

NEWSLETTER

"Providing support to people affected by Osteogenesis Imperfecta"



ISSUE NO. 90

SPRING 2008

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CONFERENCE AND AGM 2008

This year our conference and AGM is to be held at the Hilton Hotel, Dundee on Saturday 27th and Sunday 28th September. 2008 is the 40th anniversary of Margaret Grant and Dr Colin Paterson getting together to form the Brittle Bone Society.

As a celebration of this 40th anniversary, the Trustees have agreed to subsidise anyone attending the conference by up to £40 off their registration fees.

As in the past few years the Society is organising the Conference and AGM over a weekend and if you need accommodation you will have to make your own arrangements.

Some people have already started to book accommodation and the Hilton may not have suitable accommodation available. To find out call Maurice at the Hilton on 01382 315501. If you cannot, or do not want to, stay at the Hilton, the office can give you information about other local hotels.



If you use a wheelchair or other mobility equipment please give the hotel details before confirming a booking. In many cases hotels will have "accessible" rooms, but they will not be accessible to, for example, powered wheelchairs or other large equipment.

We have asked a range of different speakers to attend the conference but it will take some time before we can confirm the final programme.

We will update you on this when we can over the next few months.

If you would like to register for the conference there is a form in this newsletter which you can either cut-out or copy and send to the office.

On the Saturday evening we are having a disco with some Scottish music and of course there is a crèche, and activities for all the children will be provided throughout the weekend.

As you all know the AGM is officially the most important event of the weekend and as we need at least 30 voting members present we hope as many members as possible can attend.

I, the Trustees and the Staff look forward to seeing you at the Hilton, helping us to make this year's conference a great success.

Sheena
Chairman – Conference
Sub-Committee

MEMBERSHIP 2007/2008

Thanks to all the members who renewed their membership by Standing Order or by returning the membership form sent with the newsletter 89.

We would also like to thank our members who used the form to update us with new e-mail addresses or passed the form on to family and friends who used it to send us donations.

If there are any changes to your address, phone number, email or other details please let us know by contacting annette@brittlebone.org.

KAREN'S COLUMN



Hello everyone

I hope you are all doing well. As I write this I'm looking out on glorious sunshine and blue skies (we do get that in Scotland sometimes) but I suspect that by the time I've finished the rain clouds will be approaching.

Anyway, I asked myself what's been happening since I last wrote to you all.

Regional Meetings

As you will see in this newsletter I am doing a wee tour of the UK. We are having quite a few meetings. If you would be interested please get in touch to let me know.

If you've not been to a meeting before, I'm sure that you will find chatting to others and sharing stories and experiences helpful. Everyone is always friendly so no-one gets left sitting in a corner not talking to any one.

Adults with OI and their families!

Allow me to direct my attention to Adults with OI. I am often contacted with questions about health services, how to contact appropriate doctors and access to local services. Questions about medication and mobility concerns are also common. I am here to provide you with further information on any topic concerning you.

Benefits

I am regularly contacted for help with Disability Living Allowance (DLA) forms. If you're not sure if you should claim, you've got the form but aren't sure where to start, you've sent the form away and have been refused, or you're going to Appeal, have a read of the information on DLA in this newsletter and give me a phone for more information.

Education

It is getting to the time of year for the move up to high school. The difference between primary and high school can seem like a big leap. You may have a lot of questions and concerns.

Many contact me because they feel extra support is needed, or they are not sure of the best way to give the school information about OI.

Whatever your concern, don't hesitate to get in touch.

Children/Young People

Do you want to be in touch with others your age, talk to them about OI and share your stories?

We have already got several groups at different ages in touch with each other. Some exchange emails, others enjoy writing letters.

If you want to find out more, drop me an email (or ask your parents to) or give me a phone and I'll try to put you in touch.

Yearly Update

In 2007 we had 448 enquiries. This is up from 372 in 2006 and 263 in 2005. Most of these were by phone (223), but they also came through emails (93) and through our enquiry form on our website (95).

