



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

We hope you are keeping well. We know that many of us are still struggling to get HAE management that will enable us to achieve a good quality of life, and we want you to know about some things that are happening to try to improve our situation. We also thought we would let you know what HAE UK have been doing in the last few months.



World HAE Awareness Day

16th May was World HAE Awareness Day and we had some activities to raise the profile of HAE in the UK:

- We contacted all our Immunologists and Immunology Nurses asking them to display a HAE UK poster in their clinic waiting room, and to make our fliers available to their HAE patients.
- We sent posters, fliers and bracelets to all our members asking them to wear their bracelets and to take the posters and fliers with them to their next clinic appointment and ask for them to be made available to other patients.
- We also sent out questionnaires to all of our members which we hope will give us a better understanding of the situation across the UK for HAE patients.
- We asked our members to contact all their HAE relatives and ask them to register on our database.

HAE International supported us in efforts to have patient stories featured on the BBC website and in magazines.

One of our pharmaceutical supporters also helped us with media initiatives.

World HAE Awareness Day will be an annual opportunity to raise the profile of HAE worldwide.



World Immunology Day, April 2012

HAE UK had a stand at the two day World Immunology Conference organised by the Royal Free Hospital in London.

On the Doctor's day, Friday 20th, we were able to speak with doctors, nurses and pharmaceutical companies about HAE UK and our patient support website.

The patient day on the Saturday, was very well attended by patients with rare conditions from the London area. New HAE contacts said how much it meant to them to meet other people with HAE.

HAE International Patient Conference

17th - 20th May was our first HAE International Patient Conference in Copenhagen. 21 UK members joined Dr Hilary Longhurst and specialist nurse John Dempster, for a truly inspirational three days, meeting with HAE specialists and patients from around the world.

It is very difficult to summarise the conference, but it was all about friendships, information, inspiration and lots of fun!

It was great to meet UK friends who we had mostly known from e-mails and Facebook. We told our HAE stories and relaxed together and enjoyed just being with each other. We also met new and old friends from around the world, and were inspired by the way in which others had struggled to access treatment for their HAE.

- A young man from the Lebanon had spent many hours on the internet researching his symptoms before he was able to diagnose himself and to find a specialist to treat him.
- A young man from Manila was there on behalf of his aunt, trying to find treatment that would help her.
- A lovely young lady from the Ukraine started a national patient association to support her mother who struggled for many years without treatment for many attacks of airway oedema.

The theme of the conference was 'United we stand strong', and we all felt the solidarity that comes from being part of the worldwide HAE family. We were able to share information about the treatment options that are accessible to patients in different countries.

It is very clear that medical science has made great advances over the past ten years regarding HAE management. However the experiences of so many of us are that financial and other limitations of our individual national health service infrastructure are severely limiting our access to those treatments that would free us to enjoy good health and to contribute fully to the life of our national economy. This is one of the main challenges we face in the coming years both in the developing economies and here in the UK.

One of the great benefits of an international conference is the opportunity to network and to talk to other patients, expert physicians and pharmaceutical companies, and we have returned with lots of new ideas and inspiration for improving our situation here in the UK.



After all this intense hard work we needed to let our hair down and have fun together, and this came with the final Gala dinner and celebrations. There was some amazing talent on the dance floor and on the stage. Our very own Jimmy Grant did us proud on the social scene!

Some of us were able to finish this wonderful week end with a boat tour of Copenhagen, enjoying this beautiful city bathed in glorious sunshine.

We hope these photos will encourage you all to join us for the second HAE International conference in 2014. Let's try for 100 delegates next time!

For more information from the conference, check out the news and events page on our website.



Our website

Since our website was launched earlier this year, we have had many people viewing it.

Since the start of April we have had over 850 visitors, with 46% coming from a search engine (Google for example), 33% referred from another site (inc. the BBC and Facebook) and 21% accessing our website directly.

Facebook

Our Facebook group has proved very popular, with 77 members to date.

Can all members of the group please make sure you do not add anyone to this group who does not have HAE or is not from the UK. This is really important to ensure our posts remain in the HAE community only.

It is also important to remember that posts and comments are peoples personal opinions, not from a medical professional - any concerns should be discussed with your consultant or Ann Price, our patient contact volunteer.

Things to come

Last, but by no means least, we have a provisional date of 24th November for a HAE UK patient meeting somewhere in the north of England. Please put this date in your diary, we would love to see as many of you as possible there.

We are also planning a 2 day HAE conference early next spring in London. We are hoping to have an International HAE expert to speak to specialist nurses one day and to HAE patients on the second day. We hope to be able to give you you more details later in the year.

With all our very best wishes,

*John and Kathy Rixon,
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and Rachel Annals*

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