



Living for today, planning for tomorrow

HAEUK

Newsletter

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HAE UK is an Association of HAE Patients, working together to improve the situation for all HAE Patients in the UK

To all our HAE UK friends

So much has happened since we sent out our last news letter.

On 24th November we held our Manchester Patient Day. We hope these pictures bring back happy memories for our almost one hundred attendees!

Dr Hilary Longhurst talked about HAE management, Specialist Immunology Nurse John Dempster talked about home therapy and Dr Matthew Helbert gave a presentation on Quality of Life issues and how it might impact on the treatment and the lives of our members.

So many people said how great it was to meet up with other HAE patients who really understood their situation. We want to say a big 'thank you' to all our long term friends, 'the oldies' who were so good at encouraging and supporting 'the newbies' who are still trying to get good HAE management in place.

HAE UK is growing at a great rate. We now have more than 160 members on our Database. Please encourage all your HAE family members to register for the confidential database and to join our HAE UK facebook group.

HAE UK is a very small organisation run in most part by two or three volunteers. In order to meet the growing needs of our membership we have to develop a more formal structure. We are in the process of becoming a Registered Charity and Company Limited by Guarantee. Our Trustees will be John Price (Treasurer), Ann Price (Chair and Patient Contact) and Barrie Hurley (Business Advisor and Fund Raiser). We are very glad to welcome Barrie to the HAE UK team. Barrie brings a wealth of knowledge and experience to our HAE UK Team. We will be employing Rachel Annals for 6 hours a week as our Administrator and Website, Data base and Facebook manager. This is in addition to all the many hours Rachel works for us as a volunteer.



Your HAE UK team needs YOU!

To volunteer your skills to help build our HAE UK support, please e-mail Ann on: ann.price@haeuk.org

Also please can you consider writing the story of your own HAE journey, from first symptoms to where you are today. E-mail Ann if you would like to share your story.

HAE Management within the NHS Reforms

We are all aware of the wide variation in the level of access to HAE management and medications in different areas of the country - this is our infamous post code lottery! Because HAE medications have been funded locally by individual PCTs, many patients have been denied access to some of our HAE medications and denied home therapy. HAE UK has been concerned that the situation could be even more difficult with the new GP consortiums and the budget cuts.

HAE UK have benefited greatly this year from the help and advice from Rare Diseases UK (RDUK). RDUK have maintained a top level dialogue with the Department of Health to represent the needs of people with rare genetic conditions.

We are working on four important initiatives that should improve our access to good HAE management.

Dr Hilary Longhurst has headed up a team to write an Evidence Based Integrated Care Pathway. This document will be published early in 2013, and it should inform practice in HAE centres around the UK.

HAE UK has commissioned the writing of an updated UK HAE Consensus guidelines for the Management of Hereditary Angioedema. Hilary is heading up this project and Ann is the patient representative on the working party who will produce the updated document. Key statements about HAE management will be circulated to key stakeholders for their comments in preparation for producing a true consensus of opinion. In January we will be circulating these key statements to all HAE UK members so that your responses can inform the final document. This new document will help to improve equity of access to best HAE treatments. We hope that our new Consensus Document will be printed in the first half of 2013.

We are delighted to say that we now have a draft Service Specification document that is being released for public consultation. We will be sending an important e-mail about this to each of our HAE UK members, explaining the way in which you can play a vital part in achieving final approval for the HAE Service Specification.

The Clinical Reference Group has also submitted a QIPP recommendation promoting the rational for making Home Therapy an available option for all suitable HAE patients. We are now waiting to see if this will be accepted.

We hope very much that these initiatives will improve access to treatment for our HAE community in the future.



Wishing you all a very Merry Christmas and a Happy and Healthy New Year. From your HAE UK Team