Every time I report on our activities I am struck by how incredibly lucky we are in the UK to have so many wonderful clinicians, both doctors and nurses, supporting our HAE family. Yes, there can always be improvement, but when I compare us to other countries we are so much further ahead in raising awareness and improving treatment. And why? Well, it comes down to you, our fantastic members who spend so much time and energy in helping others to recognize and understand HAE.

In this issue, we report on our Patient Days, the success of which always depends on people like our amazing presenters and patients who share their patient stories. Also in this newsletter, read about Karen and her engagement with the ‘I am Number Seventeen’ campaign. We are so grateful to these and other members who are so courageous in getting their stories ‘out there’!

Laura (HAE UK Chief Executive Officer)

HAEi Global Conference 2020 - Frankfurt

Plans are being finalised for the HAEi Global Conference 2020, which is taking place from 14th to 17th May at the Sheraton Frankfurt Airport Hotel, in Frankfurt, Germany.

HAEi expects there to be around 1,000 attendees from around the world and it will be the biggest ever global gathering of patients, caregivers, healthcare professionals and the pharmaceutical industry.

The theme for the conference is “Creating The Path to Better Health”, where the aim is to continue finding ways for improving time to diagnosis, secure access to lifesaving therapies and raise funding that will allow HAE patients around the world to lead a safer life and fulfill their potential.

All travel grants for the event have now been allocated and we have over 25 people from the UK attending. It is still possible to book a place but you will need to fund your own travel. HAEi are offering extremely attractive registration rates which include accommodation and meals throughout the conference. To find out more, see: https://haegc20.haei.org

Welcome to our Winter 2020 newsletter

We are looking at producing hoodies and t-shirts for our members to purchase. We have received great feedback about the youngsters hoodies from the Youngsters event we held in the summer, so we thought others might like to purchase some too.

We will keep costs to a minimum, with a small percentage of each item purchased being donated to HAE UK.

More information will be available soon, please contact us if you are interested in the meantime.

Are you registered with HAE UK?

We have recently updated our membership database to ensure we are GDPR compliant. You should have received an e-mail from us in the past few weeks, asking you to update and verify your registration information.

If you haven’t received an e-mail, please get in touch with us ASAP so you don’t miss important updates from us. Similarly, please remember to notify us if you change your e-mail address so we can update your account and keep in touch with you.

HAE UK MERCHANDISE

Please check out our Facebook, Instagram and Twitter feeds to see these posts, and feel free to share!

facebook.com/haeuk twitch.com/hae_uk

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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.

With our very best wishes from Laura (CEO), Rachel (EO) and the HAE UK team

www.haeuk.org • support@haeuk.org • laura.szutowicz@haeuk.org • rachel.annals@haeuk.org
HAE UK FUNDRAISERS AND RAISING AWARENESS

In the past few months we have received individual donations from patients and family members, some of these as part of fundraising events and a couple of donation in memory of loved ones. Thank you so much to you all.

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Terry Mansfield, who runs the Railway Inn in West Horndon, is taking part in the Virgin London Marathon this year. After a really successful family fun day in his pub last summer, Terry chose to support us once again by raising funds for HAE UK whilst running the marathon.

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Go-kart challenge

Jake Towns in taking on a games challenge with some of his friends, in aid of HAE UK - Wolfpack UK

The team, Wolfpack UK, consists of 7 normal people, some of whom like to think they are aspiring racing drivers on a computer/games console, which is how the 7 friends met som 10 years ago!

Three of the team members last year took part in a 3 hour endurance event at the same track, where they were instantly hooked, and started planning a team to take on the task of driving a Go-Kart for 24 hours!

The team consists of: Jake Towns, Cy Farmer, Joshua Towns, Hamish Connell, Dave Ennis, Mike Wilcox and Dan Yates - they will attempt to race 35 other teams, consisting of 3-10 drivers, for 24 hours of non-stop action!

You can read more about this challenge and donate to Team Wolfpack UK, via their fundraising page: www.justgiving.com/WolfpackHAE

Try something new

Our Executive Officer, Rachel, has set herself a challenge this year to ‘try something new’ every month. Rachel aims to show people that, despite having HAE, it shouldn’t stop you from enjoying a variety of activities and sports.

On New Years Day, Rachel took part in the Woolacombe sea swim, in just her bikini! and in February she had a go at archery. Her plans for the next few months include flying a plane, dry skiing and taking part in a 5k or 10k run, amongst other things.