The most common topics were questions of a medical nature, surgery, medication, referral to doctors etc. Other topics we got asked about included hearing problems, dental problems and pain.

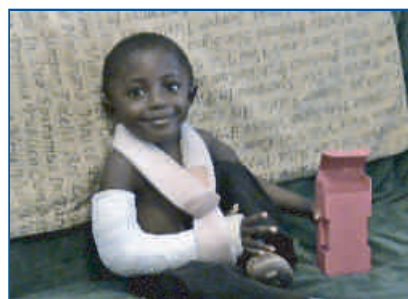
We also had a lot of enquires about Education, from Nursery through to University. Also Benefits mostly Disability Living Allowance but other benefits too such as incapacity benefit (to become Employment Support Allowance later in the year)

SUPPORTING STEVEN

Just a few weeks ago Elaine Healey, Chair of the BBS, sent a letter to our members asking for donations to support a young Nigerian boy called Steven Aghanti.

Steven has OI and needs rodding surgery, which he cannot get in Nigeria.

You, or a member, of your family may have had your legs rodded when you were younger and will know that for most people it makes a world of difference.



Elaine's appeal has been a great success. With donations from our members, Stevens family and friends, and members of the public we have raised enough money for the surgery to go ahead.

Steven will be going for his first operation at Great Ormond Street Hospital around the time this newsletter goes to print, and his second operation should be just a few weeks later.

Donations are still coming in for Steven and we will hold them in the BBS account until all his surgery bills are paid.

We will stay in touch with Steven's Mother and Aunt and let you know how things are going in our next newsletter.

REGIONAL MEETINGS

The BBS has arranged a few meetings throughout the country over the next few months. They are not just for our members, anyone with an interest in OI will be very welcome. If you would like to come to any of these meetings, or just find out more, please contact our Support Worker, Karen Whyte. You can use our freephone number 08000 28 24 59, Mon-Fri 9am – 3pm, or by e-mail at: karen@brittlebone.org.

DATE	LOCATION	WHAT'S HAPPENING?	WHO WILL BE THERE?
Sun 27.4.08	London	Family Day at Coram's Fields	Karen from the BBS. Chris Clark, Occupational Therapist Great Ormond Street Hospital
Sun 18.5.08	Belfast	Regional Meeting at the Ramada Hotel	Karen and Raymond from the BBS. Dr Faisal Ahmed, Consultant Paediatric Endocrinologist, Yorkhill Hospital, Glasgow
Sat 28.6.08	Manchester	Regional Meeting at the Hilton Hotel, Manchester airport	Karen from the BBS. Elaine Healey, Chair of the BBS Dr Zulf Mughal, Consultant Paediatrician St. Mary's Hospital

A TRICYCLE IS NICYCLE



Although the BBS spends a lot of time, effort and money on helping people get exactly the wheelchair they need, not everyone with OI needs a wheelchair.

Ben Coyne does not need a wheelchair but, at 9 years old, does need something that would help him get out and about more easily and more often.

The answer came through his Occupational Therapist, who recommended he get a tricycle.

Of course this was not just a case of going to the local bikeshop. The tricycle had to be modified, as with wheelchairs it had to be the right size, have the right wheels and the right seat.

As you can see in the photograph Ben is very happy with his tricycle.

If you think having one of your own is a good idea you can contact Christine at the BBS office to see how we can help.

LUCKY LEAP YEAR

Many people think that a leap year is something special, that it gives you a chance to do something you could not do at any other time. Well, for the BBS at least, they are right.

Once again we asked you to support our Leap Year Appeal. Just by raising £29 by 29th February you could win £30 in Marks & Spencer Gift vouchers.

As always there was a lot of support for the Appeal and you raised a total of £1,633.

We put all the returned forms in our tombola barrel and Shelly, our Finance Officer, drew the winner, who was Mrs Parr from West Sussex.

Thank you again to everyone who supported the appeal, we will be back to you in 2012!



