



PARLIAMENT, GOLF CLUBS & WISHBONES

By Patricia Osborne CEO

Since September 2010, your Trustees and I have been hard at work developing our strategic plan and we will launch the outcome at our 2011 AGM and Conference, at the Burleigh Court Hotel in Loughborough.

This document will be a template for all that we do in the next few years and will address issues about membership, research projects, support, funding, equipment, independent living, policy change, event planning, adult health care and so much more. As ever we need you to be a part of our growing remit, not least of which our hope to help improve fundraising at every level to make sure everyone is aware of matched giving, and help us raise our profile and encourage and promote things like Gift Aid. I hope that you will take up the challenge and become our voices at local level, act as ambassadors like our very own Lesley Ann Starrett in Northern Ireland where she is continuing to work for the Society even though she stepped down as a Trustee.

Get In Touch

Working as a team we can make sure that we explain what living with bones that break is really like. I hope you will continue to keep in touch with us, through every medium possible – through our website, sending us letters, commenting on Facebook and sending us your emails. Don't hesitate to drop me an email with any ideas or comments you have to patricia.osborne@brittlebone.org



Patricia Osborne CEO, Dame Anne Begg MP & Toni Potterton Vice Chair

Fundraising

There has been a great deal of activity at the Brittle Bone Society to increase our fundraising effort, with our first ever entry at this year's London Marathon, set to reach our hoped for target of £6,000, and our entry in 2011 to the Northern Ireland Deep River Rock Belfast City Marathon and the Dublin Marathon heralding the beginning of a campaign to extend our reach farther afield. We have been amazed at some of the fundraising projects you are holding; skydiving, tattoos, car boot sales, sponsored fasts, walk and pub crawls and can collections. I offer my thanks to everybody for your amazing contributions.

Continued on Page 2 ▶

TENTERDEN THANKS

I recently visited Tenterden Golf Club in the Kent area along with Vice Chairman Toni Potterton to present a 2010 award for fundraising to the President of Tenterden Golf club – Colonel Tim Wilson. It was a great visit and we received a fantastic welcome from everyone and made many new friends. Let us know whom you would nominate for an award this year.



Patricia Osborne CEO and Toni Potterton Vice Chair with members of Tenterden Golf Club

WISHBONE LAUNCH

We were thrilled to receive recognition from the organisers of 'World Wishbone Day' about our email campaign to every politician in the UK regarding Wishbone Day on May 6th. We urge them to wear yellow and support our work on that date. We have gained endorsement from the House of Lords – through Lord McAvoy – on a recent trip to Parliament, and welcome support and encouragement from Dame Anne Begg MP to take our message about OI to a wider audience. With messages of support from politicians across the UK now starting to come in, we will publish that list very soon!



Jill Murdoch Support Worker, Mark Ross Trustee with Michael McMahon, MSP

We are excited about the impact of our new soon-to-be-set-up Medical Advisory Board, which will be staffed by the UK's leading medical professionals, one of our Trustees and myself. We also recently enjoyed a day's training from top London Public Relations company SPADA. And we are doing all that we can to promote the work of our Charity and know that a concerted well planned media campaign is the best way to get our message across. If you want to know how you can build up relations with your local press then get in touch with us.

I am grateful that we continue to receive full backing from Professor Nick Bishop from Sheffield Children's hospital who continues to support the work we do. I will certainly keep you informed on the progress of this new Board, which will help us produce the best information/fact sheets possible and will also help us to keep abreast of the most relevant research and improvement in techniques and treatments surrounding OI.

Plans for VOICE 2011 are almost complete, applications are in, speakers have confirmed, all that is left for the event to take place with our grateful thanks to the Peter Harrison Foundation for funding it.

