



HAE UK Winter 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 Winter 2018 newsletter

We hope that you all had a happy and restful Christmas, despite the unseasonable weather. Snow in Winter! – who would believe it?

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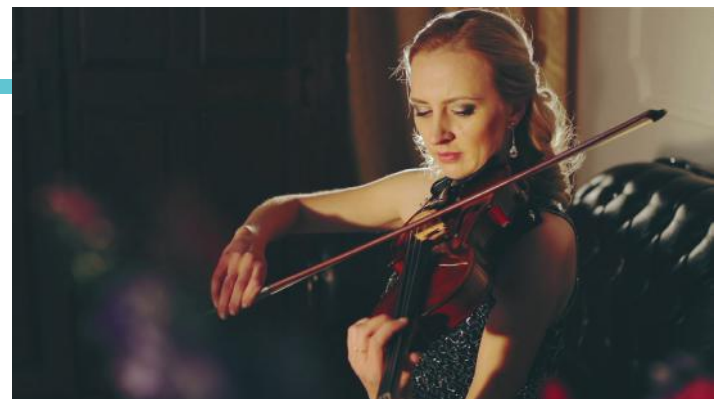
Quarterly question • Calling dentists

QUARTERLY QUESTION - What is the 2018 Global Conference in Vienna and how do I attend??

The 2018 Global Conference will bring together patients, care givers, health care professionals, and also invites industry representatives, to learn more about HAE, share experiences and knowledge in a friendly atmosphere conducted and driven by the patient community through HAEi. There are three tracks at the event: a patient track, a youngsters track and a scientific track.

The extremely attractive registration fee per person includes the following: participation in the full conference, 3 nights of accommodation in the selected room type arriving on 17th May 2018 and departing on 20th May 2018 at the Hilton Vienna (additional nights can be purchased during the registration process), breakfast each morning, lunch on Friday and Saturday, welcome reception on Friday evening and dinner on Saturday evening.

Applications for travel grants are now closed but registration for the event is still open. We have over 20 people from the UK already registered to attend and we would love to welcome more of you to join us there. Please feel free to e-mail Rachel if you have any questions about the event.



OUR ANNUAL PATIENT DAY

The Autumn Newsletter gave a report on the Scottish Patient Day which was held in Glasgow at the end of September. It seemed no time at all before we set out for Sheffield for the annual Patient Day in the middle of November. Despite Rachel organising everything so well, Laura suffers many sleepless nights before these events and this time really alarmed her husband by sitting up bolt upright at 3am one morning shouting 'I must order more lettuce!'. Laura is still not sure where that one came from.....but lack of lettuce was not a problem.

This meeting was a chance to launch our new GP information Pack, which we encouraged patients to take to their general practitioner. The idea behind these packs is that the average family doctor will never see an HAE patient, unless there is one registered in their practice. However, raising awareness can only help to improve the treatment of existing patients and may just speed a diagnosis of another. Any member who was not able to pick one up, do let either Laura or Rachel know and we can post them out to you.

Ray, one of our members works for Ford and they have kindly covered one of their lorries (pictured) and a car transporter with HAE UK logos. They will mostly be working in Europe so please let Laura know if you see one anywhere! The more strange the place, the better.....



After coffee Dr Mel York stood in at short notice for Dr Bill Egner who had a family bereavement. Dr York gave an excellent presentation on 'New Treatments and New Uses for Old Treatments' and again was an excellent speaker.

We have started having an evening reception and get together the night before 'the day'; this is the second year and it was great to see how many people came along and started to get to know one another in a social environment. We have so many loyal and enthusiastic members! And we all got to bed in reasonable time for the next day.....



Next was Becky with her patient story, her eventual successful treatment has enabled her to train as a midwife, which she obviously adores. This is the rewarding side of hearing the patient stories, how people overcome their condition to carry on with their dreams and a normal life.

We were fortunate to have as our first speaker, Dr Ravi Sargur, who has been carrying out research into bradykinin. His excellent presentation 'Why do I swell' was a really clear and concise explanation of what goes on during an attack and how the various medications act in different parts of the pathway. Many people remarked that they had never had HAE explained so well before.

Dr Sargur was followed by specialist dietician Victoria Gallivan with an excellent presentation on 'Eating for Health'. She put great emphasis on maintaining a balanced diet and a good selection of food groups. This was again very well received by attendees, particularly her advice on how to correctly assess if any one food is a trigger for attacks, which does seem to happen for some people.

Jack Cope told us all about the HAEi Youngsters Summer Camp which he attended in August, and some of the younger members of the audience enquired about when the next one was! Jack is a great addition to HAE UK and will be attending the Global Conference in Vienna with Alex to attend the Youth Track (more about Vienna later) This section of the morning was topped off by Faye Davenport relating her and Ruby's stories of diagnosis and treatment and how it affected the whole family. Faye is an excellent speaker and her sometimes sad, sometimes hilarious account, showed what a very strong family they are.

