



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

I am quite surprised to find myself writing an 'end of year' newsletter. When we all went into 'lockdown' I was sure the time would really drag.....then there was a sudden return to semi-normal and we decided to make our 10 year anniversary patient day virtual.

The annual Patient Days are an enormously important part of our calendar and they are hugely enjoyable, a chance to catch up with old friends and on opportunity

to involve the new ones. We had kept in touch with our members via Zoom meetings since the first lockdown in March, which were very successful, and our wonderful expert panel gave their time to give presentations and answer questions. But we had authorised a virtual event and was it a mistake?

Laura (HAE UK Chief Executive Officer)

OUR 10 YEAR ANNIVERSARY VIRTUAL PATIENT DAY

Well, definitely 'NO'! The virtual event has been a massive success, due in no little part to Rachel Annals who collated and helped edit the various presentations. Our wonderful panel of experts proved how we have clinical support that is absolutely top class and the patients who were kind enough to share their patient stories yet again showed how having HAE does not stand in the way of living your best life.

Inviting you to join us

People were invited to the event by being sent an

invitation card which was actually full of lovely flower seeds to plant for next year. Big thank you to Furkhanda who assisted in sending all of these out to each household registered with us. We thought this was a nice living memory of our milestone event, rather than something that might get thrown away.

The youngest members of HAE UK were sent a Percy the Pufferfish bag full of Percy goodies and a colouring competition. We had some fantastic entries for the competition, well done to all who participated, the following winners have prizes on the way to them:

Under 5s group - Dean, age 4
5-8 years group - Charlena, age 6
9-12 years group - Charlie, age 9

The cocktail party

We started our celebrations with the 'virtual cocktail party' on Friday evening. The evening pre-meeting reception has become a feature of the physical Patient Days for many years, and we were a little worried that it might be Rachel and me staring at one another over a glass. However, lots of friends turned up, notably Furkhanda (who is always a major support at all our events) drinking something that was berry-flavoured (hence part of her 'five a day' fruit and veg!) and Nikki Pitt with an enormous red wine.



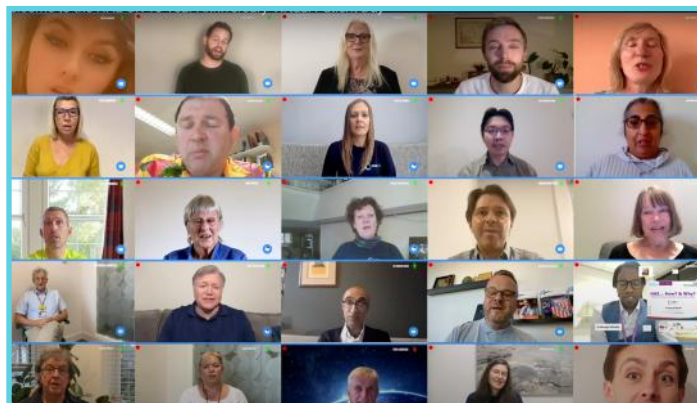
One of our Trustees, Tim Crouch and his wife Sue, definitely won the 'best turned out' prize both being in immaculate evening dress. We had circulated a menu of cocktails and snacks and it was wonderful to see everyone enjoying themselves.

Seeing everyone in the little Zoom boxes is a bit like a box of chocolates....

We also held a competition over the anniversary weekend, asking people to share photos of themselves celebrating. We struggled to decide a winner, so awarded prizes to the Sealey family and Nikki Pitt, whose winning photo's are above.

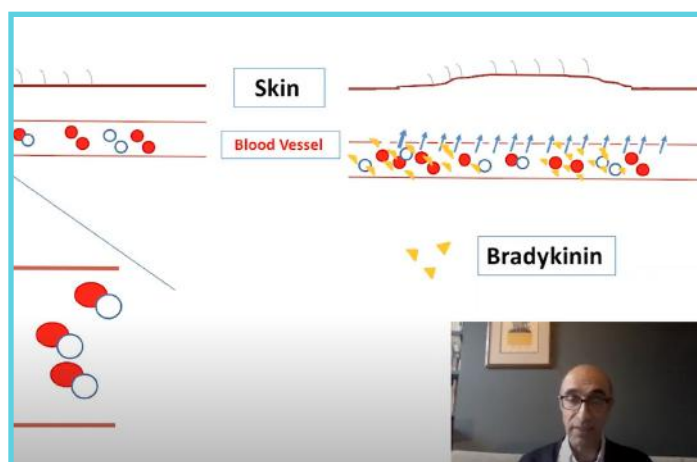
The Patient Day

There were many presentations to watch throughout the day, some introducing the various people involved in HAE UK and what HAE UK can do for members.



