



*the Hereditary
Multiple Exostoses
Support Group*

affiliated to Contact a Family

NEWSLETTER

Hi everyone and a warmest greetings to all of our new members. Welcome to our first newsletter of 2008.

It is with deep regret that I have to tell you all that we will not be hosting our usual annual Conference this year mainly due to a shortage of funds in our General account. Donations to our cause have been down this year partially because we do not have a Fundraiser in post. I am hopeful that a member will come forward this year, which will enable us to have a Conference in 2009.

We are, however, governed by the HMESG Constitution, which states that we need to hold an AGM. All our members are invited to attend and vote at such an event. Full details of the AGM are enclosed with this newsletter. This is normally a very short meeting usually lasting approximately 15-20 minutes. If there are any members who wish to join us could you please let me know as soon as possible so that the necessary catering arrangements etc can be made.

We still have a number of vacancies on the Committee which have not yet been filled. Anyone wishing to nominate himself or herself should do so to myself by Friday 18th April at the very latest.

Our new HME website is now up and running but still under construction. I would love to have some feedback from our members on the new site including any ideas/suggestions for future content.

It will come a shock to most of you, as it did to me, when I heard the news that our Secretary, Barbara Gibbs would be stepping down from her role at our next AGM. I have worked closely with Barbara since my commencement as Chair and have come to rely on her great organisational skills. She has certainly made my job easier by taking on a multitude of tasks and I know I can speak for you all when I say she will be sadly missed. All the best Barbara!

As always, we welcome comments and suggestions and any offers of help that you might be willing to give. This is your Group - thank you for all your support!

Here's to a great summer!

Christine Spencer

The Editor

Welcome to Issue 17 of the HMESG Newsletter. 2008 is going to prove a challenging year for the group as we strive to raise much needed funds to boost our sadly depleted bank balance to enable both the continuance of our ongoing support work and database project work (see page 3). The shortage of money has also meant that, regrettably, the HMESG is unable to host a Conference this year, which is a real shame. I know from personal experience the value of getting together with other people in the same boat for a chat and reassurance and it is a great pity that we are not able to offer this opportunity to all our members, new and old, this year. Let's all try and do our bit and make sure that the money flows in this year so we can stage our best ever Conference next year.

It is also with great sadness that we have to say goodbye to another member of the Committee. Barbara Gibbs has been Secretary for two years and if she thought she was in for a quiet retirement how wrong she was! Barbara has been responsible for setting up meetings, working closely with the Chair and writing thank you letters to all our fabulous fundraisers and her diligent and hard work has been invaluable to the group. Thank you, Barbara, we will miss you.

We hope that you enjoy reading this newsletter and find it both informative and interesting. And remember it is your newsletter, so please do send any comments, ideas or articles you would like to see included. You can contact me on w.tollman@btinternet.com.

HMESG Committee

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Thank you

This edition of the HMESG Newsletter has once again been produced and distributed at no charge to HMESG by Dominion Business Supplies Ltd, Medway City Estate, Rochester, Kent.

The HMESG would like to extend its most grateful thanks to Simon and Rachael Garrett-Tuffney and everyone at Dominion for their most generous ongoing support and help in this matter. It is much appreciated and will enable the money saved to be transferred to our Research Fund for the good of all our members. Thank you.

Would you like to take part in UK HME research?

Every so often we get to hear about research projects and would like to let you know about them so that you can take part if you choose. If you would like to be on our new Research Register, please complete the enclosed form. The information will be kept, confidentially, by the HMESG and used solely to send such details on behalf of researchers. I will be co-ordinating this register and look forward to hearing from you!

Talking of researchers, recently I met with Mr Daniel Porter, the Orthopaedic Surgeon who is collaborating with us on the HME Database Project and learnt that he has the most productive clinical research output in HME of any researcher worldwide.

We are so fortunate to have had Daniel's support in the Group since its inception and to be working with him on the future project of the Database. It is hoped that the Database will be embraced by sufferers of HME as a place where they can store an accurate record of their medical history while providing important information about the condition and its effect on daily living.

You can find a list of Mr Porter's publications on our website for your information and if you go to <http://ukpmc.ac.uk/> and enter the title of any particular paper, you can usually read it in its entirety, or at least a summary. Please note that these are scientific papers and not in layman's terms, but can still prove interesting reading.

