



Newsletter

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

Welcome to our Summer 2016 newsletter

Despite the shortage of sunshine, we hope this newsletter will put everyone in a holiday mood!

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THE QUARTERLY QUESTION:

I don't understand the difference between Icatibant and C1. Aren't they the same thing really?

Our Medical Advisory Panel (MAP)

HAE UK is always seeking to widen our expert base for our patients, and we are delighted to welcome two new members of our Medical Advisory Panel; Dr Scott Hackett and Dr Tariq El-Shanawany.

Dr Scott Hackett, whom many of you will remember from the Patient Day in Birmingham last year, specialises in Paediatric HAE patients and is based at Birmingham Heartlands Hospital. Scott also has clinics in many outlying hospitals.



Dr Tariq el-Shanawany is a Consultant Clinical Immunologist at the University Hospital of Wales in Cardiff. Tariq provides Allergy and Immunology clinics for patients across all of South Wales and is actively involved in teaching and research.



Scott and Tariq join our established Medical Advisory Panel of Dr Hilary Longhurst, Dr Mark Gompels, Dr Tim Crouch, Fran Ashworth, Christine Symons and John Dempster. You can read more about all of our MAP on our website: www.haeuk.org/about-hae-uk/

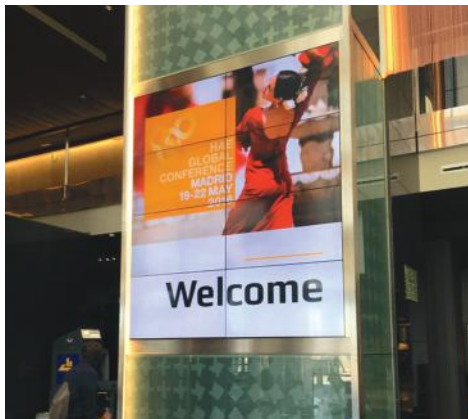
HAE Global Conference in Madrid, Spain

The third HAE Global Conference was held at the Marriott Auditorium Hotel in Madrid from 19th to 22nd May 2016. It was a very busy and informative couple of days.

It was a fantastic event with over 500 attendees from all over the world, including HAE patients, consultants, nurses and industry professionals. Nearly 30 people from the UK attended, including Alex, HAE UK's new Youth Ambassador.

The Country presentations were all fascinating and we realised just how lucky we have been to come so far in the UK with a core of experts, clinicians and available treatments.

It was Laura, HAE UK's CEO's, first International conference, so it was great for her to put some faces and personalities to names and to be able to meet the International team in person.



Rachel, HAE UK's Executive Officer, was voted back on to the International Executive Committee alongside members from Argentina, Spain, Germany and the USA. We hope that the continued UK perspective will further assist in making HAEi an even greater force than it is already.



At the end of the second day we were very privileged to see the advance screening of the movie 'Special Blood'. This movie, about the lives of four HAE patients, was produced and directed by Natalie Metzger, a HAE patient from the USA. The movie received a standing ovation from all the attendees.



The evening dinner and after party was a great way for everyone to relax, let their hair down and spend time with new found friends from all over the world.



We look forward to hearing about the

next International Conference, which will take place in 2018!

Youth Ambassador

You will remember in our Spring Newsletter we asked for applicants to become our Youth Ambassador. We had some absolutely super applicants and after a great deal of thought Alex Graham was selected to fill the post.

HAE UK sponsored Alex to attend the Global Conference, where for the first time there was a Young Persons track. There were some fantastic sessions and she has come back absolutely bursting with ideas for our younger members. Alex also took part in a competition with the other HAE youngsters to design a tourniquet, and she came 2nd!

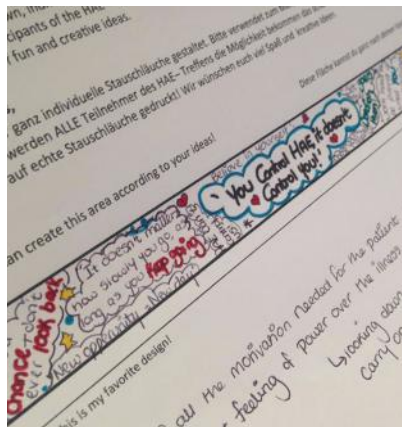


Alex has just finished Sixth Form studying Biology, Drama and Psychology at GCSE for which she is now awaiting results. She was also School Prefect for year 10-11, and a member of School Council, which gave her the opportunity to attend meetings with the school management bodies to discuss points raised by the pupils.

