

Living for today, planning for tomorrow

# HAEUK

# Newsletter

ISSUE NINE  
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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 Member** We hope you are well. It's been good to hear from so many of you by e-mail and via our confidential HAEUK Facebook Group over the past few months.



## HAE UK Patient Day - Addenbrookes Hospital Cambridge, 6th December

HAE UK would like to express huge thanks to Dr Kumararatne and Specialist Nurse Jane Goodridge from the Addenbrookes Immunology Service for facilitating our use of the Addenbrookes Clinical School for this year's patient meeting. It was a fantastic day.

We would also like to thank our pharmaceutical sponsors CSL Behring and Shire for helping fund the day.

As usual we had a packed agenda, which started with Dr Hilary Longhurst who presented the Revised Consensus Recommendations that will be published in the New Year. Dr Bill Egner then explained the implications of the NHS England Policy for the Management of acute attacks of HAE.

Next it was Specialist Nurse John Dempster, who talked about home therapy with C1 Inhibitor, and Specialist Nurse Christine Symons who presented about home therapy with Icatibant.

Later in the morning and after lunch, HAE Patients Ed Price and Keven White shared their experience of living with HAE and the positive impact home therapy has had on both of their lives.

In the afternoon we spent time in smaller groups, talking about our own concerns and listening to experiences of

the other patients, and then we were able to put questions to our panel of experts at the end of the day.

The feed back from attendees is that they found the whole day very helpful and especially enjoyed hearing the HAE patient talks. New members particularly appreciated the warmth and friendship of the long term members, and they found it very good to share their experiences of coping with our very rare condition.

## HAE UK Database

Our HAE UK membership has continued to increase. We now have over 300 members registered with us.

Please encourage any family members, including children, who have HAE to register with us. This helps us to know where HAE patients are and it helps us to have a strong voice nationally to continue to improve access to treatment for all HAE patients countrywide. To register see our website: [www.haeuk.org/advice-support/](http://www.haeuk.org/advice-support/)

If at any time you wish to unsubscribe from receiving our newsletters and e-mail information, please e-mail Rachel and she will remove your details from our mailer: [rachel.annals@haeuk.org](mailto:rachel.annals@haeuk.org)

## HAE Patient booklet

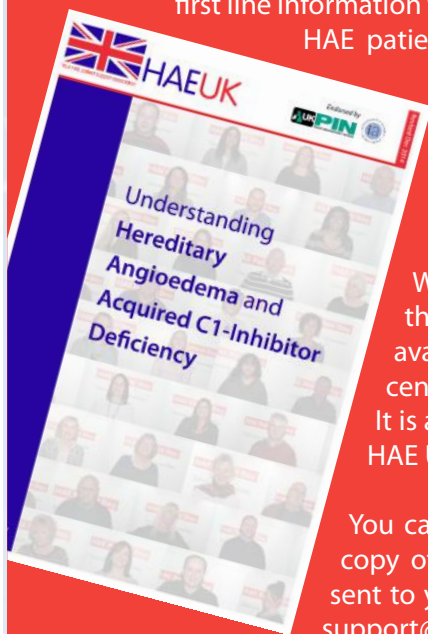
We were pleased to use our patient day to launch our HAE Patient Information booklet.

We hope that this information booklet will provide first line information for newly diagnosed HAE patients. You might also

find it useful in explaining our rare condition to family, work and school.

We will be making these booklets available in all HAE centres in the New Year. It is also available on our HAE UK website.

You can request a printed copy of this booklet to be sent to you by e-mailing us: [support@haeuk.org](mailto:support@haeuk.org)



## Changes ahead

HAE UK was set up in October 2010 to support HAE patients. In 2013 we became a registered charity. We now need to develop the structure of our organization to meet the present and future needs of our members.

We now have 5 Trustees:

Barrie Hurley - Chair of Trustees

John Price - Treasurer

Ann Price - Trustee

Ann Harding - Trustee

Ed Price - Trustee

Ann Price has given notice that she will be retiring as a trustee and volunteer at the end of June 2015 and our Chair of Trustees, Barrie, will lead us in developing HAE UK over the next six months.

We will be looking at establishing voluntary and paid roles that cover the expanding needs of our organization. We will of course keep you up to date with developments.

## Fund raising for HAE UK

Over the past four years HAEUK has been run with minimal funding. Now we will need to secure sufficient funds to responsibly employ someone to continue to develop our services.

The trustees will be looking at all available sources of support in the coming months.

Our HAE UK members have already started to raise funds for us in various ways.

Sponsored cycle rides, sponsored runs, school reunions, gifts in memory of a loved one, raffles

We are now registered with JustGiving so, if you wanted to, you can make a one-off donation,

a regular monthly payment, or set up your own page to raise funds for a sponsored event. We have also set up JustTextGiving, so people are able to make a donation to our charity by text. For more information about JustGiving, please see our page: [www.justgiving.com/haeuk/](http://www.justgiving.com/haeuk/)

It would be really helpful if members could think of big and small ways to fund raise for HAE UK over the next year.

If you work for a large company it may be that you could approach them to ask them if they would consider sponsoring us. Please contact Rachel Annals for publicity materials that will present our charity to potential sponsors: [rachel.annals@haeuk.org](mailto:rachel.annals@haeuk.org)



Thank you to everyone who has supported us so generously over the past year.

We wish everyone in our HAE UK family a very Happy Christmas and a Happy and Healthy New Year

Our very best wishes, from

*Rachel, Ann, John, Barrie, Ann and Ed*