

# HAE UK Summer 2018 *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 2018 newsletter***

A note from Laura Szutowicz, CEO:

Some 30 members from the UK attended the 2018 Global Conference in Vienna, which was a fantastic event! Many thanks to Tony, Henrik and all the team for organising and facilitating the 'long weekend' meeting. We are all very grateful for the opportunity to meet so many people from so many countries and I think some lasting friendships have been made. You can read more about the weekend later in this newsletter, also reports by our Youth Ambassadors Alex and Jack, and June and Pippa.

Here in the UK I have been busy this Spring with various rounds of the commissioning process to ensure good supply and equal access to all available HAE medication across England, Scotland and Wales. This hopefully means that there will be adequate supplies for all our patients for the next few years, although there is always the risk that a supplier will have a manufacturing problem with a batch of product which then causes a shortage. This is one reason why I try to ensure that the complete range of products are available for clinicians to prescribe so that the risk of shortage is minimised. I am fortunate that I also have great back up from the clinicians in the UK with several also attending the

meetings to put our case. There are also more new products in development which will soon be licensed and available. This increase in treatments will help to improve clinicians' choice of what is best for you.

A new initiative this Spring, kindly supported by Pharming, was the inaugural meeting of what we hope will become a UK-wide network of HAE experts. It was the brainchild of Dr Patrick Yong from Frimley Park and Royal Surrey County Hospitals and is to eventually ensure that there is at least one HAE expert in each locality who can act as an expert resource for other clinicians and will also head up research and clinical work. The first meeting was very well attended with nearly all the invited clinicians able to attend.

I have also been able to assist with issues such as a school placement. Please contact me directly by e-mail or by phone if you need help with a problem. All our communications are GDPR compliant so you can be assured that this is secure and private.

*Laura*

# OUR ANNUAL PATIENT DAY - A POSITIVE FUTURE WITH HAE

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We are pleased to let you now that we have now finalised our booking for this year's patient day. It will be held on Saturday 17th November at the Mercure Farnham Bush Hotel, Farnham.

The day will run between 9am until 5pm and will include presentations from some of our top consultants, including Dr Patrick Yong who runs the nearby HAE clinic.

The evening before the main event we will also be holding a drinks reception to give people the opportunity to relax and meet with other patients and family members ahead of the patient day.

Invites will be going out to all of our members in the next week or two, so keep an eye on your e-mails.

## 3rd SCOTTISH PATIENT DAY

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Due to popular demand we will be heading to Scotland for our third patient day this October. The event will be held at the Novotel Edinburgh City on Saturday 6th October.

Invites will be sent out to all members in the next week or two when registration for the event opens.

## BURDEN OF HAE STUDY

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You should have received an e-mail from Rachel a few weeks ago about taking part in a burden of illness study.

The study runs for a few more weeks so there is still time to take part. If you didn't receive the e-mail please contact Rachel who can re-send it to you.

## 'MY PERFECT LIFE'

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For HAE Day this year Rachel worked on a video project to raise awareness of HAE, in a positive light. It took time collecting stories and photographs and working with the



production company to put it all together. She also found the sound track, which is by Moby who allows use of some of his work for charities.

Our aim was to celebrate the courage and achievements of our members who will not let their HAE get in the way of their 'Perfect Life'.

You can view the video here <https://www.youtube.com/watch?v=HMw89bG5lk8> and we are sure you will agree that Rachel and our contributors have made a really inspirational film.

## THANK YOU TO OUR FANTASTIC FUNDRAISERS

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Declan McComb cycled 55 miles around Essex on 9th June for HAE UK. We are so lucky to have people like Declan who will give up their time and muscle power to raise money and awareness for us. It really does pay off – every time someone does something like this we get increased enquiries for information by phone and via the website.

Rose Joseph also raises funds with her coffee and catch up mornings, an annual success!

Thank you to all of you who support us with donations, whether as part of an event or a small monthly donation, it all helps us to continue to provide support to you all and is very much appreciated.

# QUARTERLY QUESTION - What should I do with my medication when I travel?

It is really important you plan well ahead of any trip, especially if you're travelling abroad. Ensure you have adequate insurance and a plentiful supply of medication.

