# HAEUK Newsletter

*Living for today, planning for tomorrow*

ISSUESEVEN
JANUARY 2014

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

***We hope you enjoyed a lovely Christmas and we would like to wish you all a happy, healthy New Year.***

## News from the last few months

Over the last six months HAE UK staff have been out and about meeting HAE patients and Immunology staff in an effort to raise the profile of HAE across England.

- Ann and John attended the opening of the Northern General Hospitals Immunology Day Unit, managed by a team of Immunologists and Specialist Nurses, headed up by Dr William Egner and Sister Fran Ashworth. The Olympic women's boxing champion, Nicola Adams, officially opened the state of the art unit which provides patient centred care and an easy to access service for infusion for both PID and HAE patients.

*Ann Price, Nicola Adams, Lynne Regent (Anaphylaxis Campaign) & Liz Macartney (UKPIPS)*

- Dr Aarn Huissoon and Dr Scott Hackett hosted a patient day for patients from the West midlands. Ann spoke briefly and lead group discussions for HAE patients, particularly sharing the New NHS England Policy for management of acute attacks of HAE and AAE.

- Dr Hilary Longhurst and her team hosted an informal social meeting for patients from The London hospital. Ann represented HAE UK and it was good to meet up with old friends and meet some new HAE patients.

- In November many of us attended a fantastic patient day in London, organised by Rachel. Read more about this day over the page.

- In December Ann and John manned a HAE UK stand at the UKPIN Conference in Liverpool. This was a great opportunity to meet with Immunologists and Specialist Nurses and with the pharmaceutical companies.

- Also in December Ann presented a patient perception of HAE to an Oral Medicines Symposium. It is really important that we share our patient stories with as many doctors as possible in order to increase the understanding in the medical community about our rare condition.

## HAE UK needs you

Because HAE UK is working on so many fronts we will need more funding in the future. This is one of the projects we are currently working on and have registered with Justgiving. We will have more about this in our next newsletter.

We would like to say a huge thank you to Mr and Mrs Talbert and to Mrs Trig who have raised a lot of money for us earlier this year. This is much appreciated.

We are also in the process of updating our website with lots of new information. If you have any information from your own personal experiences regarding either travel insurance, recommended holiday destinations for HAE patients, experience of employment regulations and/or successful applications for claiming benefits, and experiences of HAE management in children and schools, we would love you to share this information with us. We will not use anything you share with us without your express permission to do so. Please e-mail to Ann: ann.price@haeuk.org

# HAE UK London Patient Day 2013

Over 100 patients, family members, doctors, nurses and members of the pharmaceutical industry met together to share our stories and to hear presentations from our medical professionals.

It was a very busy day with lots of presentations, such as The New Clinical Commissioning Policy, The HAE Patient Care Pathway and Home Therapy Treatments. We would like to extend our great thanks to Tony Castaldo, the President of HAE International, and to Henrik Boysen, HAE International's Executive Director, for joining us to give us an international perspective on HAE management. Also our grateful thanks go out to all our Immunologists and Specialist Nurses who gave up their free time to come and talk to us – Dr Mark Gompels, Dr Hillary Longhurst and Specialist Nurses John Dempster, Christine Symons and Fran Ashworth.

We all gain so much encouragement and help from meeting with each other, and several members who were having difficulties in accessing treatment were introduced to members of our medical panel and helped in this way.

We look forward to seeing many of you again at the next HAE UK patient day.

# Acheivements over the past year

***HAE UK Charity Status***

Recently HAE UK has become a Registered Charity and a Company Limited by Guarantee.

We have established a clear structure for our team:

HAE UK Trustees:
    Ann Price - Chair of Trustees and patient contact
    John Price - Trustee and Treasurer
    Barrie Hurley - Trustee and business and fund raising advisor

HAE UK Executive Officer (with small honourarium):
    Rachel Annals - Website and confidential database manager, events organiser/planner and general administrator. Rachel will also be continuing her additional voluntary work for HAE UK.

