



Living for today, planning for tomorrow

# HAEUK

# Newsletter

ISSUESIX  
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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

## Dear HAE UK Members

It was great for so many of us to meet up in Manchester in November, and it's always good to hear from so many of you on Facebook and by e-mail.

Some very important things are happening for our HAE Community in 2013.

We have HAE Awareness Day on 16th May. Please continue to send your HAE Awareness smiles via: [www.haeday.org](http://www.haeday.org) and use the day for talking about HAE with family and friends. Rachel will be involved in producing a HAE Awareness video with HAE International, so look out for news of this.

HAE UK has been involved over the past year with producing National HAE Service Specifications that will be commissioned centrally from April 2013. Please go to our HAE UK website to view or download the document. **Central Commissioning is the single most important thing that has happened to date for our HAE community.** It will take some time to fully implement, but basically the document defines HAE services that will be funded by the commissioners to be delivered via HAE Specialist Centres that meet with specific criteria for service delivery. Central commissioning will hopefully end the post code lottery regarding access to treatment that we have experienced with PCT funding.

Another important document that is soon to be published, is Dr Hilary Longhurst's '**Evidence Based Integrated Care Pathway for the Management of HAE**'. HAE UK gave the patient perspective in the writing of this document and we are funding open access on the world wide web. This document details Bart's and the London's approach to every stage of HAE management from diagnosis through to every aspect of care and ongoing HAE management. This paper will soon be available on our website.

A third key document will be coming within the next few months. HAE UK has commissioned the writing of a **Revised UK Consensus Document of Guidelines for the Management of Hereditary Angioedema.** There has been so much progress in the management of HAE over the last decade and this has necessitated the updating of our original 2005 Consensus Document. HAE Patients will be consulted in the process of producing these new guidelines, and we will be contacting our members about this in the near future.

**These three documents will be key to improving the lives of HAE patients in the UK.**

## IMPORTANT ADVANCE NOTICE

We are very happy to say that we will be holding a HAE Patient Day in London on 16th November 2013. We have no further details yet, but please keep this date free in your diary. Our speakers will include Dr Mark Gompels, Dr Hilary Longhurst and Specialist Nurses Christine Symons and John Dempster. We will also have Tony Castaldo and Henrik Boysen from HAE International coming along to give us a world wide perspective on HAE.

We will send out invitations to all our members at a later date.

From the response to questionnaires at our Manchester meeting, and from a wide consultation with specialists, the view of the vast majority was that our main patient meetings should be for adults and young people over 16 years of age.

We are planning to have a HAE UK Facebook group for younger HAE patients so that they can share their thoughts and experiences of HAE, please contact Rachel with any comments or suggestions for this group.

We also think it would be great if any HAE families want to organize informal gatherings so that their children can have fun together and share their experiences as they want to.

**We look forward to seeing many of you in November. In the meantime, if you wish to volunteer to help build our HAE UK support, please e-mail Ann on: [ann.price@haeuk.org](mailto:ann.price@haeuk.org)**

**All best wishes from**

*Ann & Rachel*