As a very sport-orientated person, Alex is County Sports Leader for Oxfordshire, helping young children of all ages and abilities across the county to get involved in activities out of their comfort zone. She finds the feedback from the children so motivating and satisfying, and as a firm believer in positive mental attitude she

Introducing Alex...

Alex is an amazing representative for HAE UK; she was diagnosed with HAE at three years old and there is a long family history of HAE Type 1 with her mother and sister both having HAE. They have lost



two family members to the illness, so from a young age Alex was aware that she was a bit different from all her friends. But her family always explained that HAE should never let it stop her from achieving everything she wanted in life.....

encourages people and shows them how self-respect, determination and discipline can enhance your wellbeing.

Alex is also interested in martial arts and, although there were natural concerns for triggering attacks, Alex managed to train regularly and at 16 became a 1st Dan Black Belt in Shukokai Full Contact Karate. She now teaches youngsters (and adults – including her Mum!) from 5 years old up to 60+, and achieved second place in combat and kata in the National Championships.

We are very excited to work with Alex over the coming months to set up our youth wing. If you are interested in volunteering to help Alex please get in touch with us.

HAE UK charity Christmas cards - COMPETITION

This year we would really like to produce HAE UK Christmas cards to raise funds and create more awareness of our condition. So we are inviting members to submit designs for the cards!

There will be three categories; under 12's, 12-18's and over 18's. The winner of each section will see

their design printed, receive a £20 gift voucher for a shop of their choice and receive a pack of the cards.

Please submit your design to Rachel by 11th September. Winners will be chosen the following week. Following that the cards will be printed and members will be able to purchase packs of cards.

Bristol:



Our annual Patient Day will be held on 19th November 2016 at the Mercure Holland House Hotel and Spa, Bristol.

Registration for the event is open now and places are strictly on a first come first served basis.

We are delighted that both Tony Castaldo and Henrik Boysen from HAE International will be joining us for the event and we will also have Dr Mark Gompels and other specialist HAE consultants as speakers on the day.

We will also be holding a 'social event' at the hotel on the evening before (Friday 18th) which we hope as many of you as possible will attend so we can spend some time meeting and getting to know each other.

This year we are inviting children aged 12 and over to join us and we will be holding a Young Persons breakout session in the afternoon, run by our Youth Ambassador, Alex Graham. Those youngsters aged 12-16 which would like to attend must be accompanied by an adult.

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To register for our Bristol Patient Day, see:
www.haeuk.org/patient-day
(please make sure you select 'Bristol' when registering)

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Once registered we will send you confirmation and also information about the hotel if you wish to book a room for Friday 18th November.

Perth:



Our first Scottish Patient Day will be held on 1st October 2016 at the Salutation Hotel in Perth.

All those Scottish patients who tend to be unable to come to the patient day because of the distance will be able to meet one another and hear excellent presentations from, amongst others, Dr Richard Herriot and Sister Mary Brownlie.

There will be various afternoon breakout sessions and lots of chance to share experiences and make contacts.

Registration for the event is open now and places are strictly on a first come first served basis.

Children aged 12 to 16 are invited to join us and must be accompanied by an adult.

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To register for our Perth Patient Day, see:
www.haeuk.org/patient-day (please make sure you select 'Perth' when registering)

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Once registered we will send you confirmation and also information about the hotel if you wish to book a room for Friday 30th September.

Fundraising

Again our fundraisers have been very active over the past 3 months:

- Samantha Jones (who is a HAE patient) ran in the Cardiff half marathon. This is Sam's second half marathon raising money for HAE UK.
- Rick Talbot (whose daughter and granddaughter, Nicola and Rhiannon Bowen, both have HAE) donated even more money to HAE UK. This time Rick asked guests for donations to HAE UK in lieu of gifts at his recent 70th birthday party.
- Danny Owen (whose wife Michelle has HAE) took part in the London Revolution; a gruelling two day, 185 mile cycle around London.
- Rose Joseph (who is a HAE patient) ran a coffee morning in aid of HAE UK, for **hae day** :-)

Rose also donated some proceeds from her recent sponsored cycle ride.

