



HAE UK Spring 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 Spring 2019 newsletter

As the weather slowly starts to improve and the days get longer we hope everyone will shake off all the little bugs that have been apparent over the Winter and are particularly problematic for people with HAE.

One of the things that concerns us with some of the recent Facebook posts, is that people are still tolerating increases in their attack rate and blaming it on their HAE. We cannot emphasise enough that if you suddenly start having more attacks than normal, or they don't seem to

respond to treatment, this is something you **MUST** discuss quickly with your care team. It is very likely that there is some simple reason for this, be it a nasty cold leaving you with a sinus infection that then triggers more attacks than normal.....but it can and must be dealt with.

Is there anything you'd like to read about in our newsletters? I would love to hear from you, so please get in touch!

Laura (HAE UK Chief Executive Officer)

ANNUAL PATIENT DAY 2019

Preparations are underway for our annual patient day, this year we will be travelling to the Manchester/North West area. We will share details about the event with you all in the coming weeks once finalised.

SAVE THE DATE: Saturday 23rd November 2019.

FAMILY FUN DAY FOR HAE

Our Trustee, Ann Harding, is helping to organise a Family Fun Day in aid of HAE. This event will be taking place in

SCOTTISH PATIENT EVENT

We will be travelling to Scotland again for our annual Scottish patient event. Registration for the event will be open soon and all members will be invited to join us.

EVENT DETAILS: Saturday 2nd November, 10:00am to 3:00pm. The Grand Central Hotel, Glasgow.

August in Brentwood, Essex. More information will be sent out soon...we hope you will be able to join us!

#HAEDoesntStopMe

Please help us raise awareness of HAE this coming HAE day :-) 16th May

In the coming weeks we will be sharing a poster with you with the hashtag #haedoesntstopme. The idea is you print the poster, write something about yourself on it, take a selfie with your poster and share to social media using the hashtag. If you do not use social media you can always send the photo to Rachel who will upload it to our Facebook group on your behalf.

Having HAE shouldn't stop you from achieving your dreams. Please join in, share your achievements and help inspire others! Keep an eye out for the poster!

PERCY THE PUFFERFISH

At our annual event last year, the group of youngster attendees together wrote a story about Percy the Pufferfish. We are excited to bring this to you in a short story, as a simple advice book for young patients. Look out for Percy the Pufferfish, he will be coming to a book near you very soon...

PIPPA ADAMS - PUBLICATION

We all know how emotional stress can affect HAE and many of you will remember that we sponsored Pippa Adams to carry out her Psychology Masters dissertation with the subject - The Psychological Wellbeing of Patients who have Hereditary Angioedema. This was recently published in The Bulletin of Health Psychology, a very prestigious publication. Congratulations Pippa!

FITBIT PROJECT

We are sponsoring another project which is being run by the University Hospital Cardiff Immunology Department, so some of you may be finding yourselves enrolled in it!

The project uses Fitbits to see if improving physical fitness may help to reduce HAE attacks. This will be run as a clinical trial so we can look forward to another publication in due course.



young HAE UK
living for today planning for tomorrow

Our first HAE UK

Youngsters Event

Saturday 31st August 2019
9:00am to 12:30pm
Drayton Manor Hotel, Staffordshire

If you are a HAE patient, or sibling, aged between 12 and 24, we would love you to join us to learn about HAE, hear from other HAE youngsters, make new friends, learn about advocacy and have some fun!

The event will start at 9:00am with presentations and activities, followed by lunch, before a fun afternoon in Drayton Manor Theme Park.

There are a limited number of spaces for this exciting event. **Registration is essential** and strictly on a first come first served basis. You must also be a member of HAE UK. You can register at: www.haeuk.org/youngsters-event

Participation includes theme park tickets for Saturday 31st and overnight accommodation at the Drayton Manor Hotel on Friday 30th, if required.

