

NEWSLETTER

ISSUE NUMBER 85

MARCH 2006



"Providing support to people affected by Osteogenesis Imperfecta"

CONTENTS

Conference and AGM 2006 • Introducing Michael • Fundraising • Regional Meeting Wales • Brilliant Basingstoke! • Seatbelts and OI
Karen's Column • The Great Scottish Walk - Edinburgh • In Loving Memory • Money For (Almost) Nothing • Membership

In Loving Memory

Peter Wells, a former Trustee of the Brittle Bone Society died on Friday December 9 after a short illness. He was 59 and was married with a son born last March.

Peter had a wide range of interests and knowledge. He was involved in the Round Table movement and was area chairman which then led him to serve on the international committee. He was also a Freemason and a founder member of West Essex Round Table Lodge. His passions included theatre drama, music and cricket.

In 2001 Mr Wells sat on the Disability Rights Commission looking at best practice for the employment tribunal service. After the age of 40 he became involved in several charitable organisations and fundraising activities for local and national charities.

Peter will be dearly missed and a dinner supporting the Brittle Bone Society is to be hosted in his honour on the 22nd April 2006. Already £3500 has been raised by those whose lives were touched by Peter, and it is hoped that a lot more will come from the charity dinner. Our thoughts are with the family and friends of Peter.

Money for (Almost) Nothing

This has to be one of the easiest ways to raise funds for the Society. Mildred and John Price, who live in Swansea, collect stamps (of all types and sizes) that they sell on. All the proceeds they raise from selling go direct to the Brittle Bone Society. Last year they raised more than £640 however they are confident that if everyone sent their stamps then they could easily double this.

The Society would like to say a huge thank you to Mildred and John for their continued dedication over the many years and also a thank you to those of you who have been sending your stamps and getting your local libraries, schools, councils and employers to join in. For those of you who are not sending their stamps get cutting! It's really very easy, whether you send the whole envelope or cut the stamp out, but be sure to leave any franking marks on it and leave about a 1 centimetre gap round the stamp. Why not ask a local council or local library or school to collect their stamps.

With the holiday season almost upon us Mildred and John will also take old coins and old postcards. The address to send your gatherings to is:

Mr and Mrs J Price, 57 Mount Pleasant, Swansea, West Glamorgan, Wales SA1 6EQ

Give it a go. Trust us, it's addictive!!



MEMBERSHIP

Frequently people contact us because their membership has expired. Many of you pay by standing order or prefer cheque. If you have any questions about the current status of your membership or wish to become a member of the Society please give Annette a phone.

Conference and AGM 2006

As stated in the last newsletter our annual conference and AGM is to be held in the Sheffield Park Hotel, Sheffield on Saturday 29th and Sunday 30th April 2006.

On the Saturday, the meeting begins at 10 am and after the Lord Mayor of Sheffield has welcomed everyone to the City and the Chairman of the Society has spoken to all those present, Karen Whyte, the Society's Support Worker will give a talk - mostly on benefits. Then after lunch there will be the AGM and after tea and coffee, Professor Nick Bishop from Sheffield Children's Hospital will give a talk on "Osteogenesis Imperfecta what's new?" The meeting will finish at 5 pm.

On the Sunday, our very own Baroness Nicky Chapman is to speak about independent living. I am sure those people who heard her speaking last year really enjoyed her talk and we are all looking forward to hearing her again. After lunch Elaine Walker, Claire Hill and Liz Knowles, specialists from Sheffield Children's Hospital are giving a talk about their work. The meeting finishes at 4pm to give members time to get home.

After each talk there will be time for the speakers to answer any questions and they will be staying for some or all of the conference in case anyone wishes to speak to them privately.

During the talks as always there will be a crèche for those up to 14 years of age, with lots of things to do and other children to play with. As always the crèche helpers will all be experienced in dealing with children with OI and there will be a crèche on both Saturday and Sunday.

The Sheffield Park Hotel is providing an evening meal on the Saturday at members own expense. This will be paid on the evening.

The AGM takes place on the Saturday and we need 30 paid-up members to be present to make the meeting quorate so the Trustees would be very grateful if as many of you as possible attend the AGM.

We look forward to seeing you on 29th April but if you have any questions please don't hesitate to contact the office in Dundee.

