

NEWSLETTER

ISSUE NUMBER 83

SEPTEMBER 2005



"Providing support to people affected by Osteogenesis Imperfecta"

Maggie Eaton

It is with great sadness that I have to let you all know about the death of one of our members - Maggie Eaton from Preston.

Maggie spent most of her life thinking and caring for other people, family and friends and was also very much against anyone being treated unfairly.

My daughter and I knew Maggie first not long after the Society began and as her problems grew with her daughter and granddaughter having OI, we in the Brittle Bone Society office did all we could to help, as the Society continues to do for all brittle bone families.

Having known Maggie for more than 30 years she and I became good friends and spent many hours on the phone trying to put the world to rights. It became very much more friends rather than work colleagues.

I really admired her commitment and energy to help anyone in need and everyone I have spoken to all have a story of how Maggie helped them, even after she knew she was so ill. She told me that it obviously had to be and it gave her time to sort everything out so she could go in peace in the knowledge that she had done everything she could to see that everyone who needed help would still get help - especially the Accused Parents Support Group. She said she was very grateful to know that this will go on from strength to strength as an independent group as long as it is needed.

I would just like to say, like many many people I will miss Maggie for her friendship and caring and she always made time for others. She will never be forgotten.

Sincere thoughts and condolences go especially to Joanne and Rachel and Maurice and the rest of the family and her close friends at this very sad time, from all her friends in the Brittle Bone Society.

Sheena Moreland

Honorary Secretary



I bought ALL my gifts from the BBS catalogue!!



Christmas Shocking!

Yes I'm afraid it's that time of year again, the days are darker, the air is colder and Christmas is once again charging over the horizon at alarming speed.

It happens every year. We know Christmas is coming but still we are never quite ready for it. For us in the office the first warning comes when we get our Webb Ivory Christmas Catalogues through the post, and they have already been here for a few weeks!

Most of you will know about the catalogue and have probably ordered something in the past. There are Christmas, cards, crackers and decorations, toys and sweets for the kids and a selection of gifts you definitely would not find on the high street.

The best thing about it of course is that everything you buy donates money to the BBS.

If you would like a copy of the catalogue please get in touch with the office, after all if you start your shopping now Christmas may just be less of a shock!

CONTENTS

Thanks To You All • Wristbands • Re-Member • Birmingham • Meet Mrs McIntyre
Smart Boy • Karen's Column • Bathing-Tray • Maggie Eaton • Christmas Shocking

Thanks To You All

In every newsletter we like to thank people who have helped us with fundraising in the last few months. Unfortunately we cannot thank everybody every time but we do try to keep a balance between individuals, organisations and the different ways they have helped to raise money.

One of the most popular ways to raise money is to have a can collection at a local supermarket, a local football match or other event, or even in your town centre on a busy Saturday afternoon. You will probably need permission or a licence from your local authority but the BBS office can help you out with the paper work.

Of course it takes a bit of organising but simply standing politely asking people for a donation is still a great way to raise money. Already this year members and friends of the BBS have held collections all over the UK and have raised more than £7,000.

For the BBS, like most charities, sponsored events are a big part of the fundraising effort. Big events like the London Marathon, Great Scottish Walk and the Great North Run are always popular but this year the BBS has benefited from other events such as the New York Marathon, golf tournaments, motor bike races and Lands End to John O'Groats on a tricycle.

In total this year there have been 41 sponsored events so far, raising more than £42,000, and there are still more to come.

Special thanks are due to the people who organise the collections and events, but we would also like to thank the hundreds of other people, members, family, friends, colleagues and others, who have taken part....**THANKS TO YOU ALL!**

Wristbands

By popular demand the BBS now have their own charity wristbands. They are available in adults or children's sizes, they glow in the dark and they only cost you £2 each.

There are now only a few hundred left so if you want one of these exclusive, limited edition collectors items contact the office as soon as possible.



Re-Member

Just a reminder that your membership for 2005-2006 is due in October.

Many of you will already pay by standing order or be life members, but if you are not sure of your membership status you can contact Annette McIntyre at the BBS office or by email to Annette@brittlebone.org

Birmingham

My visit to Birmingham Children's Hospital has by far been the highlight of the past three months. The research and liaison nurse Susan Lea who I have worked closely with, invited me to the hospital and made all the arrangements for the day.