You must always carry your supply of C1 inhibitor or Icatibant with you in your hand luggage so it is easily accessible in an emergency. These medications can be kept at room temperature but must not exceed 25 degrees, so if in doubt, pack them in a cool bag. You will need a letter from your consultant explaining the medication you will be carrying and keep it together

when travelling. You will need to take it out of your hand luggage when entering security at the airport, explain that it is medication and keep it separate from your other belongings.

When arriving at your destination find somewhere cool and safe to keep your medication for the duration of your stay.

If you have any questions about travelling with HAE or you'd like advice on hospitals in a country you will be visiting, please contact Rachel.

## DID NOT ATTEND.....

Some units report that patients are not attending their appointments. Please remember that even if you are well controlled and happy with your treatment it is hugely important to meet with your care team at least annually. This may give your team the opportunity to suggest a more up-to-date treatment and to monitor you for the possible complications of HAE or your medications that need to be checked at regular intervals.

Also, each missed appointment costs the NHS money, so if you have a good reason for not attending, please

contact them and make another appointment if possible.

If you live a long way from your centre, increasingly centres are able to help. For example, Royal London are now offering telephone consultations, or even Skype. Royal London are also moving towards having HAE-dedicated clinics, so that HAE patients are no longer mingled with Primary Immune and other patients but will have their 'own' days. Obviously, this will take a little time to work through the system, so please be patient!

## HAEi GLOBAL CONFERENCE - VIENNA 2018

What a fantastic three days we all had in Vienna. We feel very lucky to have received travel grants from HAE International meaning more of our members could attend. There were around 30 people from the UK, and with 736 people from 57 countries, it was a fantastic and very busy event.

We heard the latest news on new medications and had great presentations from some of the top HAE doctors from across the globe. Alongside this was a poster session showcasing some of the brilliant research projects that have been undertaken, including two from Pippa Adams. There was also plenty of time to socialise with friends old and new at the two evening events. Some of us also took part in an optional sightseeing tour of Vienna on Sunday morning before heading home.



The next global conference will take place in May 2020, we are looking forward to it already!

Following we have reports from a few of our members who were fortunate enough to join us in Vienna:



## ***My Vienna experience, by Jack***

*This being my first global conference I didn't know what to expect when arriving in Vienna. When we arrived I attended a meeting that consisted of around 15 people representing their country for HAE and we were asked to talk about our experiences and stories so the pharmaceutical company could understand what it is like to live with HAE. From this meeting I learnt a lot about just how lucky this country is to have the health care we do compared to others, and hearing how all the different stories people shared, showing we have had the same story but with different health care in place.*

*Next day I attended breakfast with my mum before meeting Alex, we both headed off to the HAE Youngsters track in which around 40 youngsters took part.*



*We started with a meet and greet to get to know everyone in the room, to make sure no one was left out and everyone felt a part of the family. Our team challenge was to create a website and magazine just for youngsters to help with HAE and to create somewhere for them to learn about new treatments and talk with friends.*

*We were spilt into groups and I joined Alex, who had teamed up with three other friends she had met from the previous*



*global conference in Madrid. We started on ideas for the website and a poster, concentrating more on the poster as lot of people chose the website. On the poster we created something called 'Life Hacks HAE' which consisted of Tips to help control HAE in places such as schools, travel, the gym, and simply*



*everyday life, combining all that we have dealt with around HAE.*

*After this we had a group challenge, going out into Vienna and completing challenges that were set by the leaders. This was a great way of getting outside exploring and talking to other HAE youngsters. While outside we went on a 'walk and talk' around the beautiful Vienna Park outside the hotel which was lovely to walk round.*

*The following day we had the chance to talk to the doctors, asking them questions about HAE and learning about what is available to us and what the future has in store. I found this very good as new medicine is always becoming available.*

*On the evening of the final day, at the gala dinner, our website was unveiled, showing what we have created in the short days we were together, which I thought was fantastic.*



*My overall experience was amazing! I loved it, my first global conference not knowing what to expect. It was really good meeting new people from around the world and hearing their stories, and sharing knowledge that I have learned through my life and continue learning myself.*

*Every HAE youngster out there should jump at the opportunity to come along next time and meet such amazing people and learn so much from this growing HAE family.*

## **My Vienna experience, by June**

The very informative and interesting HAE global conference 2018 was held in the beautiful city of Vienna in May with a theme of Take Control of HAE. It was the biggest HAE conference that I have attended with over 700 attendees from 57 countries, including patients, caregivers, experts and pharma.