Helen Small, Research & Development

HMESG Youth, Rob Searle

Hello Everyone. I hope you have all been keeping well and staying out of trouble! I have been contacted by several Youth Members saying how we all need to meet up this year as the HMESG is not holding a Conference. So I am going to look at some possible options and would welcome any suggestions to put forward to Christine about this. This will be a family get together where Youth Members can do our own thing when and if we all want to. Two years ago (yes, it really was that long ago!) a group of us went to Butlins

in Skegness and everyone had a fantastic time. We took part in loads of activities including mini golf and go-karting. It was great to meet up and have a right laugh over the long weekend we spent there. Please do not hesitate to contact me on ninja60@btinternet.com regarding suggestions on where we could go so we can get something sorted quickly! But please bear in mind that it has to be fairly central so all members can get to it without too many problems! Could I ask everyone to please e-mail me

if you are interested so we can arrange dates if you are on holiday etc... as we will be looking at either the Summer holidays or October half term, depending on when you and your families are all free. I am also working on a website for the HMESG Youth Group, which should be ready to go live very soon. I think it is a good idea that we have a website so you can all check it regularly for any updates with the Youth group. I will let you all know the site address once it is all up and running.

Notice about the 2008 CONFERENCE and AGM

It is with regret that the HMESG will not be holding a Conference this year. This decision was not taken lightly but, as you can appreciate, the cost of hosting such an event is high and was beyond our current financial means. Unfortunately, donations to the HMESG have been down this year, partly due to our lack of an appointed fundraiser, so if you feel you could fill this position and help us ensure that we have a 2009 Conference, please contact Christine Spencer. The Conferences are a valuable forum for meeting friends with similar issues and sharing ideas and the speakers are always fascinating. Please help us make sure that 2009 sees the return of the HMESG Conference!

Given our status as a Registered Charity, we are, however, bound to hold an AGM. This will be held on 26th April 2008, at 4.30pm at the Innkeeper's Lodge in Beaconsfield. The AGM is open to all members who would be most welcome. It is normally a short meeting lasting approximately half an hour and its purpose is to formally ratify the accounts and elect trustees and new committee members.

Light refreshments will be available and we would ask you to contact us through the usual channels, as soon as possible, if you are planning to attend. Obviously, there will be the opportunity for social discussions and chats after the formal meeting has concluded.

Innkeeper's Lodge,
Beaconsfield,
Aylesbury End,
Beaconsfield, Bucks,
HP9 1LW



Road Directions

The hotel can be easily reached from the M25 via Junction 16. Take the M40 west exiting at Junction 2. Head for the A40 via the A355. At the roundabout turn left onto the A40. It is located at the White Hart on Aylesbury End.

Rail and Air Directions

Less than a mile north along Aylesbury End is Beaconsfield Station, only 30 minutes from London Marylebone. Heathrow Airport is just off Junction 14 or 15 of the M25 depending on which terminal you require.

If you would like to stay overnight, rooms can be booked either via the website: www.innkeeperslodge.com or alternatively by calling the hotel directly on 01494 671211. The rooms start from £59.95 per room per night at the weekend.

Lynne Colvill, Conference Organiser

GIG Parliamentary Reception 26 February 2008

First of all I would like to emphasise that it was definitely not me (nor, indeed, my husband) who organised the roof top assault on the Palace of Westminster the following day, although, during our visit, we did see some quite shifty looking characters on the TV monitors. I was reliably informed, however, that they were actually members of the House having a debate on casinos!!

We arrived in London at Charing Cross station and had a short, pleasant walk down Whitehall to Westminster. A kindly policeman directed us to the public entrance, where we and our bags were searched, given a sticker and admitted to the building. John and I had visited a few weeks earlier with our Active Retirement Group and knew how to make our way to the restaurant for a very good, inexpensive cup of coffee!

