



HAE UK Autumn 2019
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 Autumn 2019 newsletter

I feel this is a little like being back at junior school and writing about 'what we did on holiday'! We have a lot of things to report that have happened since the last newsletter.

First, we are very excited that Lanadelumab was finally passed by the National Institute for Health and Care Excellence (NICE) so that, assuming there are no substantiated objections, it will be available to be prescribed under NHS England guidelines. Effectively, this will place it in the same area as C1-INH prophylaxis, so for patients having two or more clinically significant attacks per week.

Lanadelumab is a subcutaneous injection, so will be easier to use for many patients who may not have been trained

for C1-INH self-infusion, those who have poor veins or other reasons for not using C1-INH. It is used every two weeks and gradually, once control is well-established, many people find it controls their attacks used monthly.

Rachel and I were involved all the way through the process and it was pleasing to have the NHS England team very complimentary about the evidence we provided.

There are still more innovative products being developed for HAE patients and so there is a bright future. We would urge anyone to take part in clinical trials if you are asked, these trials are essential for advancing the treatment for HAE patients.

Laura (HAE UK Chief Executive Officer)

ANNUAL PATIENT DAY 2019

We are just two months away from our annual patient day. Registration is open and places are filling fast. You can register your place via our website: haeuk.org

EVENT DETAILS: Saturday 23rd November 2019, 9:30am to 4:30pm. The Renaissance Hotel, Manchester.

SCOTTISH PATIENT EVENT

We will be travelling to Scotland for our annual Scottish patient event in a few weeks time. We only have a few spaces left so if you want to join us, please register asap.

EVENT DETAILS: Saturday 2nd November, 10:00am to 3:00pm. The DoubleTree Hilton, Glasgow.

FAMILY FUN DAY



in August we held a family fun day at the Railway Hotel in Breatwood, Essex. This event was organised by one of our Trustees, Ann Harding, and was a fantastic afternoon.

We were a little worried by the weather forecast but actually we were lucky to have a glorious afternoon.



The pub beer garden was packed, the face-painting lady was unable to take a tea break because she was so busy, and the bouncy castles saw great use! We also had garden games, craft activities, sweets and

ice creams.

Declan was a super-chef who spent the afternoon grilling burgers and delicious sausages. We had some fabulous prizes donated for the raffle and we raised over £800 in total during the afternoon!

Many thanks to everyone who supported us by donating raffle prizes and joining us on the day. And special thanks to Ann Harding, the Railway Hotel and to June and Peter Cole who came along to help.



HOME DELIVERY OF HAE MEDICATION

- Make sure your prescription is always up to date – they normally last for 6 months. If it is out of date your home delivery company cannot send you out any product – it is illegal. The home delivery company will not know that your prescription is out of date until they try to fulfil the order, so it is important to keep a diary note or have a phone reminder to order a new prescription. Contact your centre who will send your prescription on to the home delivery company.
- Order in good time; don't wait to run out of medication before you order, especially if you are not using your product very frequently!
- If travelling, make sure you have at least one treatment more than you think you will need
- Please ensure that you have at least an annual review with your Immunology Centre. Some centres, such as the Royal London, are going to be able to do this via Skype or over the phone, which will make this easier for patients with long distances to travel. Even if your HAE is well under control and you are not having any attacks, it is so important that you have these reviews as it assists clinicians to get an overall picture of how your condition affects you.

YOUNGSTERS EVENT

On Saturday 31st August we held our first youngsters event at the Drayton Manor Hotel. 14 youngsters attended and had a great time getting to know one another and learning about advocacy. Our two Youth Ambassadors, Alex and Jack, along with Rhiannon, attended the HAEi Youth Advocacy Forum in Atlanta a few weeks before and they shared their knowledge with the youngsters and they worked together on ideas to raise awareness in the UK. We

had some great feedback from the event, with the youngsters really enjoying getting to know others with HAE for the first time.

After the event we all spent a few hours enjoying Drayton Manor Theme Park, courtesy of some of our amazing HAE UK fundraisers.



OUR NEW LOGO



You may have noticed we have recently changed our logo. We have created the new modern logo to reflect our continuous working together with patients and medical professionals, to grow our organisation for the benefit of our HAE patients. The new logo will slowly appear on our literature in the coming months.

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.

QUARTERLY QUESTION - What is Lanadelumab?

Lanadelumab (trade name Takhzyro) is what is called a monoclonal antibody. This is a recombinant product (not human plasma derived) which specifically controls plasma kallikrein activity in the body and so limits production of bradykinin, which is what causes the swelling of HAE. So it is a different mode of action to C1-INH injections, which replace the C1-INH that is missing.

Lanadelumab is used regularly (twice a month) to prevent attacks. It is not an acute treatment, so will not work to stop an attack once started. It comes as a prefilled syringe that is injected under the skin, similarly to Icatibant. Preferred sites are the tummy, thigh or upper arm.

NEW CLINICAL TRIAL - Do you want to take part?

The Royal London is the first centre in the world to be running a clinical trial of a new oral medication for people with HAE.

The Royal London immunology department are enrolling patients for a trial of an oral drug for acute attacks of HAE. The hope is for this drug to control HAE attacks early enough to prevent a full blown swelling. If effective, this would be ideal for patients who are not keen on taking regular medications or using injections for acute treatment.

Male or female patients over 18 years of age, with HAE type 1 or 2, are eligible to be considered for recruitment unless their nearest immunology centre is also planning to run this trial.

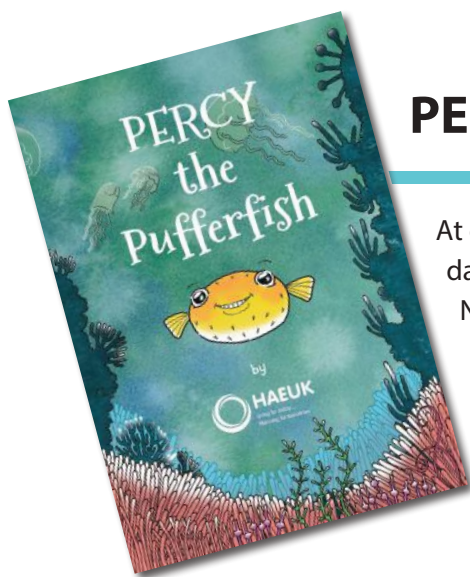
The medication is to be used as soon as the patient notices

the beginning of an HAE attack.

Any patients with 2 or more attacks in 93 days are eligible for this trial. If you are on a prophylactic (preventative) medication (e.g. Danazol, Oxandrolone or Tranexamic acid, regular C1 esterase Inhibitor), you will be asked to stop this before the trial and restart after the trial is completed. The length of time needed for stopping prophylactic medication is varied for different medications.

You would have 4 visits to the clinical research facilities at the Royal London Hospital for the purposes of this trial. There will be a fee of £200 per visit for your time in addition to travel and accommodation if required.

If you are interested to know more, please contact Dr Sorena Kiani via e-mail on:
BHNT.Advice-Immunology-Barts@nhs.net



PERCY THE PUFFERFISH

At our annual patient day in Farnham last November, we held a youngsters session alongside the main event for part of the day. The group of

youngsters together created a short story about 'Percy the Pufferfish'.

We have now had their story made into a lovely illustrated short storybook, aimed at younger patients with HAE. Please let Rachel know if you would like a copy of the book.

With our very best wishes

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

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