- Jewellery maker Shirley Granville (whose daughter-in-law Rachel Annals, has HAE) donated all proceeds from her recent jewellery sale to HAE UK.
- Some of our members have made one off donations or set up monthly donations to HAE UK via JustGiving or direct from their bank account. Each donation, however big or small, really helps us to continue our support to HAE patients in the UK.

We are so fortunate to have these brilliant supporters!

Thank you again to everyone fundraising and donating to HAE UK.

Patient research project news

Philippa Adams, whom many of you helped with her dissertation about the female experience of living with HAE, has graduated from University with a 2.1.

Thank you to those of you who helped her with her research project and many congratulations to Philippa on this great result, which now means she can go on to her Masters.

HAE UK T-shirts

Rachel recently designed HAE UK branded T-shirts for our fundraisers and also for anyone who would like to support us.

We have had quite a few donations and requests for T-shirts in the last couple of months and a few of us wore our t-shirts at the Global Conference in Madrid in May.

If you would like a T-shirt yourself, please contact Rachel who will let you know how you can get yours.



Speakers

Two of our members have been very active in raising awareness about HAE.

As an awareness activity for **hae day** :-) (16th May) we posted members copies of posters we had prepared about HAE and asked them to take them to their local GP and A&E department. We also encouraged members to offer to give short presentations at practice meetings and so on.



June Cole, who is 'passionate about education' gave a lot of thought about what she wanted to say from a patients' perspective and found it very helpful in putting together a talk about this rare genetic condition, together with photos of her and her brother's swellings (with his permission).

June then set about researching the location of local GP practices and Practice Manager names, and looked for contacts at the local Hospitals. Her own GP surgery were very receptive to meet and hear her talk about HAE from the perspective of a patient, to talk through about this rare genetic condition, and to also show photos of swellings that she and a sibling have experienced. Questions were asked and answered and the Practice Manager agreed to inform the other doctors and nurses at their regular meetings as a topic of interest.

June says 'Showing the disfiguring photos of HAE had a real impact; a picture paints a thousand words, and really illustrated the impact these huge disabling, debilitating, disfiguring swellings have on a person's body and life; whereas simply just talking about HAE swellings does not sometimes get across the message of the huge swellings and potential life-threatening situation. It was picked up immediately how a laryngeal attack could appear to mimic anaphylaxis, and how important and potentially life-threatening HAE swellings are in the face and airways, and also in the abdomen. I feel lucky that 'my' GP Medical practice is now well versed with HAE in case another patient presents with similar symptoms and has not been able to obtain a diagnosis.'

June has also visited her local hospital Patient Advice and Liaison Service to make more contacts and from this she is about to make similar presentations to three A&E departments as part of their education programme.



Another brave speaker is Sheila Witts, who has Acquired Angioedema (AAE).

Sheila writes; 'Dr Tarzi rang me on Thursday 19th May and asked me if I would be prepared to talk to 120, 2nd year medical students at Brighton and Sussex Medical School on the 27th May, on AAE. I've got to say I was very apprehensive!

'I am so glad I did, after Dr Tarzi presented his Symposium about HAE, he introduced me to his students, my talk lasted about 1/2 an hour. The students all stood up and clapped at the end of it. Dr Tarzi asked if any one would like to ask any questions (at this stage I did advise I am deaf and wear hearing aids) Dr Tarzi repeated all their questions. Some of the questions asked: "How long do the attacks last?" "How does AAE affect my life?" "How long was I in A&E?"

One student asked my husband how it affected him. Other questions were asked, I have got to admit everything became a bit of a haze.....'

Sheila is being modest, because we happen to know that her speech was very well received and provoked a lot of thought and comment from the listeners.

Well done and a huge THANK YOU to both of these ladies! Sadly there is still a huge lack of information about HAE in the wider medical community. We are hoping that one of the breakout sessions at our annual Patient Day in November will be about how to set about doing your own presentations – one thing we are constantly told by clinicians is how they value the 'patient experience' to inform their own practice.