With very best wishes,




Lord McAvoy, Toni Potterton
Vice Chair, Patricia Osborne
CEO & John Phillips Trustee

John & Gertie Farmery with Elaine Healey Chairman



BBS CONFERENCE 2011 AWARDS

For the very first time at our 2010 conference the Brittle Bone Society presented various awards recognising the effort and achievements of many of our loyal supporters. This will now be a regular segment of our annual conference and we would like to know who you would like to nominate to receive an award this year. Here is a reminder of the categories:

- The BBS Family Affair Award
- The BBS Young Ambassador of the Year Award
- The BBS Group Award
- The BBS Inspirational and Innovative Campaign Award
- The BBS Financial Excellence Award
- The BBS Extreme Challenge Award
- The BBS Long Serving / Lifetime Achievement Award

A NOTE FROM YOUR CHAIRMAN

Elaine Healey



I hope you enjoy this edition of our newsletter, I know Patricia is keen that we move to producing more issues electronically and help keep our costs down by working towards one or two paper issues per year, so let us know if that is something you agree with? I know we are also looking at introducing paid advertisement to help fund our running costs, so if you know of a business who would like to place an ad in our newsletter then let the office know.

I really enjoyed my trip to Northern Ireland in December along with Patricia and Jill, where we had the chance to speak to friends in N Ireland and emphasise our support to be a part of a soon to be confirmed event there around August this year. I know we continue to receive applications for grant assistance and we continue to do whatever we can to raise that funding to make sure people who need help receive it as soon as possible. But, we aren't just about funding wheelchairs, if we are to make our plans to offer more services a reality we will need you to help us.

I never tire of thanking our volunteers for all they do, but as we increase our programme of events and think of new ways of giving support to you our members – I need to ask you to support our new membership programme when it is unveiled in September, I also hope you will think again about devising a fundraising campaign and I really hope to see as many of you as possible at our AGM and Conference in September this year, and remember if you haven't been to a conference before we will be pleased to assist you if we can, so do get in touch with the office when the applications for Conference open around June/July.

I am really pleased we are going for VOICE 2011 with more similar events planned, our young people tell me it's a winner and I'm sure this year will be better than before. I understand there are some great surprises in store and there will be great prize of two night midweek stay offered for 6 people at a 4 star luxury holiday chalet in Scotland donated by Home Farm Breaks. We need more help like this, so please speak to your employer or family and friends and find out what you can obtain for the BBS.

As we head towards summer I remind you that there will also be elections at our Conference in September. Two of our Trustees' terms of office will end. If you would like to be considered to serve on our Board then do get in touch. Official application information will be ready in our summer (June/July) issue. My final message to you will be, if you aren't sure if you are a signed up member, then check, if you aren't please consider joining – and don't forget without you there is no Brittle Bone Society.



Patricia Osborne CEO, Elaine Healey Chairman
and Lesley-Ann Starrett NI Ambassador

BBS Fundraising

LONDON MARATHON



For the first time ever the Brittle Bone Society has a team of runners taking part in the London Marathon. Our three runners have so far raised over £6,500 but with the cost of marathon places high we really need to raise even more. Here is what each of the adventurous trio has to say so far:

Matthew told us "The training has commenced and, with under ten weeks to go, the nerves are starting to kick in. It's a long way to run but I'm hoping I can build up the distance over the coming weeks and hopefully get around in one piece," explained Matthew. "Everybody has been very generous so far both at the quiz and through my Just Giving site but I'm still seeking more sponsorship and will be, right up until I get to that starting line".

Abigail said recently "I am so, so pleased with the fundraising. I have to say I have had some very generous donations and incredible support from friends and

family. Hopefully our target will keep on rising as well, I have lots of people still to hassle!" And despite some health problems Abi says "Please don't worry, I will absolutely be running the marathon!"