There was a wonderful presentation by Ann Price, the founder of HAE UK, along with Henrik Boysen from HAE International and Dr Hilary Longhurst, detailing the background of why there was a need to start an organisation and how they went about setting it up 10 years ago.

We also had excellent presentations by many of our clinicians about topics ranging from 'HAE – Why? How?' with Dr Schuab Elkhailifa as the Superhero C1-INH 'Keeping Fit and Healthy with HAE' by Specialist Nurse John Dempster. Dr Patrick Yong gave a reprise of his History of HAE as well as an update on the activities of the HAE Clinical Network. Dr Scott Hackett was his usual expert self on dealing with children and young adults with HAE, Dr Hilary Longhurst, who is now living in New Zealand, presented on HAE and women and Dr Sorena Kiani gave a very interesting presentation on current treatments for HAE and what might lie in the future.



Dr Mark Gompels and his Specialist Nurse Lisa Smith presented on the important clinical trials are to furthering treatment and knowledge of HAE. Immunology Nurse Specialist Fran Ashworth brought us up to date on the work of the nurse specialist. Dr Dawn Harper may not be familiar to most of the HAE community but she is

a well-known doctor on TV and radio in the UK and she presented on how to get the most from your GP appointment. And Tony Costaldo gave an update on the world wide activities of HAE International.



We also had patient stories from Dana Shapiro, one of our Trustees, on how she climbed Mount Kilimajaro, and Scott Weddle and Paul Carroll, who are both amazing fitness people. The most important message from their presentations is that anyone can do it but take it slowly and gradually build your fitness, don't think it can all be done at once.

We would like to say a huge thank you to everyone who took part in presentations for our event, they are all really great!

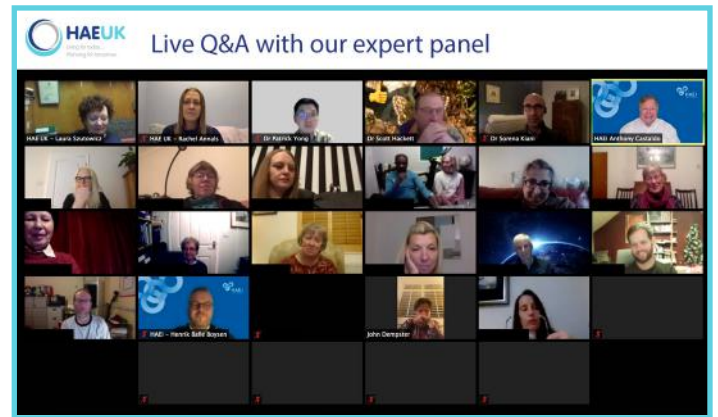
It's still not too late to watch the presentations as they are still on our website. Visit haeuk.org/pd2020 to view them.

Live Question & Answer session

On Saturday afternoon we held a live Q & A session via Zoom, with Dr Scott Hackett, Dr Patrick Yong and Dr Sorena Kiani, alongside Tony Costaldo and Henrik Boysen from HAE International.

It was such an interesting and productive meeting that we over ran time a little, but we had lots of interesting questions. One of the topics was around having Covid vaccinations and the basic message was, discuss it with

your care team but the results so far are really promising. We also touched on the importance of mental health issues and how we need to recognise these to assist people who might otherwise just say 'yes, I'm fine'



Finally - The Quiz

The day finished with a very testing quiz, Rachel is our quizmistress extraordinaire and never fails with some great questions...Did you know wombats have cube shaped poo?

We had 13 teams taking part and awarded prizes for the winning individual, couple and group.

Well done all who took part, it was a great end to our 10 year anniversary Patient Day.



THE COVID VACCINATION

Many people have been asking us about the new Covid vaccinations and whether or not they should have one. The advice from our medical advisory panel is 'YES – unless you have had a previous severe reaction to a vaccination, it is definitely a good idea'. If you have any queries please talk to your immunology team'.

Remember the best way to keep yourselves and your families safe from Covid is to remember 'Hands, Face, Space' - wash your hands regularly for at least 20 seconds, wear a face covering in indoor settings and maintain social distancing.

MEET YOUR CONSULTANT - Dr Shuayb Elkhaliifa

Dr Elkhaliifa is a clinical Immunology consultant, currently working at Salford Royal NHS Foundation Trust. He is trained at the Health Education England North West. During his training he served as a trainee representative to Regional, National, European and International immunology and allergy associations and societies including ESID, BSACI & UKPIN.