In Memory of Grace Fleischer

Trisha North decided to raise money for HAE UK in memory of her mother, Grace. Grace suffered with HAE but still tried to live her life to the fullest. Instead of flowers, Trisha asked friends and family for donations to HAE UK in Graces memory

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We have also received kind donations from family and friends in memory of Mr Christopher Mead, who sadly passed away in late 2019.

Thank you so much to our donaters & fundraisers.

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Dr Moira Thomas led the meeting. In retrospect, we had made the mistake of holding the Scottish Day on the same day as the final of the Rugby World Cup (but we booked the day before they did!) so it was a bonus for us that Scotland missed going to the final. Dr Thomas is a keen rugby supporter and so she used the rugby team analogy in her presentation about how the C1-INH and bradykinin cascade works. ...how one protein passes to another and then to another. I know I found it a very vivid and clever way to explain a complex process.

Scott Weddle, who does not let his HAE stand in the way of him being a personal trainer, sports masseur and extreme sports specialist, gave an inspiring ‘Patient Story’ culminating with the information that he was about to do a 5000 metre parachute jump. He also was very informative about how in his experience, his HAE attacks have decreased in line with him getting fitter. Other people have also found that being fitter helps reduce their attacks, which is one reason why we are supporting a clinical study being run in Wales to monitor HAE patients with a ‘Fitbit’ to see if this can be quantified.

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The day ended with a lively Q&A session, with our speakers joined by Dr Charu Chopra from Edinburgh who also gave up her Saturday to come to the meeting.

Scottish Patient Day speakers: from left to right, Dr Patrick Yong, Dr Moira Thomas, Dr Charu Chopra, Immunology Specialist Nurse Hazel Millar

Lindsay Lockhart, one of the Public Involvement Advisors at the Scottish Medicines Consortium, gave an informative presentation about how the SMC make decisions on why and how to prescribe medications, this was particularly of interest because we had been working with them in order to have Lanadelumab accepted onto the formulary for use in Scotland, where it is now available.

Hazel Miller, one of the immunology nurse specialists, presented on how to manage attacks, giving some helpful tips on how to make using medication easier and practical ways of alleviating swellings.
ANNUAL PATIENT DAY 2019 - MANCHESTER

On to our National Patient Day in Manchester. This also clashed with a local football match and several concerts so travelling up the day before by train was something of a challenge as the trains were totally rammed full! However, we all managed to arrive safely and had an evening drinks reception at the hotel. This has become a standard part of our procedure now and it is always great to meet old and new members at it.

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OUR 10 YEAR ANNIVERSARY MEETING

In November this year, HAE UK will be 10 years old! HAE UK was set up as a patient organisation by Ann and John Price and John Rixon, with support from HAEI. They held their first meeting in London in November 2010.

Shortly after that, Rachel Annals joined the team working alongside Ann to provide support to individuals with HAE and their family members, and we have been growing in numbers ever since.

In June 2013 HAE UK was registered as a charity. We now have a CEO, Laura Szutowicz, who joined the team when Ann retired in 2015, Rachel continuing her role as EO, a board of 8 trustees and some amazing volunteers working alongside us.

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It is important that in a trial that the two (or more) groups of people in a trial are as similar as possible, except for the treatment they receive. This is because it means that researchers can be sure that any differences in outcomes between the groups are only due to the treatment received, and is why most of the trials for HAE products are confined to HAE Type 1 and 2 because they have the most typical HAE.

Phase 4 trials are usually after the product has got its ‘licence’ and are used to gather information on any side effects caused by long term use of the product and how effective it is in different populations. This type of study is sometimes called a ‘post marketing surveillance’ study.

All clinical trials are strictly governed by ‘ethics’; for example it would not be ethical to have a study where one group was deliberately caused harm.

Most of the large immunology centres will be involved in clinical trials and so you may sometimes find yourself asked if you would be interested in participating. Or you can show yourself willing by asking about clinical trials and whether you might be able to take part.

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The meeting will be held on Saturday 21st November, so save the date now!

Invites will be sent out to all members in the coming weeks, so if you are not sure if you are registered as a member, please e-mail Rachel to check.

We look forward to seeing many of you there.