Lee told us "The training is going really well, I am running every day and last weekend managed to do 20 miles in 2hrs 40 mins. This was a double achievement as it was quite a high climb on the route. The one down side is the continuous aching of my knees and the fact the blisters on my feet make it feel like I am walking on bubble wrap... I won't mention the chaffing either... haha. The fund raising is going well also, I am getting quite a lot from the collecting tins, as well as my local pub holding a raffle, I am also organizing a quiz night. Earlier in the year I had a charity casino as part of my 40th Birthday celebrations and managed to raise over £200 from this".



Matthew Bowel
www.justgiving.com/brittlebonesocietymarathon2011



Lee Ford, www.justgiving.com/lee-ford



Abigail Player, www.justgiving.com/abigailplayer

THANK YOU!

For all your support

Our thanks go out to everyone for their kind donations to the Brittle Bone Society. Here are a few examples of those who have fundraised in the past few months.

Mrs Sylvia Copestake, her daughter, daughter-in-law and granddaughter took part in the Woman's Challenge in Hyde Park and raised £328.60. Mrs Vicky Adams took part in the Swindon half Marathon and raised £113. Mrs Jo Bennet and her children Chloe and Oli took part in a Big Fun Run and raised £145. A coffee morning was held at Korniloff Residential Home and raised £230. Linda and Amy Shemilt held a can collection in Nantwich on 20th November and collected £173.23 and also held a can collection in Morrisons in Nantwich on 8th and 9th January 2011 where they collected £580.

FUNDRAISING EVENTS

Challenge Scotland

Fun and memorable Walking, Running and Toddling events for all abilities over 12, 6 or 1 miles, all starting in Edinburgh's Holyrood Park on Sunday 5th June 2011. If you want to get involved contact Christine or visit our website.



British 10K London

The Brittle Bone Society has 18 places in the British 10k London Run, 3 of which are still up for grabs. The race route through the heart of this historic capital city is unrivalled anywhere in the world and takes runners past many of the iconic and most world renowned sights that the great city of London has to offer. If you are interested in taking part in this amazing run for the Brittle Bone Society please contact Christine to register and receive a BBS race pack.



Dublin Marathon

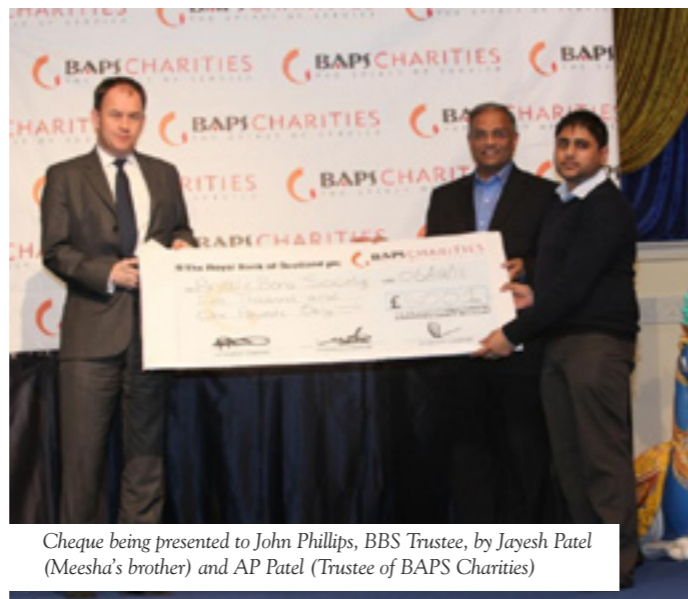
Want to take part in the "Friendly Marathon"? The Brittle Bone Society has secured 5 places for this year's event taking place on October 31st. To get involved contact Christine at chris@brittlebone.org



SPECIAL SERVICE IN MEMORY OF MEESHA

Vice Chairman Toni Potterton and Trustee John Phillips were delighted to attend the beautiful BAPS Shri Swaminarayan Mandir Temple recently in London, as invited guests to represent our charity at a memorial service in honour of Meesha Patel. Toni confirmed that John delivered a beautiful address about Meesha, expressing much about her achievements and her involvement, especially relating to the creation of our youth event, VOICE.