At 4 o'clock, we were directed to the Members Dining Room. This is a lovely long room, overlooking the river Thames. It had tables laid up with cloths (but alas no food), chairs placed all around and a fantastic carved ceiling. If there was no food, there was certainly wine and soft drinks being offered in plenty. The room soon filled up, but not uncomfortably so, with representatives of many rare illness groups. Some wore badges - I made John and I one each with our HME logo on, and I was asked many times what the initials stood for. In return I asked other people which organisation they represented but as with Hereditary Multiple Exostoses, most of the names were long and difficult to remember, so I am not much the wiser on that point. I had a long talk with one lady and although we sympathised with each other, and swapped symptoms etc. neither of us got to grips with the relevant names of the condition suffered. As I was leaving she said, "what do those initials stand for again"?

After being welcomed by our host Evan Harris MP for Oxford West - a doctor, who is obviously a champion of the cause of rare diseases, we were addressed by Alastair Kent, Director of GIG. We were told that a rare disease is a condition which affects less than 1 in 2000 people. There are currently between 6000 and 8000 identified Rare diseases, but this number is continually growing. 3.5 million UK citizens may currently be affected by a rare disorder.

Patients affected by rare diseases are hugely diverse but many of them have similar issues and concerns such as:

- Difficulty in securing a diagnosis and in finding knowledgeable medical specialists
- Lack of co-ordinated care
- Isolation - many patients affected by rare diseases don't know anyone with their condition
- Access to education, support and employment

His general advice was that support groups must work and pull together for the cause of the common good.

A lady, who I have to be honest and admit I couldn't quite understand, followed this with a short talk. I couldn't hear her very well either, which didn't help. However, she was followed by a talk given by the mother of a 13 year old girl who has a very rare illness, and the gist of her talk was that support group members really do need to act together. In her particular case, the parents of 6 girls, with their daughters, meet up twice a year for a social event.

She said their mutual support gave the girls and the parents immense confidence. The reason that no boys were involved was that there are only 4 known such cases in the UK! Sorry, I never did find out the name of the condition.

Two hours passed very quickly and at 6 o'clock we had to make our way back to the station. I don't suppose I shall ever meet those people again but it was, in a strange way, comforting to know that we are not actually an isolated group - of course we have our own particular rare disorder but there are groups like us all over the country, struggling away to raise money, to raise awareness and to hope one day for a cure.

Barabara Gibbs

And now it's time to meet another of our Committee Members...

Hello, my name is Brian and I am the Web Designer for the HME web site.

I'm 31 and married to a wonderful lady called Rosina. We've been married for 4 years and February 29th was our first official 1st Anniversary!

We live in Preston with our 2 cats, 1 dog and hamster. Rosina is currently looking after me as I had an operation last year on my ankle that has put me out of action for quiet some time. When she's not helping me she can be found either at the gym or helping her disabled aunt with her cousins. We do try and lead an active lifestyle despite my condition deteriorating over time due to the HME and the effect it has on me.

I was diagnosed with HME at the age of 4 or 5 when my parents noticed the 'knobbles' on my knees were causing me to go "knock kneed" and took me to the hospital where they diagnosed me as having, as it was then called, extra bones. Well that's what the doctors told my Mum and Dad...I get it from my father. I've had roughly 9 operations to remove the lumps and bumps that have grown over the years the most recent been the one mentioned above in my ankle that was quiet extensive and intrusive surgery.

We had always assumed, myself and my wife and family, that HME just affected me and my father as we couldn't trace it any further than him, and the doctors were less than helpful with the condition and causes. They just said when I stopped growing they would stop growing too. Alas, as I'm sure a lot of you are aware, this is not the case and I have noticed them still popping up all over the place.

I joined the mailing list when I found the group on the internet, and when they were asking for a new web designer to come forward, I felt that I had some spare time and the knowledge needed to make a go of it. I also wanted to be an active member of the group and have already attended two of the meetings so far. Hopefully I will be able to get Rosina to come down to the next one as well as she has always been unable to attend previous gatherings due to prior commitments, so we're both looking forward to meeting lots of new faces and people.

Bri

Travel Insurance & Medical Conditions

People often find that they can pay more for travel insurance if they have a medical condition, especially a serious or rare one, and in some cases find that some insurers will not provide cover at all. This doesn't mean insurance isn't available, you just need to shop in the right places.