DISABILITY LIVING ALLOWANCE

Disability Living Allowance (DLA) is a benefit for adults and children with disabilities. It is for people who need help looking after themselves and those who find it difficult to walk or get around. Not everyone will be eligible for DLA.

The applicant's entitlement is not affected by any personal income. Receiving DLA should not negatively affect any other benefits.

Here is some further information below that the applicant might find useful.

Care Component

Care refers to anything you need others to do for the applicant. This is split into High, Middle and Lower Rates. The decision as to which rate the applicant will qualify for is based on the level of care needed through the day and/or night.

Mobility Component

Mobility refers to your ability to get around (mostly outdoors). This is split into a Higher Rate and a Lower Rate.

It takes into account factors that would affect your mobility, such as the time it would take you to walk a set distance and any pain/discomfort you are in while walking.

An award at the Mobility Component Higher Rate, allows you to be eligible for the Motability scheme.

General Hints

- Read all the available information before starting the form
- Phone and have a chat with Karen at the BBS
- Keep a diary
- Be descriptive; explain where you get pain, how long it lasts etc.
- To show the difference between mobility needs during a fracture and mobility needs with no fracture, give an example of your last fracture, include the help you needed (care), how your mobility was affected (pain, exhaustion, physiotherapy, recovery time)
- Where it asks you to quantify (how often does this happen), do your best to answer the question accurately
- Where possible include letters from relevant medical professionals, sometimes and OT, Physiotherapist, or Nurse can be a good idea
- Take a photocopy before you post it
- Send it in on time!

Refused?

It is possible that your application will be refused. In this case you have two options

- 1) Revision – your papers will be reviewed again and you can submit additional evidence. This can be a good option if you feel the decision maker has not understood the effects of OI
- 2) Appeal – you will attend a Tribunal. A panel of 3 or 4 people will go over your answers and ask you questions about your day to day life.

These can be complicated procedures, so if you want more information on this or any other aspect of DLA/Benefits, contact Karen.

Karen Whyte - Support Worker

karen@brittlebone.org - Freephone: 08000 28 24 59

2008 CONFERENCE & AGM

Saturday 27th & Sunday 28th September

Hilton Hotel, Earl Grey Place, Dundee, DD1 4DE

REGISTRATION FORM

Please use BLOCK CAPITALS

Contact Name Daytime Telephone

Address Evening Telephone

..... Fax

Postcode E-mail

Please give details of everyone who will be attending and indicate whether they will be attending for one or two days.
For details on how to pay your registration fees please see overleaf.

Name	Age	Saturday? Y/N	Sunday? Y/N	Wheelchair? Y/N	Special Dietary Requirements

Will you require crèche/childcare facilities?

YES/NO



Payment Details

Conference & AGM 2008

ATTENDEES

..... ADULTS FOR 1 DAY	@ £12
SAVING £20 PER ADULT!		
..... CHILDREN (AGE TO 14) FOR 1 DAY	FREE!	FREE!
SAVING £10 PER CHILD!		
..... ADULTS FOR 2 DAYS	@ £24
SAVING £40 PER ADULT!		
..... CHILDREN (AGE TO 14) FOR 2 DAYS	FREE!	FREE!
SAVING £15 PER CHILD!		
	TOTAL	_____

Payment by cheque

Please send a copy of this page and cheque for the total above to -

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

Payment by Credit/Debit Card

As you know there has been a growing general concern about identity theft and the security of credit/debit card transactions. Therefore we no longer suggest that you make a credit or debit card payment by post.

You can, however make a credit/debit card payment by phone.

To pay by phone, call 01382 204446 between 9.00am and 4.30pm, Monday to Friday.

Please have your completed registration form and card details ready when you call, then forward this page to the office by post.

For office use only

Date processed/...../..... Processed by

Notes

HOW FAR WOULD YOU GO?

Just how far would you walk, or run, to help the BBS?

Three people have already signed up for the British 10k London Run which takes place on Sunday, 6th July 2008. That means we only have three places left!

The 10k, about 6.25 miles, run is based within the city of London, leading from Piccadilly to Buckingham Palace passing Trafalgar Square and St Paul's Cathedral on the way.