Sheena Moreland

Chairman - Conference Sub Committee

Introducing Michael

I joined the Society at the beginning of October as the Finance Officer and Raymond, Sheena, Annette, Christine and Karen have helped me to settle in well. Since joining I have learned a lot about the Society from my colleagues and have been working on our annual accounts and liaising with the auditors. All the contact I have had with the members has been really nice and I am looking forward to meeting more of you at the AGM in April.

My partner Anne and I moved to Scotland a little over a year ago and we are thoroughly enjoying being here as we do a lot of walking and I play quite a lot of golf and so far the weather has been very kind!

Michael Nicholson

Finance Officer



Fundraising

Hello, my name is Christine Hope and I can help you if you want to fundraise for the Brittle Bone Society. I would like to thank the many people who regularly fundraise for us. We would not be able to continue helping people with OI without your help.

Fundraising helps in two ways. Firstly it provides vital funds for the Brittle Bone Society which is very important. Secondly it helps people to learn about OI and the work that the Society does.

There are lots of ways to fundraise. Please contact me if you have any ideas and we will help you.

I thought just now I would show how you can make use of any contacts you already have.

Employers

There are many ways your employers can help-

- Could you persuade your employers to make the Brittle Bone Society their Charity of the year?
- Many companies operate a "matched giving scheme" where they will donate the same amount of money raised by fundraising - up to a limit!
- If you make a donation through your payroll, gift aid (28p per pound) will be added and the Government will also donate an extra £1. Hence a £10 donation from you will give the Brittle Bone Society £13.80!
- You could have a worst tie competition at work where the winner gets 50% of the takings and the Brittle Bone Society gets 50%.
- Or perhaps a swear box so that every time someone swears they put 20p or 50p in the box - this can really mount up.
- Or you can arrange a sweepstake for a sporting event and allocate some of the proceeds to the Brittle Bone Society.
- Many companies arrange fundraising events each year and ask their employees to decide which charity the money goes to - why not suggest the Brittle Bone Society?



Local Groups and Clubs

If you really think about it I'm sure you will find that you have contact with an organisation or that you have a friend, neighbour, relative or colleague who has contact with an organisation. The Brittle Bone Society has been supported in the past by many different types of clubs including:

Bee keeping clubs	Sewing groups	Scouts and guides
Rotary clubs	Round table clubs	Lions clubs
Woman's groups	Swimming clubs	Amateur football
Hockey teams	Golf clubs	Musical groups
Churches	Bowling clubs	Amateur dramatic societies
Schools	School PTAs	

These groups often do fundraising every year and look for different groups to support. Why not try to make it the Brittle Bone Society this year?

Regional Meeting Wales

As advertised in the last newsletter we held a Regional Meeting in Cardiff on 18/2/06. This was attended well (although not as well as we'd hoped) by a wide variety of people with OI.

The day started off by giving everyone plenty of time to talk. Then Christine gave a talk on fundraising and the financing of equipment. Karen followed this with an informal open discussion on Education where she discussed a variety of issues and responded to various questions. A benefit of having such a wide range of people there was being able to draw on the experiences of others.

We then broke for lunch and again enjoyed the opportunity to speak with others. We then used the buffet lunch as an opportunity to speak to each other about everything from education to the weather.

In the afternoon Karen gave a talk on Disability Living Allowance, going over the application form in full. One thing that came across from chatting to others was the difference between local councils and regions which is something we come across in everything we do (from sourcing funds for wheelchairs to education.)

Everyone who was there seemed to enjoy themselves and Christine and Karen definitely enjoyed the opportunity of being able to put faces to names and meet and speak to the members. It seemed that the most valuable information for our members came from swapping stories with each other and sharing experiences.

Brilliant Basingstoke!

Last year the Basingstoke Charity Relay Challenge raised £1600 for the Brittle Bone Society. This is an annual event where teams of 6 run a 50 mile cross country race. The organiser Mr Cyd Hill is very kindly once again supporting the Brittle Bone Society and hopes to raise even more money this year.

Do you know of any keen runners who would enjoy taking part in this well organised event? It begins at Emsworth Quay and finishes at Down Grange, Basingstoke with free food and drink and the presentation of trophies.