The basic fact is that travel insurance is designed principally to help people cope with the costs of needing emergency medical help while abroad. This is by far the most costly risk people typically face when travelling. The costs can be especially high in countries that do not offer free health care, like North America. But in Europe, emergency medical repatriation to the UK can cost many thousands of pounds.

Insurers face high potential costs from these medical risks, so if you present insurers with a higher likelihood of making a medical-related claim, as anybody with a serious medical condition will, then you will pay more for travel insurance. You may also need to contact a specialist insurer who has experience of medical underwriting to cover your holiday.

The most important thing for customers with a medical condition to remember

when they want travel insurance is to plan ahead and shop around with the right providers. Here are some tips on finding the right insurance:

Don't leave insurance until the last minute and rely on the mass-market insurers, or tour operators that sell insurance as part of a package holiday. Many of these won't be able to cover medical conditions.

Go to specialists - more and more insurers have specialist knowledge of medical conditions and can offer you cover.

Shop around - insurance policies differ on both cover and price, so compare the quotes you receive to make sure you get the best deal.

If you have any problems trying to find specialist insurers, use a broker. They can do the hard work for you.

You can contact a broker through the British Insurance Brokers Association, who host a website and a dedicated customer helpline:

Telephone: 090 1814 0015

Website: <http://www.biba.org.uk/>

Email: enquiries@biba.org.uk

Editor:- I personally have never had any problems getting holiday insurance cover for my son George, even when he was waiting for an op when we took out the cover - perhaps I have been lucky. Let us know of any problems you have had in this area!

Fundraising

Since the last newsletter, so many of you have, yet again, been busy undertaking fantastic fundraising efforts on behalf of the HMESG. A huge thank you to everyone who continues to raise money for the group - your efforts are truly appreciated and especially important at this time given our current limited funds. If I have missed anyone out below please accept my sincere apologies and thank you.

The children have been busy again! **Ryan Spencer** raised £35.80 by holding a Halloween raffle at school - well done Ryan and thank you to Mrs Lavelle, the Headteacher who provided a 'spookycraft' prize. Not to be outdone, Ryan's friends **Lauren Scrafton** and **Aimee Trewick** ran a cake stall at East Herrington Primary School raising £50.00. Congratulations girls and many thanks to your Mums and Aimee's Gran for helping with the baking! **Bethany Tollman** made a speech to over 200 parents at the Roseacre Junior School Year 6 Leavers Concert explaining the effect of HME on her brother, George. As a result a collection of £154.00 was made. Well done Bethany!

It is especially touching and appreciated when families think of the HMESG at their time of great sadness following the loss of a loved one. **Mavis and Griff Lloyd** (Grandparents to Samuel Lloyd) donated £50.00 in memory of their Aunt, Dorothy Wilkes and **Peter Wilkes** also donated £25.00 in her memory. Many thanks to Audrey Georges and Wendy Hunter for their immense kindness in thinking of us at this difficult time. Similarly, **Mr and Mrs Hammond** sent £20.00 in memory of their daughter Amy who they are sure would have approved of our Support Group. Thank you very much.

It is equally as appreciated when the HMESG is remembered at times of happy family celebrations and **Mary and Peter Dowse** (great aunt and uncle of George Tollman) have sent cheques totalling £422.50 for the HME Research Fund as a result of donations in lieu of presents on the occasion of their Golden Wedding Anniversary. Thank you very much and many congratulations to you both on your special occasion.

Sheila Parkes raised £96.20 following a coffee morning where she also sold, amongst other things keyrings and pens. Thank you for your hard work. The Perfect Light Lodge of Instruction, at the request of **Alan Bernard**, sent a donation of £70.00

We continue to have some very fit (and mad) benefactors! **Gaynor Baker** raised £200 running the Great South Run on a very wet and windy Autumnal Sunday morning. Congratulations on a marvellous achievement and thank you Gaynor!

Ian Fraser Associates is busy preparing to hold a Charity Golf Day at the Berkshire Golf Club in Ascot. There are 18 teams of 4 competing and all proceeds from the day are being split between Jeans for Genes / HME Support Group, NSPCC and Nordoff-Robbins Music Therapy. Good luck to all those taking part and we hope the weather stays fine! We look forward to letting you know how much is raised in our next edition. In the meantime, thank you very much to **Ian Fraser** and all his colleagues.

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

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