In 2007 over 24,000 runners from all over the world took part.

Hundreds of thousands of pounds were raised for charity. This year another three people still have the chance to enjoy the atmosphere, the music and maybe shed a few pounds - while making them for the BBS.

There's still time to train and prepare yourself for the 10k run, but first you have to book your place so contact Christine at chris@brittlebone.org if you are interested in taking part.

For those of you who prefer to walk around town there is an Edinburgh Christmas Walk on Sunday, 7th

December, 2008.

There is a 17 mile, about 27 kilometres, walk, a less exhausting 6 mile walk, about 9.5 kilometres, and a children's walk with an "Elves Hunt" to keep them going.

At the end you will get refreshments, a medal and a certificate, just to prove you did it. You will also get a thank you letter from us!

If you are interested in this please contact Christine at chris@brittlebone.org for more information.

A BIG THANK YOU TO...

As we have always said, the BBS is very grateful to all our members, families and friends throughout the United Kingdom and here are some of them who have helped us in the last few months:

COFFEE MORNING

The Bibbings Family from Derbyshire held a coffee morning in St Paul's Methodist Church this year and were able to raise £115 for the Brittle Bone Society which they asked to be put towards the BBS Leap Year Appeal. We are very grateful to everyone who helped for all their hard work.



BEER FESTIVAL

Kinross-shire's Round Table raised £5,010 by holding a Beer Festival in September in Kinross. The 30 real ales and 8 ciders (and lots of soft drinks) were thoroughly enjoyed by around 400 people including several members and staff of the Brittle Bone Society. A big thank you to all the Round Tablers for their hard work.

DUMFRIES AND DISTRICT ROUND TABLE

The Society was very grateful to receive £800 from Dumfries & District Round Table which they collected at the annual Santa Sleigh during Christmas 2007. Thank you to everyone who helped Santa!



FESTIVE COLLECTION

Danny Lambert-Clarke and his friend Jamie Roth, are both students at Darlington College.

Danny's brother has OI so they decided to raise money for us. They raised £151.65 for the BBS by dressing up as Santa, and his twin brother, and doing a street collection in Darlington.

GOLF DAYS

A Big Thank You to the people of the Darlington area who raised £1,655 at their 2007 Golf Day. This was the second year the BBS have benefited from their golf day, in 2006 they raised £3,300. A special thank you to Jonathan Stansfield, and Jamie Dennis, for all the hard work they do to make the golf days such a success.



A BIG THANK YOU (CONT'D)



BRAVE TO BE BALD

Catherine Potterton, a Trustee of the BBS decided to raise money by asking people to sponsor a headshave, which she did on New Years Eve. From friends, family and a page on the justgiving website she raised a total of £320!

STANDISH COMMUNITY HIGH SCHOOL, WIGAN

Brenda Murgatroyd, who lives in Wigan, collected a cheque for the BBS, £1,800 which was raised by the children. We thank them for all the hard work they did to raise such an amount. We would also like to thank Brenda for collecting the cheque and giving a talk to the school.



WOKINGHAM FRIENDS OF THE BRITTLE BONE SOCIETY

Once again our friends in Wokingham have been organising various events as well as getting donations from work places and the rotary club helped as well to raise the amazing amount of £2,900. The photo is of one of our members Natasha Okopski receiving some of the money which was raised by the local rotary club.

MAP LINK (UK) LTD

We were very lucky to receive £900 from MAP which they raised at their annual ball. The Brittle Bone Society was nominated by Karen Keachie from Kilmarnock whose son Gregor has OI.



PLAY YOUR CARDS RIGHT.... AND YOU CAN RAISE MONEY FOR THE BBS

Gertie and John Farmery are practically full-time fundraisers for the BBS. In December they ran a "Play your Cards Right" stall at a Christmas Bazaar organised by the Lions Club. This was only one of the many events they did last year to raise a total of £9,100.

That's a **VERY BIG THANKYOU** to Gertie & John!!