



the Hereditary Multiple Exostoses Support Group



NEWS BULLETIN

Hi there and welcome to our Christmas news bulletin. It has been a while since our last newsletter and as usual I thought it best that I should update you as we head towards the close of this year and tell you about the Group's plans for 2009.

It is with great expectation and excitement that I have to inform you that we will definitely be hosting our annual conference next year. A date has been set for Saturday 16th May 2009 at a venue we have visited before, the Westley Arms, Birmingham followed by a disco in the evening. The Committee are working hard to pull together an exciting and varied programme of events and further information will be posted out to our members in the New Year.

As with all ventures like this it is important that we are able, at this early stage, to have an idea of the number of people who would be interested in attending this event. Creche facilities will be provided for our younger children (under 8) and bowling for the older children. However these arrangements, including the catering, obviously need to be booked in advance and I would therefore like to ask if you would be so grateful to reserve your places by calling our Helpline number on 01438 861866 by the end of January 2009. Help us make next year's Conference a huge success. Thank you.

I would like to take this opportunity to thank you for all your help and support during 2008 and wish you a Merry Christmas and a prosperous New Year.

Christine Spencer

Volunteers needed for HME Research

As many of you know Mr Daniel Porter is a Consultant Orthopaedic Surgeon in Edinburgh who has a special interest in HME. He needs volunteers to help with two research projects he is running.

The HME alignment project is looking for families with children aged 5-18 who have HME. The aim of the project is to find out if angles at the knee relate to stature and number of exostoses. Also, to learn what the range of knee angles is in children with HME. Families will be asked to measure angles of the knee (measuring device provided) and also to provide leg and height measurements. There will also be a questionnaire to complete.

The other project is a study of wrist function in adults with HME who are 40+ years of age. This project requires a trip to Edinburgh, an examination of wrist function and also an x-ray.

Interested? We would love to hear from you - please call me, Helen Small, Research Development Trustee, on 01865 751332 or email helen.small@ox1.co.uk for more details. Thank

Donate online

Two year's ago some of you may remember that I did the Boxing Day Dip for HMESG and raised £536.40 for our cause!

I am doing it again this year. This time with the help of Ryan and a close friend. The Boxing Day Dip is a charity event where people in fancy dress swim in the sea on, of course, Boxing Day. There are several such dips held around Europe but the largest is organised in the North East of England. Participants are expected to wear fancy dress and jump into the North Sea.

This event attracts 1,000 dippers each year. Up to five thousand spectators turn out to witness the dip including the City's Mayor and Mayoress and is usually televised. Originating in 1974 the dip is one of the oldest events in the country.

PLEASE HELP ME REACH MY TARGET!

I have set up a fundraising page with Justgiving. Donating through Justgiving is quick, easy and totally secure. It's also the most efficient way to sponsor me: HME Support Group gets your money faster and, if you're a UK taxpayer, Justgiving makes sure 25% in Gift Aid, plus a 3% supplement, are added to your donation.

So please sponsor me now! Use this link:- www.justgiving.com/christinespencer Alternatively you can pledge you donations by emailing me on support@hmesg.co.uk.

Many thanks.

Please do not forget to let us know if you move house or change e-mail address! Thank you.