THE QUARTERLY QUESTION

I don't understand the difference between Icatibant and C1.
Aren't they the same thing really?

There does still seem to be a lot of confusion about the various products that are used for treating HAE.

Firstly, attenuated androgens (Danazol, Stanozolol, Oxandrolone) are mainly used as prophylaxis – in other words, to prevent attacks. They act by stimulating the liver to produce more C1. Tranexamic acid, when used as preventer of attacks, is thought to work by sparing the C1 and so allowing more of it to be present to prevent oedema

In order to prevent attacks, prophylactic treatment needs to be taken regularly. Tranexamic acid can also be used when the 'prodromal' symptoms of an attack appear, but it is probably not so effective taken this way.

The initial cause of the swellings in HAE is excessive production of bradykinin, a normally occurring blood protein. The production of bradykinin is regulated by C1-INH, so if you have low levels of, or non-functioning, C1-INH the bradykinin has no control mechanism. The bradykinin activates receptors on the cells that causes blood vessels to dilate and plasma to leak into the surrounding tissues, causing the swelling and pain of an HAE attack.

Icatibant is what is termed a 'bradykinin antagonist'

in other words it blocks the receptors of the cell and prevents the action of the bradykinin. The problem is that it has a relatively short period of activity so if the attack goes on for longer it may be necessary to use another dose of icatibant.

C1-INH infusions are a replacement therapy; they literally replaces what your body is lacking. A person with HAE lacks the C1-INH blood protein that, amongst other actions, controls bradykinin production. The replacement C1-INH can have a longer-lasting action than Icatibant, but much depends on the individual.

So they are not the same, they have different modes of action; one being to control the production of bradykinin (C1-INH) the other to interfere with the action of bradykinin (Icatibant).

The important thing to remember with both products is that the sooner they are administered the better, and that neither of them act to reduce the swelling that has already occurred. That has to disperse naturally, and so the less swelling the better.

We cannot say often enough; the sooner you administer either C1-INH or Icatibant the better!

Re-registering with HAE UK

We are currently reviewing the information we hold about our members and updating our records accordingly.

To ensure the information we hold about you is current, we are e-mailing you all on a person-by-person basis, asking you to re-register using the new form on our website.

We would also like you to encourage all of your family members with HAE to also register, this will

enable us to build an accurate picture of patients across the UK and we can better support you all.

Please keep an eye out for this e-mail in the coming weeks. Once re-registered, all new members will receive one of our new Welcome Packs through the post in the coming few weeks.

Rather than waiting for your e-mail, you can register by following this link:
www.haeuk.org/advice-support/register

Supporting HAE UK - Help us to help you

Test donate

You can make a one off donation to HAE UK simply by sending a text. To do this text 'HAEU01' and your amount (e.g. HAEU01 £10) to 70070.

Payroll Giving



Payroll Giving is a flexible scheme which allows anyone who pays UK income tax to give regularly and on a tax free basis straight from your wages or pension. This happens before tax is deducted from your income.

To set up a regular donation to HAE UK please complete the Payroll Giving form: www.givingonline.org.uk/HAE-UK_2407/index.html

Setting up a monthly standing order

It is easy to set up a standing order direct from your bank account to the HAE UK account - we are happy to provide you with these details upon request.

JustGiving

If you are planning a fundraising event, you can set up a JustGiving page to make donations easier for your donators. You can also log on to JustGiving to support other who are fundraising

Shopping online or booking your summer holiday online?

...why not register with **easyfundraising** and nominate HAE UK as your chosen charity? By doing this, each time you make a purchase online with one of the 2,700+ participating retailers, a small donation will be made to HAE UK, with no cost to you!

Retailers include Booking.com, Hotels.com, First Choice, easyjet, Amazon, John Lewis, Argos, eBay, Next and many many more. To register see: www.easyfundraising.org.uk

Thank you

If you have an suggestions or ideas for our next newsletter, or a question for our Quarterly Question, please e-mail us, we would love to hear from you.

We wish you all a very happy summer

*With our best wishes from Laura (CEO) & Rachel (EO)
and the Trustees*

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