



# 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.

## Dear HAE UK friends.

A lot has happened in the past year and we think it will be most helpful to share the key issues with you all.

### What HAE UK did in 2011

We launched our new HAE UK website [www.haeuk.org](http://www.haeuk.org) as well as our confidential discussion forum and the HAE UK Facebook group. Huge thanks to Rachel Annals for her brilliant work on these projects. Rachel has now taken on the role of Website Manager, and, together with Furkhanda Haxton she will manage our discussion forum and Facebook group as well.

We worked with The Genetic Alliance and Rare Diseases UK who have a very active lobby in Parliament seeking to make the voice of rare disease patients both heard and effective in developing government policy.

We have developed a dialogue with the four main pharmaceutical companies producing HAE medications.

We have raised the profile of HAE in the media.

We have actively supported four HAE patients who could not access treatment in line with the consensus document recommendations. This is always a long and time consuming process and it is very traumatic for the patients, but we were successful in all four cases.

HAE UK has actively supported the Shire submission for Icatibant in Wales and Scotland.

We worked closely with the PIA over the second half of 2011 to develop questionnaires for Immunology Departments and prepare Freedom of Information requests to all PCTs in order to gain a better understanding of the accessibility of HAE medications and treatments in line with the Consensus Document recommendations. HAE UK has now sent out FOI requests to all PCT cluster groups, but unfortunately the PIA were unable to send out the questionnaires to Immunology Departments and HAE patients as intended.

As most of you will know the PIA closed its doors at the end of 2011 so HAE UK is now the only Patient Support Association for HAE Patients in the UK. We are a new and small patient association run entirely by volunteers, and we need to plan very carefully how we can best support the needs of HAE patients and each other in these times when the NHS is facing cut backs in so many areas.



HAE UK has a founding board of four members - John and Kathy Rixon, and John and Ann Price. We are now developing a committee of people who are able to bring their own particular talents to the work of HAE UK.

### Our committee members are:

Rachel Annals - our web site manager who also manages our discussion forum, our Facebook group and she holds our confidential HAE UK database. Rachel is a professional designer and takes care of our newsletters and publicity material.

Furkhanda Haxton - our Patient Representative for Wales. Furkhanda also helps to manage our Facebook group.

Louise Easton, who has four 'HAE' children - our contact person for parents whose children have HAE.

Mike and Kate Lowe - Mike is a professional journalist, he and Kate will be helping us with 'patient stories' and media publicity.

Barrie Hurley - who is now partially retired from his role of company director. We didn't want him to get bored, so he has agreed to bring his many talents to our committee.

Anouk van Oosten - a PhD student of Medical Sciences, she will monitor new scientific papers on HAE research for us.

## Our plans for the next six months

We want to raise the profile of HAE UK with Immunology Departments. We will be circulating publicity material to all Immunologists and Immunology Nurses, and we will have a promotional stand at the two day PID Conference in London on 20th and 21st April.

We would like to increasingly work with HAE centres round the country to support all HAE patients.

We will be inviting London based patients to the PID and HAE Symposium for Clinicians and Patients on Saturday 21st April (see more, right)

We will be participating in the Shire Patient Preference Survey (see more, right)

We will be working with Rare Diseases UK to produce a full page article on HAE as part of Rare Diseases Awareness Day

We will be attending the HAE International World HAE Patient Conference in Copenhagen (See more, right)



*Best wishes*

*John and Kathy*

*John and Ann*

## How you can get involved

Please encourage all your HAE relatives and contacts to visit our website [www.haeuk.org](http://www.haeuk.org) and to register with us. HAE patients need the support that HAE UK can offer. Also, as a HAE community we need to understand the situation for all HAE Patients regarding access to treatment etc. Our confidential database will help us to help you

Visit our confidential discussion forum and request to become a member of our Facebook group to share your experience of HAE and access to care. We need to talk to each other.

We need 15 HAE patients to participate in a Shire Patient Preference Survey. We will have more information on our web site soon, but do contact Ann via e-mail: [ann.price@haeuk.org](mailto:ann.price@haeuk.org) or by phone: 01273 813659 to talk about volunteering for this important survey.

For any HAE patients registered with a Consultant at Great Ormond Street Hospital, The Royal Free Hospital or Barts and The London - please contact your Immunology Nurse for an invitation to a PIDS and HAE Patients and Clinicians Symposium at The Russell Hotel, Russell Square, London WC1B 5BE on Saturday 21st April. The programme will shortly be available on our website. This will be a great opportunity for HAE UK members to meet up and to share issues around HAE management. Dr Hilary Longhurst will be running a workshop on Patient support.

Look out for news coming soon on our website about World HAE Awareness Day to see what we can all do to raise the profile of HAE. HAE International are hosting the first Worldwide HAE Patient Conference in Copenhagen on the 17th to the 20th May. Look for more news on our website soon, and on the HAEI website. A small group of us will be attending this very exciting conference. Please e-mail or phone Ann Price if you would like to join us.

Lastly, a very important way in which we can all help. Please support the Rare Disease UK initiative by writing to your MP about the NHS provision for rare diseases. See more information on our website soon.

## Who to contact

We look forward so much to keeping in contact with you all and working together in HAE Patient support.

For more information or advice please contact  
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