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(HAE UK Chief Executive Officer)

HAE UK is an Association of HAE Patients, working together to improve the situation for all HAE Patients in the UK

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

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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.

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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

QUARTERLY QUESTION - How can I travel safely with HAE?

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 younger 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.

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, 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: rachelannals@haeuk.org

Due to the fantastic fundraising efforts of some of our members, we are able to purchase 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 in accompany them. Parents/guardians of all attendees will be welcome to meet with other parents in a separate room whilst the young event is taking place. You will also be invited to join us for lunch.

#HAEDOESNTSTOPME

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

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