Everything ran like clockwork and felt seamless from start to finish. The Hilton hotel was in a great location, situated a very short walk from the railway station by CAT, the express train taking only 16 minutes from Vienna Airport.

Conference registration was very easy. Everyone was given 'interactive' lanyards with our name and country and details of which conference sessions we had signed up to attend, and a rucksack with a program and other very useful information.

Tony Castaldo and Henrik Boysen gave an inspiring and brilliant introduction to the conference and kept the conference flowing over two full packed days.

Some highlights from the conference:

- Worldwide leaders in HAE giving eloquent talks, presentations on HAE and future developments, including potentially subcutaneous C1 inhibitor, new tablets being trialled and even the possibility of a liquid filled drink in the future, all so very encouraging and exciting.
- Pharma sponsors with stands packed with information and hand-outs. The literature was very good and catered for all age groups.
- A poster session to view and ask questions with displays of extremely useful, informative posters about HAE with representatives from respective countries, providing another chance to mingle, meet and talk to people from other countries.
- Updates from the countries/ regions around the world of developments in their areas.
- Guest speakers, including the Health Minister from Macedonia.
- A motivational speaker from Denmark who seemed to get everyone engaged with some fun interaction activities.

During the conference there was ample opportunity for people to meet, talk and interact with others who have HAE. The conference indicated that in some regions/countries there is still lack of awareness in ER departments and GP practices about HAE, and that some countries may not have



access to modern medicines for HAE, an area which HAEi are focusing on to address. I know from my own experience about lack of awareness of HAE, so have presented and talked to A&E departments and my GP practice about HAE, which really helped.

A Q&A session took place at which a panel of HAE experts from around the world answered written questions assigned randomly to an expert to answer, and then the microphone was opened to the audience for more questions; a very illuminating session.

A social on the last night was a themed typical Viennese meal with everyone sitting on benches at long tables, with staff in costume, and live entertainment.

On the last morning there was an optional guided city tour by coach and on foot. I found it very informative and well organised, giving a great flavour and history of the beautiful city.



I am sure all the attendees left the conference feeling uplifted and that they were more informed about HAE and better able to take control of their HAE.



## **My Vienna experience, by Alex**



*The global conference in Vienna was one of the best experiences I have had in a long time. I got to meet others with the same condition as me. Speaking to others my age who understood how it feels - how it was to have this condition was both satisfying and humbling. It was good to understand different countries and the treatment availability for each of them.*

*Creating a website and a magazine with the youngsters to expand the knowledge and awareness of condition was a really fun project to work on. Being able to see our ideas come alive was extremely humbling and fulfilling.*



*My highlight was meeting old friends and creating new ones - friendships that will last a lifetime. Many of these I met at the global conference in Madrid and still talk too.*



## **My Vienna experience, by Pippa**

*I was lucky enough to attend the HAEi International Conference in Vienna to present both the research projects I had completed at university.*

*The theme of the conference was Take control of your HAE, I feel this really summed up my experience in Vienna. It did not feel like a conference, it felt like you were part of a community, even a family you belonged to. Everyone was so positive about their experience and their HAE journey but even more positive about what is to come in the future and how it could improve their HAE further to control the condition.*

*The poster session really helped build upon this, patients, carers and professionals were really interested in my findings*



*and how this applied to them. What I truly found interesting is how it patients felt it applied on an international level and they felt the same themes/findings were discussed and how they could be resolved throughout the conference.*

*I was misdiagnosed with HAE but, since completing my research projects, I have found everyone's experiences have been so overwhelming that it is part of my HAE experience. To know on a global scale, working together to try to resolve these issues, only more positive things can come in the future to help control this condition.*

*Please let me take the time to also thank everyone who took part in my research projects and for sharing your story, as this would not be possible without you.*

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