Currently he is a trustee member at UKPIN, council member of the section of pathology at Manchester Medical Society, member of the National Education Strategy Group for Allergy, editor at Rheumatology Journal, served as an expert advisor for MTEP/NICE in addition to few other leadership and managerial positions at various organisation and societies.

Dr Elkhaliifa published mainly in the field of Immunodeficiency, autoimmunity, drug allergy and anaphylaxis, and participated in The British Society for Rheumatology's Choosing Wisely UK 2018 recommendation.

Innovation in education is his passion; he has been honoured with multiple awards including the Excellence Report Award (Ref No. 1125633) from Central Manchester University Hospitals and the Dragon Den award from Health Education England (HEE) with Dr Calisti for their work on the Drug Allergy App project.

Music, dancing, meditation and traveling are keeping him sane; the world after covid-19 took away traveling; but kept him with three which are satisfactory for now.

ESID: European Society for Immunodeficiencies
BSACI: British Society for Allergy & Clinical Immunology
UKPIN: United Kingdom Primary Immunodeficiency Network
MTEP/NICE: Medical Technologies Evaluation Programme/ National Institute for Health and Care Excellence



MEET YOUR CONSULTANT - Dr Patrick Yong

Dr Patrick Yong works as an Immunology Consultant in a large networked service providing care for people in Surrey and Berkshire. He qualified in medicine from Bristol in 1998 and trained in immunology in London.

Dr Yong has a particular interest in the organisation of care for people with HAE, and has helped establish a UK network for clinicians in the UK with an interest in HAE, which he currently chairs. He hopes that this will contribute to further continuous improvement in the care

of people with HAE. He also has a keen interest in research with over 25 published papers.

Dr Yong has also been a very valued and popular contributor to our Patient Days over the past few years and our recent Zoom meetings.



NEW TREATMENTS

Bertralstat, the oral prophylaxis treatment manufactured by Biocryst, is available in the UK under an 'Early Access Medicine' scheme. This means that, even though it is not fully licensed, clinicians in the UK can prescribe it where they think appropriate. So this is yet another product available to our clinicians to use for patients. It has shown some very good results in clinical trials.

Lanadelumab has now been licensed and patients who fulfill the criteria for C1-INH prophylaxis now have the choice of either C1-INH or Lanadelumab. It is working very well for many patients, but not for others. Never,

ever feel it is 'your fault' if you don't get good results or have side effects from any of your HAE treatments. It is important you discuss with your immunology team, they really need to know so they can ensure you get the best possible treatment for you.

As we always say, there is no 'one size fits all' for HAE treatment and what works really well for one may not necessarily work as well for someone else. So it is wonderful news that there is an ever-widening pool of HAE treatments for people to try.

NEWS FROM THE CLINICS

The Royal London has become a recognised UK ACARE centre, Angioedema Centre of Reference and Excellence. Many more centres will become accredited in the UK in 2021, helping create an interactive network of HAE reference and excellence around the world.

Dr Hilary Longhurst and her husband have recently moved to live in New Zealand. They are very keen trekkers and, as a thank you for Dr Longhurst's support over the past 10 years, HAE UK gave them some vouchers to use in outdoors store in New Zealand. Even with the new sites

to explore, Dr Longhurst still found time to record her 'Women with HAE' presentation for our Virtual Patient Day!

Professor Marcel Levy, CEO and Haematologist at University College London Hospital, is returning to his homeland of Holland, to be the Chief Medical Advisor there. Professor Levy has a special interest in HAE and some of you may have seen him; he is going to be much missed in UK.

LOOKING FORWARD TO 2021

Phase 3 clinical trials will be starting in UK of two very exciting products, a monoclonal product garidacimab which targets FXII (this could be a very interesting product) and an oral bradykinin antagonist ('oral Icatibant'). Dr Sorena Kiani at Royal London is the lead investigator for both of these.

Later in the year, hopefully, there are two more products that will be entering the Phase 3 trials, these being usually the ones before going for licences. So many new products coming up for HAE patients!

We will be holding two Zoom meetings in the first quarter of 2021, with Dr Mari Campbell who is the clinical psychologist working with Immunology patients, primarily at Royal Free. Dr Campbell will be investigating how to deal with the anxieties of having a rare disease and dealing with the extra burden of Covid -19 in her first presentation. The second meeting will be a Q&A answering patient questions.

We are really excited at this opportunity to give our members access to clinical support like this. More information will be available soon.

*With our very best wishes for
a safe and happy Christmas and a healthy New Year
from Laura (CEO), Rachel (EO) and the HAE UK team*