

NEWSLETTER

"Providing support to people affected by Osteogenesis Imperfecta"



ISSUE NO. 91

SUMMER 2008

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CONFERENCE AND AGM 2008

As you all know, this year's conference and AGM is to be held in the Hilton Hotel, Dundee on Saturday, 27th and Sunday 28th September. As this is a celebration of the 40th anniversary of the Brittle Bone Society, the Trustees decided on a subsidy of up to £40 off registration fees making the conference fees - adults for one day £12 each and for 2 days £24 each, with children up to the age of 14 free. You can get registration forms from the office in Dundee or there is one included in this newsletter.

A representative of Dundee City Council is coming to welcome everyone to the City of Dundee. We are delighted to say that Dr Keen from the Royal National Orthopaedic Hospital, Stanmore is giving a talk on adults with osteogenesis imperfecta on Saturday morning then there

will be questions and after this there is the AGM. As everyone knows we need 30 voting members to make the meeting quorate so would be very grateful to all who come to the AGM.

As some Trustees are leaving the committee, we will be looking for members who are prepared to take a role as a Trustee. We will be sending out nomination forms and information on the role and responsibilities of being a Trustee within the next few weeks. If you want further information you can call me or Raymond and we can have a confidential discussion.

On the Saturday afternoon Dr Paterson is to give a talk on the history of the Society, when he and Margaret Grant set it all up. Where would we all be now if it hadn't been for



them! Then hopefully Margaret and Dr Paterson will try to answer any questions from the floor. After afternoon tea Dr Catherine DeVile from London will be speaking about Pain. I am sure many of you will remember her being at conferences before and how helpful and understanding she always is.

Then one of our members will tell us of their experiences of living with osteogenesis imperfecta and answer questions.

On the Sunday Dr Ahmed from Yorkhill Children's Hospital, Glasgow will keep

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.

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us up to date with bisphosphonates and of course will answer any questions then there will be a talk from our Support Worker, Karen Whyte about Benefits and then of course she will answer any questions. To finish off the conference two of our "young" male members will give us the benefit of their experiences of life with osteogenesis imperfecta and will try to answer any questions.

During the talks there will be two crèches and as usual there will be plenty for each group to do and also plenty helpers there as well. We are hoping to have two seminars during the weekend – one about discussing wheelchairs and another meeting where Caroline Bowditch, a dancer with the Scottish Dance

Theatre would like to come along for anyone interested. Caroline can understand what it is like to have osteogenesis imperfecta as she has it herself.

On the Saturday evening there will be a disco which hopefully everyone will enjoy. We may have a demonstration of some Scottish Fiddle Music for a short time and we may also be lucky enough to have a demonstration from some of those who took part in the Dance seminar! It is also hoped that many people who helped in the beginning in all sorts of ways will come along to the disco and meet old friends and new.

If anyone has any questions or comments about the conference, please contact me at the office. Should the

staff not know the answer and if I am not in the office, the staff will leave a message for me and I will contact you as soon as possible. You will see that we have enclosed a book of tickets for our Annual Raffle with this newsletter. Should you wish any more tickets please contact the office in Dundee and please make sure that all the tickets are sent back by Friday 19th September. Thank you to everyone who participates in raising money for the Society and therefore helps everyone with brittle bones.

I look forward to seeing as many of you as possible in Dundee in September.

Sheena Moreland, Trustee and Chairman of Conference Sub-Committee

TO ALL MEMBERS OF BBS



My name is Victor Aghanti. I am Steven's Father. The boy from Nigeria that was diagnosed for brittle bone diseases and presently receiving treatment at the Great Ormond Street Hospital.

Steven and his family are using this medium to say

thank you to all member of the Brittle Bone Society that has contributed financially through the site to his cause to making him walk. We are really very grateful, may God bless you all a million fold. Amen.

Steven has really improved greatly since he came to England. Since the commencement of this treatment he has been doing great. Words can't explain how much we are so grateful to everyone who has been part of this great journey of ours.

Steven has done his first operation and he is recuperating very very well from it. We are preparing him now emotionally for the second operation which may come up by July 2008.

I really appreciate your concern for my son. Thanks and God bless you all, *Victor Aghanti and family.*

If you would like to see for yourself just how Steven is getting on you can visit this BBC webpage:
<http://news.bbc.co.uk/go/em/fr/-/1/hi/england/7459504.stm>

KAREN'S COLUMN



Well, what a busy time I've been having. You'll have noticed from the

last newsletter, that we had quite a few events planned, here's a wee account of how we got on.