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Karen's story

I have lived with Hereditary Angioedema (HAE) all my life and was symptomatic with external swellings from about 2 years old. Though I was a “difficult” baby, so may have been having internal attacks from birth.

Like many HAE patients, and people living with other rare conditions, I spent my childhood in and out of GP surgeries and hospital clinics. Even though I was born with the condition, mine was due to a genetic mutation, not heredity, which is even more rare, so there were no family clues to help with diagnosis.

My earliest memory is being about age 4 and seeing a child in an allergy clinic look at me delightedly, saying very loudly to my Mum’s absolute horror “look there’s someone else with a face like me!”

I was seen by many doctors and consultants, who all thought I had allergies. I remember coming home from one appointment & seeing my dad’s face when he was told by my Mum that he had to dig up all the primulas he had lovingly planted, “just in case”.

The hardest time for me was in my early teens. My parents had that support from birth? As a result I changed confidently changed exponentially with that support. I wonder how different my life would have been if I, and my family, had that support from birth? As a result I changed my career and now work in the NHS as a HealthMakers Peer Support & Volunteer Coordinator which is a programme I started in East Berkshire back in 2014. HealthMakers are there to help anyone living with health issues to take more control of their condition & improve their quality of life.

I was finally diagnosed with Hereditary Angio-Neurotic Oedema when I was about 14 years old. Thankfully it’s no longer called that, as it created a certain amount of stigma, and I was often made to feel I was over reacting to period pains or being a hypochondriac.

When I was diagnosed, I didn’t know anyone else with HAE which was rather challenging. That’s why I’m so passionate about peer support! I didn’t meet another person living with HAE until I was 50, when I attended my first HAE UK patient conference. My ability to manage my health confidently changed exponentially with that support.

I was fortunate to grow up with a supportive family and friends. I have been able to work whilst living with HAE and hold down a job my whole life. I have many wonderful people in my life who I would never have met if I didn’t have HAE.

I do however have to be realistic with what I can and can’t do. I have lost count of the number of events & holidays I’ve had to forgo or cancel at the last minute, and the £’s I’ve lost in deposits and tickets not used.... but I still try to live my life to the full.

I also like to share what I can on social media and within the National and local health arena, raising general awareness of the number of people who contend with rare conditions on a daily basis. In addition to this I also like to help the patients & their families & carers to have more understanding of the importance of gaining self-management skills and building appropriate peer support networks.

It’s vital to have hope when living with rare diseases such as HAE. Research is still being conducted and new treatments are still being developed. Things have changed a great deal in my lifetime but knowing that people are devoting their lives to improving the lives of those living with the HAE and other rare conditions gives hope of improved quality of life & maybe a cure. I hope that the advocacy and volunteer work I carry out continues to make a difference.

I believe patient involvement in research and health & care service delivery is vital and key to improving the care we receive. That’s why I agreed to become a Changemaker & I hope by being a part of the #IAmNumber17 campaign it can continue to raise awareness for HAE and all the rare conditions and ensure those who live with these conditions receive the peer support and self-management skills they need to live life to the full.
On to our National Patient Day in Manchester. This also clashed with a local football match and several concerts so travelling up the day before by train was something of a challenge as the trains were totally rammed full! However, we all managed to arrive safely and had an evening drinks reception at the hotel. This has become a standard part of our procedure now and it is always great to meet old and new members at it.

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In your own fundraising event, a personal challenge, shopping online via easyfundraising or by making a regular or one off donation through your bank account or wages. Please contact us for more information.

We have a few individuals who are taking part in fundraising events in the coming months:

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We have also received kind donations from family and friends in memory of Mr Christopher Mead, who sadly passed away in late 2019.

Thank you so much to our donaters & fundraisers.
Every time I report on our activities I am struck by how incredibly lucky we are in the UK to have so many wonderful clinicians, both doctors and nurses, supporting our HAE family. Yes, there can always be improvement, but when I compare us to other countries we are so much further ahead in raising awareness and improving treatment. And why? Well, it comes down to you, our fantastic members who spend so much time and energy in helping others to recognize and understand HAE.

In this issue, we report on our Patient Days, the success of which always depends on people like our amazing presenters and patients who share their patient stories. Also in this newsletter, read about Karen and her engagement with the ‘I am Number Seventeen’ campaign. We are so grateful to these and other members who are so courageous in getting their stories ‘out there’!

Laura (HAE UK Chief Executive Officer)