We were very privileged to have great International input at our Day! Michal Rutkowski, President of HAE

Poland, Regional Patient Advocate for Eastern Europe and Vice President of HAE International, gave an excellent insight into 'Treatment in Eastern Europe' and the differences from treatment here in the UK. Despite our grumbles about the NHS and treatment we are really fortunate to have so many dedicated clinicians, expert in HAE and access to many modern treatments. And, as Dr



York pointed out, more on the way!

John Dempster gave an excellent presentation on the importance of good planning before we broke for lunch and the all important opportunity to network.

Our first speaker after lunch gave no one a chance of a quick sleep! We were honoured to have Anthony Castaldo, President and founder member of both HAEA and HAEi. Tony was previously Associate Inspector General at the United States Federal Reserve, so a great example of what well-managed HAE patients can achieve. His 'retirement' project of his dual Presidencies sees him tirelessly jetting all over the world, helping to set up new country and regional groups and advocating for improved treatment everywhere. He was an inspirational speaker and gave us all such a sense of belonging to one big forward thinking and moving family. How can we not succeed?

Anna gave us her story of how she eventually got a diagnosis and, now well managed, she is in the throes of a psychology degree. She also won Laura's personal award for 'best dressed lady'

Our final speaker was Pippa Adams MSc. HAE UK gave a small financial grant to Pippa to support her dissertation

for her Masters degree (which she passed with a 2:1). Pippa has produced a superb piece of work on 'The Psychological Wellbeing of patients with Hereditary Angioedema' which has been presented at two European conferences and was also presented at the UK PIN meeting in Brighton in December. We hope to be able to use this work further for use with our telephone counselling line in due course.

Pippa was the last of our presentations, we then had 'break out' groups hosted by Dr Patrick Yong, Fran Ashworth, John Dempster, Paul Carroll, Christine Symons, Pippa Adams, and finished up with a Q&A session.

It was difficult to believe it was all over for another year!

Our great thanks to, in no particular order, our fantastic speakers, our ever helpful medical advisory panel, our Trustees, our International colleagues. Particular thanks to Rachel who organises the venue and all the logistics so well, and to Furkhanda who mans the registration, sells raffle tickets and is general all round help.

And a HUGE round of thanks to our members and their families who make running these days worthwhile.....

GET TO KNOW YOUR IMMUNOLOGIST/TEAM



Sister Christine Symons is a nurse Consultant in Immunology & Allergy at Derriford Hospital in Plymouth.

Christine started her nurse training 33 years ago this month and has remained at Derriford Hospital all this time. She began working in the immunology and allergy department when it was established in 1996. Her first baby was 6 months old and she was offered the opportunity to work just one morning a week with the new immunologist, Dr Ed Kaminski. The last 22 years have seen many changes and a few grey hairs! The department now has 2, nearly 3, consultants and 7 nurses and train junior doctors and nursing students.

Christine went on to have a second son and she lives with her husband and sons (when they are home) in a market town on the edge of Dartmoor about 15 miles from Derriford. The commute which used to take 20 minutes now takes an hour or more. This has been a dream job and takes over most of Christine's life but has given her extraordinary opportunities to travel and meet the very best people: from world class clinicians to inspiring patients and colleagues. Christine relaxes by reading, travelling and catching up with family and friends.

YOUTH AMBASSADORS

Two years ago now we appointed Alex Graham to be our Youth Ambassador and she has done great work since then to encourage younger members of HAE UK. Her presentation at the Patient Day 2016 was inspirational showing exactly how fantastic the up-and-coming generations are.

We are delighted that Jack Cope has agreed to take on the dual role with Alex, his first 'official' engagement will be attending the Global Conference in Vienna. He and Alex will be on the 'Youth Track' and we look forward to them reporting back on all their exploits and ideas.....

CALLING ALL DENTISTS

Do you attend a dental practice that understands HAE and is happy to treat you? Please send the practice name and address to Laura laura.szutowicz@haeuk.org so she can contact them to ask if they are prepared to be included on our register of HAE friendly dentists. This is a question we are frequently asked by patients so we are keen to be able to recommend dentists to you to help you feel confident with being treated.



Brady the bear has created a place just for you to have fun!

Brady can talk to you about HAE, you can play Brady's matching game and he is working on even more ways to help you understand HAE!

The Brady Club is an online safe space customised for children diagnosed with HAE and their siblings. We hope this page will help the youngest HAE patients to better understand, manage and cope with their disease whilst offering fun ways for them to feel inspired, empowered and connected to other children who share their questions and want to have some fun too!

The Brady Club International has been created by the US Hereditary Angioedema Association, HAEA, for the benefit of HAE youngsters worldwide.

www.brady.haea.org • www.haeuk.org • support@haeuk.org

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