John said in his speech that he was struck by the warmth of the words that people used to describe Meesha, and the Brittle Bone Society was grateful to receive this very large amount of money, totalling £5,001, in memory of Meesha, who was a leading light in the charity. The Brittle Bone Society is honoured once more to be invited back to this beautiful Temple on 10th April when Trustee Simon Mckeown will take part in a sponsored cycle event run by the Temple leaders, and we are humbled that we are set to receive a further donation from this very kind group.



Cheque being presented to John Phillips, BBS Trustee, by Jayesh Patel (Meesha's brother) and AP Patel (Trustee of BAPS Charities)

WHEELS FOR THE WORLD

By Maureen Groom, Advanced Occupational Therapist



In November 2010 I went as part of a team with Wheels for the World to Nyeri, Kenya. Wheels for the World is a Christian charity which takes old wheelchairs, has them renovated at Parkhurst Prison and then sends them out to countries in Africa and Eastern Europe where poor people have no chance of obtaining wheelchairs and walking aids. They also set up workshops where repairs can be done and aim to visit each place every two years.

300 wheelchairs, as well as pushchairs, buggies and walking aids were waiting for us and the team of 4 OTs, 3 technicians plus administrators and interpreters saw 372 adults and children in 6 days and distributed over 250 wheelchairs. Some just wanted a new walking aid to replace the home-made one that they were using, and some children with severe disabilities and complex needed much more time to assess and provide the adaptations needed to ensure that they were safe and supported in the wheelchair. With thick foam and duct tape plus lots of spare parts and ingenuity on the part of our technicians, we managed to find something suitable for most of the adults and children that we saw.

I was really pleased to be able to find the ideal wheelchair for a man with Type 3 OI! Some of the children were very disabled but many were so happy to get a wheelchair and the parents were very glad of a pushchair or buggy instead of having to carry their child. Even some of the adults were carried in or crawled on all fours as they had no other way of moving around. It was very tiring but extremely rewarding. As a team we were blessed by the graciousness and patience of the people we saw – many had to wait many hours to be seen and we felt that we had done something really worthwhile.



Wheels for the World are always looking for wheelchairs and are able to repair and replace parts on most of the wheelchairs they obtain. They are always especially grateful for children's wheelchairs and walking aids as these are almost impossible to obtain in the countries where the distributions occur. If you have a privately funded wheelchair and would like to donate it please contact www.throughtheroof.org.uk If you have obtained your wheelchair through the Wheelchair service please check whether it should be returned to them.

Maureen Groom
Advanced Occupational Therapist,
Birmingham Children's Hospital



BBS WISHBONE TATTOO

Following in the footsteps of BBS Trustee Emma Lewis - On Friday 28th January 2011 three brave people were tattooed to raise funds for the Brittle Bone Society (BBS) - they were Sally, Tom and Claire.

A huge thank you to everyone who has donated so far, and to those who haven't please give whatever amount you can to support the Brittle Bone Society. Sally, Tom & Claire have so far raised a massive £1538.00.

Sally said:

"As a mother of someone with OI I know first-hand how important this charity is for people affected by the condition, their siblings and parents - especially just after the child's been diagnosed. In our case, when Emma was born we'd never even heard of OI. We were told by the hospital to go home and wait for her to die. Without help and support from the BBS in these first few months I don't know how we would've coped. Indeed Emma continues to be an inspiration to us and those around her at the age of 27, I would like to thank the BBS for helping us along the way, and I hope my getting myself a tattoo/life-long scar at the age of 60 will help raise enough to help another family."

ANOTHER TATTOO!

Michelle Dwyer-Parish

Another BBS member has also recently had a wishbone tattoo, something which means a lot to her. Michelle said "I have for many years wanted a wishbone tattoo, as it's a symbol of the OI which I suffer from. My grandfather, father, aunt, second cousins, great uncle, myself and two of my sons all have Osteogenesis Imperfecta. This will always be a part of me, and I'm proud to have such a rare condition, so I thought finally why not have the tattoo to also be with for the rest of my life – it just symbolises my condition".