Our Huge thanks to all the wonderful volunteers who have helped in various ways over the past year. We will be working with these people and with new volunteers over the next year to develop our HAE UK website, to provide a comprehensive range of information to support all of our members.

### *Integrated HAE Patient Care Pathway – Dr Hilary Longhurst*

Early in 2013 Dr Longhurst published her detailed care pathway for HAE patients, and I'm sure this will inform the practice of many HAE specialists in the UK.

HAE UK funded the availability of the paper on the world wide web, and there is a link to this on our website.

### *Revised Consensus Guidelines for the management of HAE and AAE.*

We originally had a UK HAE Consensus document published in 2005, but things have progressed at a great rate over the last eight years. It was important for HAE UK to sponsor the writing of Revised UK HAE Consensus Guidelines.

All Stakeholders, including patients, were invited to look at a series of statements about HAE management and to indicate their level of agreement or disagreement with each statement. Using this method we have achieved a very high level of consensus (over 90%) for all the proposed statements about HAE management.

Ann is representing HAE patients on the writing panel, and Dr Hilary Longhurst heads up the team. The final Consensus document will be published early in 2014 and it will be freely available on the web (link on our website). The Revised HAE Consensus Guidelines are very progressive and will help to inform HAE management over the next few years, both in the UK and Internationally.

### *NHS England Service Specifications for treating Acute Attacks of HAE and AAE.*

Probably the most important achievement to date for HAE patients in England has been the publication, in April this year, of the NHS England Service Specification for treating Acute attacks of HAE and AAE. You can find the full version on our website and soon we will have a 'Patient Summary' of the policy.

The most important aspect of the new policy is that we now have central commissioning for HAE. In essence this means that funding will be made available centrally to pay for all HAE services outlined in the policy. This puts an end to the post code lottery that made HAE patients very vulnerable to variations across the country in local PCT funding policies.

The new service specifications will not necessarily cover everything that we would all like, because in these days of a cash strapped NHS, we could only get approval for a service that would not amount to more than the current budget for HAE. However the policy will regularly be under review and hopefully the policy will become more progressive.

Basically the Policy states that:

- All HAE patients should be seen by a HAE Specialist that has been accredited as a HAE centre able to provide all the services in the policy.
- Every severe attack of HAE affecting Abdomen, face or airway should be treated with C1 Inhibitor or Icatibant. Early intervention reduces the incapacity of the condition.
- If, after appropriate preventative medication, a patient still experiences frequent attacks, they should be offered training for home therapy with C1 Inhibitor. If for any reason intravenous home therapy is not appropriate then icatibant should be made available.

Please do read the full document on our website.

Ann has a three year role as a patient representative on the Clinical Review Group who, under the leadership of Dr William Egner, have produced the HAE Service Specification. The Clinical Review Group will be monitoring and revising the policy over the first five years.

## What next?

Over the next four months Ann and Rachel, together with our volunteers will be developing our website to give a more comprehensive range of information. This is a massive task, so please be patient with us as we put it all together. We will also be producing a small patient information booklet which we hope will be endorsed by UKPIN for use in all HAE centres.

We are also hoping to have HAE passports available for HAE Awareness Day in May. These will be cards that you can use in A&E departments to hopefully fast track you to the appropriate treatment.

## Last, but not least

*– The Second International HAE Patient Conference in Washington DC - 15th to 18th May 2014.*

This is going to be such a valuable conference and we are hoping that a number of our UK HAE Specialists and Specialist Nurses will be able to attend. There are a limited number of travel grants for patients and family members who apply to attend, on a first come first served basis (NOTE: there is a $100 registration fee and you must ensure you have a US Visa or ESTA before you can accept a travel grant). Please see the HAE International website for full details: www.haei.org. We know that only a relatively small number of us will be able to attend but it will be great to have as many of you as possible come to this great event.

Thank you to everyone in our wonderful HAE family for supporting each other like we do.

Our very best wishes, from

*Rachel, Ann, John and Barrie*