



the Hereditary Multiple Exostoses Support Group

Affiliated to Contact a Family

NEWSLETTER

Welcome from the Chair

Welcome to Issue 19 of the HMESG Newsletter. It is with great excitement that I can announce our plans for our next Annual Conference. This will take place on 26th March 2011 at the University of Liverpool. It is important that our meetings are held at various locations around the country and I am hoping that we will see some new faces at our Conference next year. We are hoping to have a wide and varied range of speakers and an interesting itinerary for the younger ones. Further information will be posted out to the members in November. In the meantime if you have any questions concerning the conference or maybe you have some suggestions for its content please do not hesitate to drop us a line.

We have agreed our Aims and Objectives for 2011 and these include, as always, raising awareness of the group, our continuance in supporting our members and the HME database.

We still have a number of vacancies on the committee namely Newsletter Editor, Conference Organiser and Research Development. I am sure there are members out there who would be willing to come forward and offer their time and expertise. Come on and join us – we are a friendly bunch! Please contact me if you can offer any support.

Christine Spencer

A word from the committee...

Roz Gordon, Vice Chair/Fundraiser – We would like to thank our members who have recently been holding fundraising events – without your support none of what we do would be possible at all and whilst there are too many to mention everyone by name, our thanks truly goes out to each and every one of you. With that in mind, if you are thinking of hosting an event locally, have ideas for a fundraising event or would like some help please drop us a line. We will do what we can to help and support you. We will also place the information on the website letting other members know of the events going on in the local area.

We still have our pens, calculator rulers and trolley coins for sale, so if anyone needs anything please contact us, maybe you could sell some in your workplace. Contact us for more information.

We have also got a few ideas in the pipeline at the moment, so please keep checking the website for more updates. Thanks again everyone for your support. Roz

Dawn Searle, National Contact – Hi everyone I am Dawn Searle I am the voice at the end of the Helpline if anyone needs help or just a chat. I am also the National Contact, which requires me to post our membership packs to our new members. We are updating our membership packs and looking at what should be included in there for our members. If any members have any ideas for inclusion we would welcome your ideas..

To cut down on the photocopying and printing costs incurred on producing these packs a £10 joining fee payable upon registering with the Group will be introduced from January 2011. It's a small price to pay for all the information that is in the pack.

I look forward to everyone coming to our next exciting conference on March 26th 2011 – make a note in your diary. Please come and support it there are going to be some great speakers giving updates regarding research into HME.

Many thanks
Dawn

Stephen Harding, Treasurer

Many thanks to all of our supporters of the financial donations that have been made. The end of summer holidays heralds the looming deadline of 31 October if you have a Tax Return to complete. However, even the chore of this task can be lessened with a donation to the group. If you calculate that a tax refund is due from the return then an 'X' in box 12.7 will mean that the sum will be donated to the group. However, the sum can be shared by filling in an appropriate amount in box 12.8. In either case the charity code of "XR 57 119" will need to be entered in to 12.9 and an 'X' in box 12.10 will even give the group GIFT AID tax relief as well as your donation. Unfortunately if your return suggests that further tax is payable then I am afraid that the system does not allow us to assist you!!

All of you not troubled by Tax Returns can still donate – we accept cheques of any kind and can even convert unwanted foreign currency so dig deep!

Hope your summer has been a good one and we thank you for your on-going support – financial and otherwise.

Stephen

Brian Gordon, Website Designer

In the coming months we are hoping to be able to accept donations via online pay sites these will be linked through the website. We are hoping it will speed up the transfer of monies raised from members fundraising events and purchases as well as making it easier for people to support us without having to wait for local events or conferences – As soon as we have more information we will let you know.

We still have the message board on the website so if anyone has a question or wishes to just chat with others on there it is available to all members and you may find some answers to your own questions on there too.

Tina Read's report on Preimplantation Genetic Diagnosis (PGD) for HME has been updated on the website if you would like to read about it then you can find it on our website under the Research tab in the menu.

Please keep an eye on the ticker at the top of the website for all the latest news.

Brian

Lynda Tams, Secretary

My name is Lynda Tams and I joined the HME Support Group over 10 years ago when my son, Adam, had been diagnosed with the condition. We thought there was nowhere to turn for help. In 2008 the role of Secretary became available and it was at that point that I decided to give something back to the group for all the help and support they had given us as a family over the years. My role is varied and includes arranging teleconferences, typing up minutes of the meetings and thank you letters. I work full time and manage to fit the role around my day job.

There are a number of vacancies on the committee at the moment and I urge people to seriously think if they can help the group in any way. The work the committee do is voluntary and to be honest my role does not take up too much of my free time. Come on join us, we would love you to come on board and bring your ideas and suggestions to the meetings. As a family we have made some very valued friends within the group and I am sure you can to.

Hope to see you all at the conference in March and hope you will support the hard work the committee do.

Lynda

Stephen Watson, Trustee and Committee Member

I have been involved in the HME Support group since the beginning. I have had the condition since birth having inherited it from my father. I have a sister who has it but my other two brothers and other sister do not. Up to the age of 30 I was regularly in hospital having lumps taken out of most of my joints eg knees, ankles and fingers. I have not been in since although as I am getting older they are beginning to "grate" particularly around my knees. I have two children; Hettie aged 20 and Elliot who is almost 17. Unfortunately they both have the condition, which I am very conscious of. They both deal with it very well. Hettie has been in hospital quite recently having a couple of lumps removed from her knee.

Until I knew of the group, which wasn't all that long ago, I was utterly convinced that we were the only family that had the condition. It was not until we went to a genetic clinic in Manchester that told us about the Support Group that we began to realise we were not alone. Since then we have been made aware about other families right across the county who also have the same condition.

In having children my wife, Katie and I were almost convinced that I would pass on the condition. This took a tremendous amount of thinking and talking about. As it was that's how it turned out. At least were expecting it. My sympathies are with those where it comes "out of the blue" particularly. It is in those circumstances where I think the Group is so important.

Stephen

Judith Fletcher, Overseas Contact

New overseas members have dried up somewhat since April last year. We had previously been averaging about one per month. We have over 80 overseas families registered with the group. However after the last newsletter was circulated to those overseas members I received 16 undeliverable messages! If you are overseas and you are now reading this online remember to let us know if your email address changes. That way you don't miss a newsletter and you can read it hot off the press!

Judith

Patron for the Group

At the moment the group does not have a Patron as Jodie Prenger's term of office has expired. The committee would be interested if anyone can suggest someone we may be able to approach to raise awareness of HME and support us a charity.

Newsletter

If any member has an item they would like put in the newsletter just drop us a line. The newsletter is for the members and we need your input, so come on get those thinking caps on and send your ideas to the group we will do our best to get them published.

Change of Address

Please don't forget to let us know if you change your home address, email address or home phone number. We won't be able to find you to send out important conference information if you don't keep us updated.

Disclaimer: Please note that any views expressed herein, by individual group members, are not those of the Group as a whole and separate entity. The HMESG cannot accept responsibility for any goods or services mentioned in the Newsletter