Michelle's tattoo

BBSArts

TRUSTEE TAKES TO THE BOARDS

By Harry Venet

When I started at secondary school – more years ago than I care to remember – I was quite shy and my late mother had the foresight to see that joining the school Dramatic Society would probably help. I, however, didn't share her foresight and my acting career at school didn't last beyond one meeting; football was much more satisfying. So when, in my middle fifties, I joined my local amateur drama group I had no experience to draw on. I joined with my wife Rosemerry, since we found that as we approached middle age (will we ever get there?) we were involved in more and more separate activities and were looking for something we could do together.

I started small – doing props and helping with set building – but everyone in the drama group was very friendly and eventually the confidence grew. My first part in a main production was in Harold Pinter's *The Birthday Party*, which opened with me coming on stage and doing various pieces of "business" before I had to speak the first line. I really felt the power and I believe it conquered any stage fright I might have had from the beginning. Small parts were followed by larger ones. I joined other drama groups whose productions filled in the gaps in my own group's schedule, and my increasing confidence led to me to start my own music show on a local community radio station, become chairman of my first drama group and treasurer of another and do regular readings for the blind – not to mention my role as a Trustee of the BBS. Retirement is certainly full to the brim and I wouldn't have it any other way.

My "career" in drama has taken me to places I never would have gone to. I have performed at the world-famous outdoor Minack Theatre in Cornwall (incidentally in an award-winning production) and I was honoured to appear before Her Majesty the Queen as part of her Golden Jubilee celebrations. So if anyone out there is wondering whether to have a go at something they have always wanted to do but were too scared to try, I would say, "Just do it". You never know where it might take you.



Trustee Harry Venet (right) in Ilkley Players' 2009 production of Arthur Miller's *The Crucible*



SKYDIVE

By Dumfries High School Teacher, Neil Grant

In a moment of sheer madness I agreed to a tandem skydive on 20th November in order to raise money for the Brittle Bone Society. I have the absolute pleasure of teaching a pupil at my school who has Osteogenesis Imperfecta (Brittle Bones) and I would do anything that helps makes his life and that of other people with a similar condition better. Credit for making this skydive a reality has to go to a pupil at my school called Nicola McRobert. Nicola came up with the idea of raising money for the Brittle Bones Society and from there it has snowballed into becoming a tandem sky dive, race night, school fun night and non-uniform day to name but a few.

Despite virtually the whole of the UK suffering due to the snow the area where we were jumping was virtually unaffected and the jump took place. It was one of the most amazing experiences I have ever had. The moment I dropped out of the plane will be one I treasure for the rest of my life. The weather on the day was clear blue skies which was amazing given what was going on elsewhere in the country. Nicola was an absolute star and didn't show one ounce of nerves in the lead up to the jump. There are many (more likely to be nearly all) teenagers and teachers in my school who wouldn't have got in the plane let alone jump out of it at 14000ft!!

Neil & Nicola have raised a whopping total of £3083 so far from their fundraising events.

DUNDEE EAST END PANTO GROUP

The Brittle Bone Society received a phone call from Martin McKay of the East End Panto Group when he learned the local Charity had some beautiful dresses that they were not able to sell and were sadly gathering some dust. This is the second year of the group who were acting in the production of 'Jack and the Beanstalk' and the charity staff were only too happy to help out the young actors. In return the cast and members of the group raised a donation of £100 for the Society. Trustee Yvonne Grant went along to meet the cast and collect the cheque.



Yvonne Grant, Trustee with some of the Panto cast

BBS & KENYAN ADVENTURE

Exciting opportunity for ten BBS adventurers!



