is staffed by the appropriate healthcare professionals. It was decided to invite Professor Kassim Javaid (Research) to join the MAB and Dr Richard Keen (Adults), both of whom were pleased to accept. There is recognition on the MAB that it will be of immense help to see more adult specialists and those taking forward important research to join forces on the MAB.

STRATEGIC PLAN 2016-19

We listened to your input on this our most important document going forward - staff and Trustees have scoped out the plan which will help us navigate our way over the next few years. It will be approved at our next Trustee Meeting in July in London, and we hope to have it endorsed by all our members at the AGM.

We will issue a summary note of the next Strategic Plan at Conference and will report on it during our Business Section and AGM.

TRUSTEES – AGM CALLING NOTICES

Another year over, it’s time to extend sincere thanks to the Trustee Board who give their time and expertise to steer the work of the BBS. My thanks to those Trustees stepping down this year – to Simon Mckeown, Samantha Renke and Jacky Boyd. They have each made their indelible mark on our beloved charity. They will all remain firm friends and allies of the work that we do. The Charity knows we can call upon any of them to help us again in the future. I am delighted our Secretary John Phillips has agreed to go forward as Vice Chairman, Mirrick Koh will be proposed as our new Secretary. Both Helen Chappell and Yvonne Grant have indicated their willingness to continue serving on the board and this too will be a formal proposal in the forthcoming calling papers. We have also invited Professor Nick Bishop and Professor Faisal Ahmed to join the Trustee Board. I was humbled that my fellow trustees endorsed my wish to remain as Chairman, it’s an honour and I hope all these proposals will gain your support at Conference.

In his last action as Secretary of the Board, John Phillips shall soon send out the formal calling notices of the AGM and list the detailed proposals as agreed at the last Trustee Meeting.

We both look forward to meeting up with old friends and new at what promises to be another exciting annual conference event in my home town of Manchester.

See you all soon,

Elaine & Patricia

P.s. we hope that most of you will have read our latest Electronic Newsletter (e-zine) – to receive email bbs@brittlebone.org or fill out the form online.
PATIENT DAY EVENTS & VOLUNTEER NEWS ACROSS THE COUNTRY

BBS NEW PATIENT DAY EVENT DUNDEE - funded by Awards for All Scotland - 28TH FEB 2015

The first of our new smaller localised events was held in Dundee on Rare Disease Day and was a great success with over 70 members in attendance. Talks were heard from Healthcare Professionals from Yorkhill Hospital for Sick Children, Genetic Alliance and NHS Yellow Card as well as talks from BBS staff, volunteers and supporters. Margaret and David Grant joined us for the day and we also had our Chairman Elaine Healey, Trustees Jacky Boyd & Yvonne Grant and our Treasurer Robert Gordon. Look out for Patient Day events near you.

PATIENT DAY - SHEFFIELD 8TH MAY 2015 WISHBONE DAY CELEBRATION

BBS staff and supporters descended on Sheffield for Wishbone Day to host the second of our Patient Day events. The event was supported by local healthcare staff from Sheffield Children’s Hospital and NHS Yellow Card Medicines.

SUPPORT GROUP NEWS

Our North East, Scottish and Republic of Ireland Support Groups met up for informal chats, coffee and cake, and to celebrate Wishbone Day. The North East group celebrated their first birthday. All events were well attended with over 20 people at each. 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

North East Support Group

Scottish Support Group

BBS have a series of updated fact sheets ready to share; if you would like one, you can find them at: http://www.brittlebone.org/index.php/about-oi/factsheets/ or if you call the office on 01382 204446 we will send you what you need.
PHOTO GALLERY: PATIENT DAYS
PHOTO GALLERY: PATIENT DAYS AND WISHBONE MOMENTS
MILLIE SIMPSON STEALS THE SHOW

Our very own poster girl Miss Millie Simpson took centre stage and grabbed the limelight recently on the Jeremy Kyle TV Show – a showcase programme of inspirational families dealing with health challenges. BBS staff unanimously agreed that to see little Millie’s face light up when she saw her Nan in the TV audience would melt any heart. It’s great we have families like the Simpsons raising awareness and ensuring that we let others understand just a little bit more about OI.

BBS MOVIE CATALOGUE GROWS – BBS PARENTS FILM

BBS Trustees and staff are truly grateful to Ben Wiles and his production team for the now almost complete series of films about the work and the people in the BBS family. We have films about our annual conference, VOICE youth event, a film made in part with our youngsters talking about what it’s like to live with OI – and a film about life with OI from a parent’s perspective, which can be viewed along with medical talks on our YouTube channel: https://www.youtube.com/watch?v=Pe7GwmM2CAM

MALEAH DOES IT AGAIN!