Could you spare a couple of hours to act as a marshall at one of the checkpoints throughout the race?

If you would like to learn more about this event please phone Cyd Hill on 01256 781239 or visit the webpage at:

<http://uk.geocities.com/emsworth.relay@btinternet.com/>

Seatbelts and OI

Enquiries have come in recently on the legal standing of people with OI wearing seatbelts (both in a wheelchair and without). There is no specific legislation that excludes people with OI of any type from wearing a seatbelt. In individual circumstances it is possible not to wear a seatbelt in a car but only where a medical exemption certificate has already been obtained. If this has not been obtained, it is an offence for which you may be fined or have to appear in court. It would also effect your driving licence and insurance.

While at first glance there seem obvious reasons for a person with OI not to wear a seatbelt, please bear the following unofficial guidelines in mind and consult with your doctor or specialist. A seatbelt may cause damage in a small accident (for example whiplash) however not having a seatbelt on may lead to more severe consequences.

Wheelchair Users Travelling as Passengers

This will often involve a wheelchair being positioned in the back of a car. In this instance please bear in mind:

- The wheelchair should be clamped with suitable clamps to the main structure of the car
- A seatbelt should be in place that can hold the wheelchair in place to prevent movement
- A seatbelt should be in place to hold the wheelchair user in place.
- This should happen every time you travel in all vehicles from taxis to school transport.

Wheelchair Users as a Driver

All of the above applies, but please also bear in mind:

- Air bags: many with OI have their air bags disconnected (something that should only be done with appropriate medical certification) If not wearing a seatbelt in a crash then there is the potential to be thrown from the seat either onto the steering wheel or window with no barrier to protect you.

People with OI who drive on a regular basis know there is a risk of whiplash in a small accident. But you must balance this against injuries that could occur in a more severe crash should you not be wearing a seatbelt or have your air bag disconnected.

If you have any questions about this or any driving matter, please do not hesitate to contact Karen who will be happy to help.

The Great Scottish Walk - Edinburgh. 18th June 2006

Volunteers needed! This event allows you to choose between a one, six or twelve miles walk around this beautiful city. Over 7000 people took part last year and around twenty of them were taking part to raise money for the Brittle Bone Society.

It is a fun family day out. Many of the walkers are in fancy dress. There is entertainment provided at Meadowbank Stadium where the walks start and finish and free water at stations throughout the route. Local radio station buses drive around throwing sweets to the children. The Brittle Bone Societies Under 18 Boys Team has won the trophy twice, each time completing the walk in less than two and a half hours. However many others make a day of it and the cafes in the Grassmarket are full of walkers enjoying a bite to eat! Opting for the six mile walk will give you time to have lunch and still have time to visit one of the city's art galleries or pubs!

We would love to have 50 people walking for us this year. Please contact Christine (who has completed the twelve miles three times!) or go to www.greatscottishwalk.com for more information.

Karen's Column

Perhaps the most important thing to let you know is that I have been with the Society for one whole year now, how quickly time flies. In that time I have dealt with just over 300 enquiries, and a total number of 700 separate issues, have held two Regional meetings (London and Cardiff) and have visited three hospitals (Great Ormond Street, Birmingham Children's Hospital, and Glasgow, Yorkhill). I would just like to say thank you to everyone (family members, individuals, medical staff and of course the office staff and volunteers in Dundee) for making my time enjoyable. I look forward to seeing everyone at the conference and speaking to you on the phone.

Now, down to business.

I have been contacted a lot recently from parents/health professionals who would like a pen pal for a child. It can be difficult to match up ages, interests and type of OI so I am putting out an appeal for other children to get in touch (with your parents' permission) and hopefully we can get a little network together.

And for the adults, I am still running family in contact which is basically putting families in touch with each other to get the opportunity to speak with others in a similar circumstance or to discuss a general issue, for example a medical procedure etc.

On this note, I regularly speak to families and individuals about various medical treatments from spinal fusion to bisphosphonates and put them in touch with other families and individuals. I will be happy to speak to anyone about any questions or concerns they have about the condition or the effect it has on them. I look forward to hearing from you.

As always I am here to be contacted (by phone, letter email or fax) about any issue.

Karen Whyte

Support Worker

karen@brittlebone.org

Freephone 08000 28 24 59