I got to meet a huge range of families with children of a variety of ages, here's a wee snapshot of some of the highlights

- *Seeing the Dexa scanner in operation okay when you've seen one you've seen them all but I was amazed at how tiny and simple it was*
- *Talking to families and finding out what kind of support they needed*
- *Hearing about the different issues that were faced by children of differing ages and abilities I knew that OI was hugely variable between people, but it was not until I actually saw this that I could really get to grips with the notion*
- *Having medical terminology explained to me in a simple way. Let's face it we all get bogged down by the terminology at times. Dr Shaw and Sue took time to explain things to me and did not make me feel silly for asking basic questions*
- *Following the visit I had the chance to speak with someone from the hospital who deals with the dental aspect, this has been amazingly useful as this has been something that I have been trying to get more information on and speaking to someone about it is much better than reading about it.*

It really was a great visit and I learned a lot. Thanks to all the staff and families who made the day so helpful and enjoyable.

Over the next year or so I hope to visit the main hospitals and OI clinics throughout the UK. I have already visited Yorkhill Hospital in Glasgow and hope to arrange a visit to Great Ormond Street Hospital before the end of the year.

Karen Whyte
Support Worker

Meet Mrs McIntyre

Congratulations to our Admin Assistant, Annette Graham, who recently married and is now Mrs. Annette McIntyre.

The picture shows Annette and Vic, her new husband, just after the wedding ceremony.



It has taken everyone in the office a little time to get used to the change in name but now it is in the newsletter we have no excuse.

Smart Boy

The SMART awards are open to any young people aged up to 19, living working or attending school in the Stockton Borough area. Each year ten awards are made in ten categories, each recognising the effort made or achievement reached by pupils in particular circumstances.

This year Cory Atkins, who is not yet six years old, was nominated by his school for the award in the "Bravery to overcome a Challenge" category, and he won!

Anyone who has met Cory would agree that he is, as the school said in the nomination, "warm, friendly and determined" but he won this award because he is, "becoming a popular school pupil" "independent" has a "thirst for knowledge", "never complains", and "has inspired many in our school!"



The photograph was taken at the official awards ceremony when Cory, and the other SMART winners were officially presented with their awards.

Understandably Cory's parents are very proud of him, as we all are.

CONGRATULATIONS CORY!

KAREN'S COLUMN

**Regional Meeting,
Saturday 22nd October 2005 2.00-5.30
Coram's Fields London**

I'm sure many of you will have heard about the upcoming Regional Meeting at Coram's Fields (near Great Ormond Street Hospital) in London. For those of you who have not heard, this event is aimed at giving families with young children/babies the chance to get together and have a natter with new families, those with older children and all others. It looks set to be a relaxed and informal afternoon.

If you are interested in attending, give us a call so we can register you. If you have received an invitation and have not returned it (whether you are going or not) please return this immediately or register over the phone using the usual number or by email (karen@brittlebone.org)

BACK TO SCHOOL

Many of you will have started back at school recently. I hope that you are all enjoying it (is that groan I'm hearing!) If you have been having difficulty with any aspect of the education system then give me a call. Similarly, if you have found your local school very helpful in meeting your needs, I want to hear about this too.

As always, I am here to answer questions on any topic and to listen to you when times are not so good. Just call or email.

INSURANCE PROBLEMS?

Over the summer holiday period several people have contacted us about problems with travel insurance. Even some companies and brokers who specialise in this type of insurance are refusing to quote. People who have used the same company for years have been refused cover.

At the BBS we are currently researching to find out how many have been affected by this and, in particular, the reasons given for refusal. We then intend to contact the insurance companies and their professional association and if necessary lodge a formal complaint on behalf of everyone who has contacted us.

If you have had any problem with travel insurance contact me.

Karen Whyte
Support Worker

Bathing-Tray

For many years it has been difficult for me to have a bath, without incurring stress for my carers and myself, such was the inaccessibility of the property's bathing facilities.

I am now delighted therefore with my new 'Chiltern Invadex' custom-made Bathing-Tray, which has been created especially for me and supplied by the Stoke-on-Trent Disability Resource Team.

Based upon the 'Chiltern Invadex Shower Trolley', the device I have been provided with is a shower-come-bathing-tray, which is permanently fixed to the bathroom wall. When I take a bath, the tray is opened up and its legs are unfolded to support the structure at ground level. Once finished bathing, the legs are folded up underneath the structure, like an ironing board, and the bathing-tray is pushed back against the bathroom wall, secured with a metal pin device.

Now I can bathe in ease and safety.

If you are interested in learning more about the 'Chiltern Invadex Shower Trolley' check out its website as follows:

http://www.chilterninvadex.co.uk/showeringandbathing/shower_trolleys.htm