Maleah is following in her uncle Ben Wiles’ footsteps; her creativity knows no bounds. Maleah produced another very helpful and informative video which you can find here: https://www.youtube.com/watch?v=4sqbXIywabA

JORDANNE ON A QUESTION OF SPORT – BBS PATRON GETS QUIZZING

BBS patron Jordanne Whiley, appeared on A Question of Sport in April. Go to the link: http://www.bbc.co.uk/programmes/p02p1sqy to see Jordanne talk about her remarkable winning streak. As always we couldn’t be more pleased with all of Jordanne’s achievements on the court and all the work she does to raise awareness for OI.

Find BBS on: 

Find BBS on:
COOL BONES/GALA DINNER/CRÈCHE & TALENT SHOW MEMORIES

Event for 11-15 year olds, our annual dinner event, talented children performing and cute kids being well cared for — whilst parents enjoy the talks. Registration form can be found on our website.

CONFEREACE PRICE SCHEDULE

<table>
<thead>
<tr>
<th>COSTS</th>
<th>Rates</th>
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<tbody>
<tr>
<td>All prices include VAT at current rate of 20%</td>
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<tr>
<td><strong>BBS</strong> Members &amp; Non-Members</td>
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<tr>
<td><strong>Full weekend package per person (single occupancy)</strong></td>
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<tr>
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<td><strong>Full weekend package per person (double/twin occupancy, based on two sharing)</strong> sharing – please note single occupancy rate applies if 1 adult sharing with child</td>
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<td><strong>Children age 5 to 12 full weekend rate when sharing with two full paying adults.</strong></td>
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<tr>
<td><strong>2 days (Saturday &amp; Sunday) with Saturday night accommodation (single occupancy)</strong> Includes celebration dinner on Saturday evening</td>
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<tr>
<td>Cost per person</td>
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<td>£210.00</td>
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<tr>
<td>No of people</td>
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<tr>
<td><strong>2 days (Saturday &amp; Sunday) with Saturday night accommodation (double/twin occupancy, based on 2 adults sharing)</strong> Includes celebration dinner on Saturday evening</td>
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<tr>
<td>Cost per person</td>
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<tr>
<td><strong>1 day (Saturday) with Friday night accommodation (double/twin occupancy, based on 2 adults sharing)</strong> Includes group dinner on Friday evening only</td>
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<td><strong>Day delegate only for 1 day (Friday evening meal)</strong></td>
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<tr>
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<td>£28.50</td>
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<td><strong>Day delegate only for 1 day (Saturday) – includes access to exhibition area, conference &amp; workshop sessions plus a buffet lunch, and celebration dinner (per person)</strong></td>
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<td><strong>Day delegate only for 1 day (Sunday) – includes access to exhibition area, conference &amp; workshop sessions plus a buffet lunch (per person)</strong></td>
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<td><strong>Day delegate rates for Children</strong> (not inclusive of evening meal – please add an additional £15 if evening meal required)</td>
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</tr>
<tr>
<td>Cost per person</td>
<td>£29.00</td>
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</tbody>
</table>

NB. To gain access to the assisted conference fund we recommend you apply as soon as possible to BBS HQ. Please complete the application form provided on our website www.brittlebone.org. Funding is allocated in accordance with a fair process including helping those who haven’t previously attended, however all circumstances are given due consideration. Alternatively you can call the office and ask for a form to be posted.
POLICY AROUND THE GLOBE

PATIENTS ACADEMY

Dublin EUPATI

Trustee Jacky Boyd attended a patient workshop event for the Brittle Bone Society on April 22nd at Dublin Castle, Dublin. We asked Jacky to find out what was going on with the group called EUPATI. There seems to be plenty for us to get involved in from the notes Jacky has taken down. Full reports of the Event are on the BBS website. The BBS are keen to get as many of our member representatives to attend events like this and to get involved. (Read Jacky’s report below and be inspired:)


EUPATI is a patient-centred team of 30 organizations, led by the European Patients’ Forum, with partners from patient organisations (The European Genetic Alliance, the European AIDS Treatment Group, and EURORDIS), university and not-for-profit organisations expert in patient and public engagement, along with many European pharmaceutical companies. Their common goal is to help you be more educated and involved in your health care. The BBS will post updates on the next EUPATI event and will be looking for members to attend.” One is coming to Scotland soon!