We have been asked by Kenyan Adventure if the BBS would like to take part in a really exciting event – a BBS Challenge Event in Africa, which would be a volunteer trip for people to work on local community projects in developing areas including Teaching in Schools, Community Building, Community Work with Children and Sports Coaching. The BBS Challenge Event in Africa would raise money for the BBS and enable those taking part to spend time with volunteer projects in Africa.

A ten day trip would cost £1,995, which can be broken down into three sections:

- £845 (cost of trip)
- £500 (approximate cost of flight)
- £650 (straight to BBS and with Gift Aid this is £812.50)

If 10 people travel, £8,125 is raised for BBS.

Due to the terrain and standards of facilities at the majority of projects, they would need to plan in advance in greater detail for wheelchair users to take part but this can be done.

Please contact Christine at chris@brittlebone.org if you would like more information. www.kenyanadventure.com

TEAM EXTREME

Friends Barry Murphy and Mark Golder started off challenging each other to try the spiciest dishes from their local curry houses, this developed into trying recipes made with Barry's own homemade chillies and eventually they began trying the hottest chillies they could find.

Recently the Guinness Book of World Records named the Naga Viper Chilli as the spiciest in the world and Barry saw this as the perfect challenge for him and his friend – collectively known as Team Extreme.

On Saturday 26th March 2011 Team Extreme each drank a shot glass full of Naga Viper Chilli sauce and they filmed the whole experience for broadcast on YouTube. This time they did not do their daredevil stunt simply for fun – they did it to raise funds for the Brittle Bone Society.

You can view the results of their stunt at: www.youtube.com/user/OfficialTeamExtreme

And support the guys by donating via their JustGiving page: www.justgiving.com/nagaviperchallenge



BBS OUT AND ABOUT

By Jill Murdoch

Since my last report I have been very busy out and about. In November 2010 I visited Belgium along with BBS members Penny Clapcott and Leah Rednall to attend the first International OI Youth Weekend. The event was organised by ZOI in Belgium and was attended by young people from all over Europe. The event gave everyone the chance to learn about the challenges faced by those with OI in different countries and to share ideas and issues. The next of these events will take place in September 2011 in the Netherlands. For more information visit the BBS website.

As mentioned in the last Newsletter I was involved in planning a Parent and Carers Information Day in Glasgow which was a joint venture between the BBS, the Royal Hospital for Sick Children, Yorkhill, National Osteoporosis Society and Short Stature Scotland. Then day was attended

by around 70 parents, carers and children and the feedback received was that the event was extremely informative and the delegates learned a lot both from the speakers and from sharing ideas with each other. We hope to work alongside Yorkhill on future events.

During February I attended Volunteer recruitment fairs, paid a visit to the Scottish Parliament to launch Wishbone Day and attended University intern presentation events connected with a study that our charity is involved with. I also met up with senior personnel from the Department of Work and Pensions regarding Welfare Reform policy affecting our members. I look forward to our next POINT meeting at Great Ormond Street in May, and it's exciting to think how much we can do, once we get the new Medical Advisory Board up and running.



Kid's Club at Parent/Carer Information Day, Yorkhill Children's Hospital



Festive Lunch in Belfast



Jill with organisers of an International OI Youth Event in Belgium

BBS HOLIDAYS

The Brittle Bone Society is aware that a huge challenge for people with OI can be finding the right holiday and all that goes along with it. We are currently researching this topic as a whole so if you have any hints, tips, suggestions which you think could help fellow members please let us know. Below are some initial findings. We plan to publish further information on the Holiday page of our website www.brittlebone.org

Home Farm Breaks

Home Farm Breaks consists of 3 fully adapted cottages fitted out to the highest spec and designed to meet your individual needs. For more information and booking please visit their website www.hfbscotland.co.uk or call 01738 441180 remembering to tell them you heard about them from the BBS. The company have kindly donated a mid-week break to us which we will use as a prize for at our VOICE event in April.



