



## HAE UK Winter 2020 *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 2020 newsletter***

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>

# 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.

You too can help raise money for HAE UK by taking part

## London marathon



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.

You can read more about Terry's story and support him by donating to his fundraising event, by visiting his JustGiving page:  
[www.justgiving.com/Terry-The-Railway-Hotel](http://www.justgiving.com/Terry-The-Railway-Hotel)

## 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 some 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](http://www.justgiving.com/WolfpackHAE)

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:

## 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

## In Memory of Christopher Mead

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.***

# OUR 10 YEAR ANNIVERSARY MEETING

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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.

This coming November we will be holding our 10 year anniversary patient day just outside London. We invite all patients and family members to join us for an informative meeting with some great speakers, and a social gathering in the evening.

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.

## QUARTERLY QUESTION: I often hear about clinical trials, what are they and how do I get involved?

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Clinical trials are the way new medications are assessed and evaluated in order to ensure they are safe and effective for use in humans. They normally happen in a minimum of four stages;

Phase 1 use very small numbers of healthy volunteers to ensure that the product has few and/or relatively tolerable side effects.

Phase 2 goes on to use larger numbers of people actually with the condition, for which the treatment is to be used. This is to make sure the treatment is safe and has some effect on that condition. Phase 2 trials also help to find out what is the dose of treatment might be needed to be effective.

Phase 3 has the largest numbers of patients and they are 'randomised'; that is no-one knows who goes into which various groups. Some may have the product, some the best available other treatment and some may get 'placebo' (dummy) treatment.

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.

HAE UK encourages people to take part in clinical trials wherever possible because it is so important to get new and better treatments to the market.

# I AM NUMBER 17

HAE UK was one of 13 Rare Disease patient groups invited to propose a representative to be featured in the **I am Number 17** campaign about Rare Diseases which is an initiative of Genetic Alliance and backed by Takeda.

The basis of the title of the campaign is that one in seventeen people suffers from a rare disease in their lifetime, so they are actually not that rare!

The representatives, designated as 'Changemakers', were paired with an artist who created an artwork to symbolise the experience of living with a rare condition. Our Changemaker was Karen Owen, whom many of you have met at various Patient Days. She was paired with artist Jazmin Parsons who created a portrait of Karen which was part of the 'I am Number 17' exhibition

Karen used the phrase 'Live with not suffer from' to sum up her experience of living with HAE and feels that Jazmin's portrait sums up the many faces of her life with HAE.

## 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 a troubled marriage, probably not helped by stress of a child who was constantly ill, and they separated shortly



after I started senior school & whilst I was dealing with entering puberty. So my stomach aches and swellings increased in effect & frequency thanks to the combined effect of stress and hormones, which I now realise were all known triggers. All the symptoms still weren't tied together and at least one clinician implied I was 'an attention-seeking neurotic female!'

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 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.

My own self-management regime is based on being mindful of the three possible scenarios we face every day - Well days, hiccups/change days



**Jazmin and Karen at the Oxo Gallery**

and emergency mode. I follow a healthy lifestyle, try to ensure I get enough sleep, that I eat well and have a good work/life balance. This does mean I have to make sacrifices from time to time, and it's important to pace myself by building down time into my routines. I try to not let my condition stop me from being sociable with friends and family.

However, I do see myself as lucky.

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.

# 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.

So onto the day itself, we had a great opening speaker in Dr Dawn Harper. She is a GP in her day job with a particular interest in Women's Health but she is also well known for her appearances on TV where she co-presents 'Embarrassing Bodies' and is one of the medical experts appearing on This Morning and also on the radio on



***Dr Scott Hackett and Michal Rutkowski (HAEi)***

Women's Hour. Dawn gave a very useful and insightful presentation on really speaking to your doctor and getting to the bottom of problems. She also has a wicked sense of humour and was very funny!

Next was one of our medical advisory panel and a favourite speaker, Dr Scott Hackett who is one of the very few specialist paediatric immunologists in the UK and as such looks after the younger generation of HAE patients. His presentations are always full of information and presented in an easy to understand way and again with humour.

We then had another star, Dr Shuayb Elkalifa from Salford Royal. He was one of the team that ran the 10km for us back in May and he just fizzes with energy. He was tasked with the job of explaining the science behind HAE and he

tackled this by casting himself as the 'Superhero C1-INH' and using members of the audience to be Factor XII, kallikrein and Rachel got cast as 'the bad guy' bradykinin! Dana Shapiro managed to film this and put it on our Facebook page, it is great fun and well worth scrolling through our Facebook page to find!



***Rachel Annals and Michal Rutkowski (HAEi)***

One of our greatest supporters is Michal Rutkowski, HAEi Vice President and President of HAE Poland, who has been coming to our Patient Days for several years now. He is one of our most popular speakers as people love hearing about HAE around the globe and the various activities of HAEi.

Our Patient Story was our wonderful Alex Graham, one of our Patient Ambassadors, who told us her patient story and also updated on the Young Advocates group.

In the afternoon, Patrick Yong gave a different presentation of the hows and whys of new treatments and the importance of being involved in clinical trials.

Our presentations ended with June Cole giving us a look at the various activities she has done to raise awareness, but particularly her going into GP surgeries and A&E departments to tell them all about HAE. June is a very good ambassador for HAE UK and she and her husband Peter deserve our heartfelt thanks.

The day finished with some patient breakout groups, mentored by Lisa Smith, John Dempster, Scott Hackett, Patrick Yong and Lorena Lorenzo, then a Q&A session to wind up.

# SCOTTISH PATIENT DAY 2019

In the UK we are very lucky to have a lot of expert clinicians to call on, and this year our Scottish Patient Day was held in Glasgow. So the Glasgow team were called on to help and, as always, they were magnificent!

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.



***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 explanation of 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.

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.

Dr Thomas presented again on getting the most from your appointment and also the new products coming in the future, many of which are being researched at centres across the UK.

Dr Patrick Yong travelled up from Surrey to give his popular presentation on the 'History of HAE'. Patrick is also the lead on the HAE Consultant Network, which is now functioning as a division of the UKPIN which is the UK association of immunology doctors and nurses.

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.

# OUR MEMBERSHIP DATABASE

## 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

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.

## RARE DISEASE DAY 2020

Each year HAE UK supports Rare Disease Day. This year we have been helping raise awareness of HAE with a number of social media posts with facts about HAE and snippets from some of our members patient stories.

#7daysofhae #haepatientstories #rarediseaseday2020

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

[facebook.com/haeuk/](https://facebook.com/haeuk/)  
[twitter.com/hae\\_uk](https://twitter.com/hae_uk)  
[instagram.com/uk\\_hae](https://instagram.com/uk_hae)



*With our very best wishes*

*from Laura (CEO), Rachel (EO) and the HAE UK team*

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