FEATURED TRUST SUPPORTING THE BBS – BOPARAN TRUST

We would like to take this opportunity to thank all the Trusts and organisations that fund our many applications for specialised equipment. In this edition we wanted to feature an item about Freya Rock (right). Freya can now happily push her little new born baby brother in his pram thanks to getting the most suitable wheelchair. Mum said, “It’s made such a difference”.

The Rock family want to thank the generosity of the Boparan Trust for their support and the BBS for their contribution. A representative from the Boparan Charity will be attending our Annual Conference as VIP guest of the BBS.

http://www.theboparancharitabletrust.com/

SHCA AT JONES DAY

CEO Patricia Osborne attended the SHCA meeting which involves a coalition of patient-related groups and corporate members with a strong record of campaigning on behalf of people with rare and complex conditions in need of specialised care. The group usually meet at the House of Lords but due to Election restrictions had to seek suitable premises. Thanks to BBS Secretary and Trustee John Phillips, representatives from all the charities involved were welcomed to the law firm’s new conference suite to conduct the meeting. You can find out more about the meeting here:

www.shca.info/blog/blog.php

BBS SUPPORTERS SCHEME NETS £4,000

We wanted to say THANKS to the fantastic individuals who signed the pledge to become a BBS Supporter. We will unveil more about this popular new way of supporting the BBS at our Annual Conference.

Just £10 contribution per year, or you can give more (or less) – can make a HUGE difference.

Being a Supporter is for those who like what we do but may not wish to become involved in events or require any other support, they simply want to see our charity flourish and grow and provide practical funding support. Perhaps an ideal birthday gift or Christmas Present.
Our Youth Event Voice for 16 to 30 year olds took on a different theme this year. We went on an outdoor activity weekend, held at the Calvert Trust, Kielder Waters. There were 20 delegates in attendance and some new faces. Dr Jenny Walsh came along to offer support and was available all weekend for delegates to talk to.

The weekend started off rather wet and windy, however we were all kitted out with waterproofs, and off we went in our two groups. Activities included archery, laser clay pigeon shooting, driving around the beautiful estate on golf buggies, and of course the highlight of the weekend – zip wires and abseiling.

Feedback from the weekend was extremely positive, with everyone feeling they had been able to take part in activities they had never previously considered trying. Our Filmmakers Ben Wiles and Ben Shelly were on hand to capture all the activity with thanks to Mark Lambert-Clarke for his assistance. You can view all the fun and laughs by going to our YouTube channel: https://www.youtube.com/watch?v=0OqhPzY5bo

Since the runaway success of the outdoors Voice event – BBS have received calls from members to consider a similar challenging event for our 30 plus age group. If you would like us to arrange an event like this one and you fit the age bracket. Please get in touch.

Contact Coreen@brittlebone.org
We were thrilled to hear from longstanding supporter Mr Des Kealey, from Peterborough that the famous singing monk Father Francis Maple featured in a concert at the start of July. Chairman Elaine Healey attended. Des, aged 93, continues to amaze us with his drive to fundraise for the BBS. In the last year alone because of Des’ strong ties with his local community and St Oswald’s Church, along with the pupils of Oakham College have raised a total of £3261.68 for the BBS.

If there are any events you would like a BBS representative to attend – please get in touch.

Longridge Branch’s fundraising has raised another £1400 making a total of £7800 in the last year – we would like to thank John and Gertie Farmery, Jacqueline Quin and everyone else who helped raise the outstanding amount. The Longridge Branch have been outstanding fundraisers for over 40 years, since 1973, and the BBS is indebted to them for all their work.

BBS supporter Jenny Jones and her family organised a Grease themed ball at the Spread Eagle on Saturday March 21st. Trustee Andy Mills attended with Anna Williams. Jenny’s daughter Abbie Paige Jones received a proposal from her boyfriend Lewis – now her fiancé – in the photo booth on the night.

Everyone involved donated their time and fabric and Bee Crafty donated the wadding. The winning raffle will be drawn on Wednesday 14th October 2015 at Bee Crazy at 11.30am. Ticket prices are £1 for one ticket and a strip of five for £5.
THANKS TO ALL OUR FUNDRAISERS  bbs@brittlebone.org

BBS SUPERSTARS IN THE LONDON MARATHON 2015

The Brittle Bone Society would like to congratulate both its London Marathon runners on completing the race with such amazing times of 04:18:33 and 05:13:57 while raising much needed funds.

BBS RUNNER AND TRUSTEE
MIRRICK KOH - REACHES £2000

“It was an amazing experience running the London Marathon for the Brittle Bone Society – a fantastic charity which meant that every step of the 26 mile course, no matter how painful, was totally worth it!”
http://uk.virginmoneygiving.com/MirrickKoh

RICHARD DORAN - BUZZING SUPPORT

An amazing £1000.