London Coram's Fields

This was a fun relaxed day with quite a few families turning up. We were also lucky to have a few of our volunteers able to come along, both new and old friends. Everyone enjoyed chatting with each other and just sharing experiences, while the kids enjoyed playing with the toys and looking at the goats!



Sheffield Children's Hospital

SCH had a family day for all the families who attend there clinics. The day was really good fun, our Chairperson Elaine Healey and I had a wee stall for the BBS and we both really enjoyed chatting to everyone there on the day.

Here's a photo of our Chairperson Elaine Healey with two of her children who made good use of the circus

skills activities!



Belfast

Raymond and I went to Ireland, it was my first time there and we were welcomed by our Trustee Lesley-Ann. This was the first meeting the BBS had had in Ireland for a while and so for everyone it was a chance to catch up with old friends and meet many new faces.



Dr Ahmed from Yorkhill in Glasgow gave a very informative talk on Bisphosphonates and I gave a talk on Disability Living Allowance.

If you are interested in further events in Ireland (and would maybe like to help organise them), please do get in touch with the office.

Manchester Regional Meeting

This one is Hot of the Press. We've just finished the

Manchester meeting. We had a lovely time, Dr Mughal from St Mary's Hospital for Woman and Children gave a very interesting talk on Bisphosphonates. There was a wide range of families and adults there affected by OI, but as always at these events everyone found something in common.

Our Chairperson Elaine Healey started of the day by telling her and her families story. Everyone heard something they could identify with. Reports are that the kids all enjoyed the crèche and apparently they were one of the best behaved crèche groups so far!

Then after that, it's Conference Time!

The Next Step - School

It's that time of year where people are leaving school, starting school, moving to the big school etc. If you would like more information for class teachers more information on the type of support the school could provide or have any questions about the education system. Just get in touch.

University

There are many of you leaving university or just beginning on that lifestyle (lifestyle of intense learning of course!). If you want to find out more about university, (should you tell

your lecturers you have OI?), etc. Do get in touch. You might also be interested to know about something called Disabled Students Allowance, but you'll have to call me to find out about it.

Calling all University and School Leavers

So you've made it through School and or University. Perhaps you'd be interested in sharing your experiences with some young people with OI! If you are interested in being in touch with a person with OI who might be going through similar experiences to yourself and you are willing with OI who might be going through similar experiences to yourself and you are willing to share your experiences

(good and bad), drop me an email, I'd be delighted to hear from you.

Benefits

No newsletter would be complete without me saying something about Benefits. Check out my article in the last newsletter about Disability Living Allowance. All I'll say is if you are unsure about anything connected with Disability Living Allowance please get in touch.

Looking after Yourself

This applies to everyone with OI. If you have any questions about OI, access to appropriate services (Consultants, Physiotherapy, Occupational Therapy) etc,

please do get in touch.

Perhaps you've not seen a consultant for quite a few years and aren't sure who to get a referral to. Or perhaps you are bothered by back pain and are not sure if you need a referral to Physiotherapy'. Whatever the situation, get in touch with your concerns and questions.

Bye for now,
Karen Whyte
Support Worker

Monday – Friday 9am -3pm
E-mail:
karen@brittlebone.org

BRITTLE BONES HAVEN'T STOPPED JACK BEING A WINNER!

Jack Binstead, 11 years old, from Chessington in Surrey has won a Children of Courage award from Woman's Hour magazine.

Jack was just a month old when his mum, Penny, heard him scream in pain. Terrified, she rushed him to hospital, where doctors told her he had a broken right leg. Then, just four weeks later, when she was cradling Jack in her arms, she heard a crack. This time Jack's arm had broken.

That's when Penny began to suspect he might have brittle bones, and they had the diagnosis confirmed just

before Jack's first birthday. Since then Jack has had 49 fractures and is confined to a wheelchair. Jack has an eight year old sister, Charlotte.

In January 2006 Jack took up wheelchair racing, training three times a week. Then at the start of 2007 he set his sights on the Mini London Marathon in April.

Disaster struck five days before the race when Jack broke his leg in two places. Despite being in agony, he pleaded with doctors to let him race. Amazingly, Jack was the first of the wheelchair racers in his age

group to cross the finishing line.

Penny said "He completed it with a broken leg and achieved a personal best. He's an amazing and courageous young boy".



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

A BIG THANK YOU TO...