Adapted Apartment in Kato Paphos, Cyprus

Fully accessible two bedroom apartment in the Kato Paphos area of Cyprus. For availability or further information please call 01923 266184 or e-mail: angiemills21@hotmail.com



VOICE 2011

With VOICE 2011 creeping ever closer planning is well underway. This year's event, for which we have received a generous grant from The Peter Harrison Foundation, will be held at the De Vere Wokefield Park, Reading, RG7 3AH. This year the theme is Sports & Healthy Living whilst still keeping elements of last year's main topic of Independent Living. There will be the opportunity for delegates to try out some sporting activities such as Boccia, Dance and Archery while also delving into relationships and mental wellbeing. Delegates will also get the chance to have 1:1 sessions with an OI experienced consultant, Physiotherapist and Occupational Therapist. Amongst all this there will be plenty of time for fun, getting to know each other and sharing good ideas.

There will be a full report & photos in the next edition of the Newsletter and on the website following the event. Our VOICE youth events and all other meetings can only happen due to generous donations and fundraising. If you would like to donate please do so via our website, by calling the office or by sending in a cheque.

We will donate £50 to the BBS for every booking we take from one of their members.

FUNDRAISING EVENT UPDATE

Here are some events coming up this year. If you want to get involved in any of these events or have an idea for an event of your own please contact Christine at chris@brittlebone.org

09/04/2011	Street collection	Newcastle - come along and support our collectors
10/04/2011	Marathon	Brighton
17/04/2011	Marathon	Virgin London Marathon - support our runners
22/04/2011	Collection at store	Morrisons in Perth - collectors needed!
08/05/2011	5K	Bolton
20/05/2011	Collection at Store	Sainsburys Dundee - collectors needed
22/05/2011	Coffee Morning	Leeds and Grandma's Cookbook
05/06/2011	Challenge Scotland walks and runs	Edinburgh - walkers and runners needed
06/06/2011	Dress as a Skeleton day	At a Newcastle School for Wishbone Day and other events
12/06/2011	2 Castles challenge	Warwick
22/06/2011	Collection at store	Morrisons in Crewe
10/07/2011	British 10k London	London - Join the BBS team for the 10k around centre of London
15/08/2011	Three Peaks Challenge	Shropshire
27/08/2011	Cardiff Big Fun Run	Walk, jog or run to support the BBS
31/08/2011	Dublin Marathon	Marathon runners needed urgently!!
Ongoing	Car boot sales	Kent
Possible 2012	BBS Challenge Event in Africa	Participants needed!!

CONGRATULATIONS AND BON VOYAGE TO SHELLY

Sadly we are losing our finance officer Shelly as her husband Raymond who is also in the same business of number crunching, secured a top post in London. It's sad when a valued member of staff leaves, but we wish her well and know that she will remain a firm friend of the Brittle Bone Society. Thankfully one of our many office volunteers who is training to be an accountant has agreed to step in for a brief period until we complete our review of the position.



BBS UPDATES

You can now find the Brittle Bone Society on Facebook - **Brittle Bone Society (Official)** and follow us on Twitter - **@BrittleBoneUK**.

Regular news and updates will be posted using these sites and they are also an easy way for you to get in touch with us.

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IMPORTANT NEWS: NEW BANK ACCOUNT

From 1st November 2010, The Brittle Bone Society's main bank account has changed. Please make a note of our new bank details as follows and please make all future donations into the new account. Our CEO recently attended a Charity conference and was amazed at the high returns other charities were making in making best use of Gift Aid, It's so simple to do, and we hope many more of you will remember to encourage Gift Aid when fundraising for the BBS.

Account name:	<i>The Brittle Bone Society</i>
Sortcode:	83-5000
Account No:	10479306
Address of our bank:	<i>The Royal Bank of Scotland, Dundee Chief Office, 3 High St, Dundee, DD1 9LY</i>