For more information, please contact Rachel at HAE UK on: rachel.annals@haeuk.org

Due to the fantastic fundraising efforts of some of our members, we are able to purchase the theme park tickets for all attendees. Each attendee under the age of 16 will also receive a theme park ticket for one parent or guardian to accompany them. Parents/Guardians of all attendees will be welcome to meet with other parents in a separate room whilst the youngsters event is taking place. You will also be invited to join us for lunch.



MANCHESTER HALF MARATHON

The Immunology Department at Salford Royal Hospital, Manchester, are running in the Manchester Half Marathon on 19th May 2019. We hope some of you will be able to go and cheer them on!

They are raising money for HAE UK and will be wearing HAE UK t-shirts.....anyone wishing to support them by donating can visit their Just Giving page: www.justgiving.com/Lucy-Common

'WE ARE HAE' WEBSITE

Pharming has recently launched a disease awareness website for people with HAE in the UK. You can learn more about symptoms and triggers, get travelling tips and understand treatment options. If you would like to know more please visit the website: www.wearehae.co.uk

QUARTERLY QUESTION - How can I travel safely with HAE?

It is really important you plan well ahead of any trip, especially if you're travelling abroad. Ensure you have adequate insurance and a plentiful supply of medication.

You must always carry your supply of C1 inhibitor or Icatibant with you in your hand luggage so it is easily accessible in an emergency. These medications can be kept at room temperature but must not exceed 25 degrees, so if in doubt, pack them in a cool bag. You will need a letter from your consultant explaining the medication you will be carrying and keep it together when travelling. You will need to take it out of your hand luggage when entering security at the airport, explain that it is medication and keep it separate from your other belongings.

When arriving at your destination find somewhere cool and safe to keep your medication for the duration of your stay.

If you have any questions about travelling with HAE or you'd like advice on hospitals in a country you will be visiting, please contact Rachel: rachel.annals@haeuk.org

HAEi YOUTH ADVOCACY WORKSHOP

We are really pleased that three of our UK youngsters will be travelling to Atlanta, Georgia, USA, in the summer, to participate in the first HAEi Youth Advocacy Workshop. This will be a very busy few days where they will also meet with other young HAE youngsters from all over the world. We hope they will all have a fantastic time.

These three youngsters will then be joining us at our Youngsters Event on 31st August to share some of the things they have learnt. We hope lots of our UK youngsters will be able to join us for this fun day.

C1 INH SUPPLY

Since the extreme shortages of C1-INH at the end of last year, supplies are starting to return to normal. CSL Behring stress that in order to ensure everyone gets supplied, they are continuing their policy of delivering smaller amounts fortnightly, instead of larger amounts less frequently. They hope that using this strict supply control will be sufficient to replenish their supplies and deliveries can then start

returning to normal in the coming months.

If you are having particular difficulties please contact HAE UK in person via e-mail or phone for advice and/or support. We are here to help you, anytime, but can only respond to individuals who contact us in person.

HAE PATIENT SURVEY

The HAE Clinical Network is a group of HAE expert doctors, with one doctor from each region, that we have been involved in setting up. The network is chaired by Dr Patrick Yong, whom some of you will have seen and heard from at the 2018 Patient Day. The team have developed a survey and they hope the results will inform them on where they can improve their services for HAE patients, and also hopefully tell them what they do well!

Some of you have already completed this survey, but it would be great if we could have more. The survey is quite long, about 50 questions, so will take about 20 minutes to complete, but it is a really important piece of work so please do take part if you can. Thank you.

The survey can be found at:

www.surveymonkey.co.uk/r/HAEUK_patient_survey

OUR MEMBERSHIP DATABASE

We e-mailed you all a while ago about our membership database and letting you know we are in the process of setting up our new system. You can expect to receive an

e-mail from us in the near future, please respond to it so we can include you on our new system and continue to send you important information and invites to our events.

HAEi GLOBAL CONFERENCE

The next HAEi Global Conference will be held in Frankfurt, Germany in May 2020. This will be an exciting event with over 600 patients, family members, HAE experts and

industry professionals travelling from all over the world to take part. More details about this event will be available from HAEi soon.

With our very best wishes

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

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