“It felt surreal when arriving at the start line, everyone was buzzing, the support received from the crowd in the final few miles was astonishing and pulled me through, and running for the Brittle Bone Society means everything to me and I couldn’t think of a better charity to run for….. running for a great charity gave me the power to cross the line”
https://www.justgiving.com/Richard-Doran1/

WOKINGHAM FRIENDS
DO IT AGAIN FOR BRITTLE BONE SOCIETY

A group of friends who named themselves the Wokingham Friends of the Brittle Bone Society and have been fundraising for the Brittle Bone Society for many years, have recently made another tremendous donation of £1886.

LIZZIE BRAVES

NO CHOCOLATE OR CRISPS

Lizzie Owen very bravely decided to give up chocolate and crisps from Easter Monday until Wishbone day to raise money for the BBS. Lizzie’s amazing willpower has raised £375 – well done Lizzie and thank you!

DRY JANUARY FOR THE BBS

Jamie Dennis and Shelia Turnbull raised a super total of £348.60 by abstaining from alcohol for the whole of January!

JACK AND RUARAIDH 5K SUCCESS!

Well done to Jack Lewington and his friend Ruaraidh Harris both 11 years old, who successfully completed a 5k run for the BBS, despite Jack having OI – we are all very proud of them. They took part in the Edinburgh Meadows 5km Fun Run on 8th March 2015 and raised a tremendous £1162

BBS TREASURER ROBERT 40 YEAR MILESTONE!!

Wishing our hard working BBS Trustee and Treasurer Robert a very Happy 40th birthday and thanking him for the amazing £712.70 which he raised from his 40th birthday party celebrations.

EVA BAUMBACK 65 MILES CYCLE CHALLENGE

11 year old Eva who has OI challenged herself to cycle the 65 miles Devon Coast to Coast - she did it in 11 hours and has raised a brilliant £406

Eva told us “Yesterday I finished my ride. I started from Westward Ho - North Devon Coast at 7am and Finished at Saltram - South Devon Coast at 6pm. Thank you to everyone who sponsored me. It was a big challenge but I loved it!!”

PENDLEY HOUSE, HEMEL HEMPSTEAD SCHOOL HEROES

Raised £204.60 during their charity week fundraising for the BBS which included a cake sale – thank you to Anna Bennett the House Captain and everyone else from the school who took part. Also thanks for tweeting all your updates on twitter for the BBS.

MARATHON MAN - DAVID HALPIN

Ran the Chester Half Marathon 2015 in May and has raised £196.25

THANK YOU COFFEY FAMILY

£270 donated from their OI Cake party in May.

MACCONNELLS — WISHBONE WONDER!!!

Lucy and Orla MacConnell's school and after school club raised €439 from a yellow day held at the school.
Coreen Kelday has moved up from the position of Office Co-ordinator to take on the post of Support Development Officer. This role will encompass all the components of the former Support Worker’s role, however as Coreen has spent the past 2/3 years developing the volunteer arm of the society and encouraging support group activity we have merged both together. Coreen will begin to plan a series of training dates with POINT.

CONGRATULATIONS TO COREEN

FOND FAREWELL TO CHRISTINE

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 raise funds. Remember to let us know about your fundraising events and we will promote them on the BBS website www.brittlebone.org , Facebook and Twitter.

IMPORTANT NOTICE

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.

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/

BBS were very sad to bid a fond farewell to Christine Hope. Fundraising Officer Christine, is off to work for another local Dundee charity. Having worked for the BBS since 1999 we were all very sorry to lose her talents, but we all wish her every success in her new role. Christine was a very popular and helpful member of staff, seen here pictured with floral tribute from the Trustee Board. Local Trustee Yvonne Grant joined in with staff and generously treated everybody to a farewell lunch where we presented Christine, an avid book reader, - with a kindle. We are assured that Christine will keep in touch.

DATES FOR YOUR DIARY

if you need further info on any event below please contact

BBS 01382 204446 or e-mail – bbs@brittlebone.org

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<td>12 July</td>
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<td>28 August</td>
<td>Tough Mudder South West</td>
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<tr>
<td>11-13 Sept</td>
<td>BBS Annual Conference Manchester</td>
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<td>13 Sept</td>
<td>Great North Run</td>
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<td>17-20 Sept</td>
<td>Olfe AGM Oslo</td>
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<td>10 Oct</td>
<td>Glasgow Big Fun Run</td>
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<tr>
<td>5 Dec</td>
<td>London Santa Dash</td>
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