A BIG THANK YOU TO - Ruth Andrews from Rugeley, Staffordshire for all the fundraising she and her family and friends continue to do on our behalf. Having attended various fairs already this year raising more than £350, now she has been to the Alrewas Show on 19th July, will be doing the Kings Bromley Show on 26th July, a can collection at Sainsbury's Cannock on 9th August, the Whittington and Fisherwick Country Fair on 6th September and a can collection on 11th October at Dobbies near Cannock. There will also be a Christmas Fair in Rugeley in December and another 2 fairs as well. Ruth says she is not doing anything new - just tombola, name the dog, cakes sales, selling small gifts and cards which she has made and she has roped in her family and friends to help her, so if anyone is interested in doing some of what Ruth is doing, please get in touch with Christine at the office in Dundee.

THE LONDON MARATHON

David Errington from Reading ran on our behalf in the London Marathon on 13th April and finished it in an impressive 4 hours 25 minutes! Well done David and thank you on behalf of all the members of the Brittle Bone Society. So far he has raised £2,149 and you will see in his photo how he stood out in the crowd, wearing red. He also had "Daddy Cool" printed on the back of his shirt! Many thanks to David and all who supported him on the day. If anyone thinks they would like to take part in the London Marathon or to support the Brittle Bone Society please do not hesitate to contact Christine at the office in Dundee and she will do her best to help you get organised.



ST PIRAN'S SCHOOL

St Piran's School in Maidenhead sent in £61.33 from a collection at one of their Chapel Services. This came from pupils, staff and parents who attended. This is the third time the school have raised money for us and they are happy to do so because one of our members, Jane Errington is their School Secretary. Many thanks to you all.

LUCKY LEAP YEAR

You have now raised £2,606.50 in our Lucky Leap Year appeal.

SALSA NIGHT

A Salsa night was organised in Dundee on 10th May by Gill Smith, a friend of the Society and £320 was raised for the Brittle Bone Society. The staff of the Society and family and friends went along and had a really enjoyable evening. You will see Christine Hope, the Fundraising Officer of the Society, her husband Jeff and Leigh – the Salsa teacher who tried very hard to keep everyone right and did exceptionally well! Thanks to everyone who supported the evening and to Leigh as well for all her hard work.



SUE AND PAUL MACKIE

Sue and Paul Mackie from Wallington, Surrey very kindly held a can collection in Sainsbury's Wallington and raised £265 on our behalf. As you see Sue and Paul seemed to be enjoying themselves although working very hard!



A BIG THANK YOU (CONT'D)

POND PARK PRIMARY

Pond Park Primary School, Lisburn, Co Antrim, Northern Ireland held a Musical Evening and Reception earlier this year. We believe it was a wonderful day in the lovely surroundings of Hillsborough Castle and we were very grateful to receive their cheque for £750.00. Once again it is the personal connection that really helps us, but this time it is not staff. The connection is through the family of young girl who attends the school.

MRS C. WILSON

Mrs Chrissie Wilson held a Mother's Day Raffle at the Open Day held by her husband's club, the Abingdon Wargames Club. She raised £125 and the Club donated a further £50. We can assure everyone who supported us that the money will be put to good use!

WEDDING OF THE YEAR?

We are delighted to congratulate one of our members Sharon Kennedy who married Lee and now they are Mr and Mrs Woods. Sharon said "I wanted to share my wedding photo with you all. It was made especially lovely with family and friends. They included Louise Moyo and her daughter Jane. Louise is a member of the Society and we used to write to each other when her daughter Jane and my son Daniel were babies. It was lovely to see them. It was also really nice that Julie Atkins sent us a very nice gift with their best wishes.



DAWN SOLMAN

Head Girl at Cedars Upper School in Leighton Buzzard sent the Society a cheque for £1,500. The students and staff of the School nominated the Brittle Bone Society to receive this generous donation and we thank them for all their hard work in raising the money and for thinking of us.

CADBURY TREBOR BASSETT

We are very grateful to Cadbury Trebor Bassett, Sheffield for the cheque for £155 raised through fundraising activities.

DOMINIC HYAMS

More fundraising done for the Society by Dominic Hyams from St Albans. As you see in the photo Dominic played the snare drum and a wonderful evening was enjoyed by one and all. The evening was called "Salmon Chanted Evening" and Philip Salmon, the tenor, sent the Society a cheque for £7,214 for which we are all very grateful.



BRIAN MCCLURG

Pamela McClurg's husband Brian was very brave and had his chest waxed for the Society. As you will see from the photo Pamela's daughter Ashley obviously enjoyed helping the lady doing the waxing! The Family sent £539.50 to the Society and wish to thank everyone who supported them and came to see Brian suffering – for a very good cause.