

HAE UK Summer 2017 *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 Summer 2017 newsletter

Welcome to the Summer Newsletter! I hope that the fine weather will continue at least until the first of our Huddles, which Rachel has arranged for the end of August.....see later in the newsletter.

The General Election has sent shockwaves amongst the Rare Diseases community with two of our best Parliamentarian supporters, Nicola Blackwood and Ben Howlett, losing their seats. Fortunately Philip Dunne, MP for Ludlow, is still Minister of State for Health and is a great advocate for Rare Diseases and will ensure the implementation of the Rare Disease Strategy.

Later in this newsletter we reveal more details about the two patient days.....we look forward to seeing as many

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THE QUARTERLY QUESTION:

I am travelling abroad this summer and am a little worried about what to do with my medication. Can you help?

of you as possible! For those of you who have not been to one of our patient days before, we try to aim for a mix of information and socialising, and for those of you new to HAE UK it is a great way to meet other people with HAE and to put faces to the names. The theme for the Patient Days this year is 'Living Well with HAE'.

EMERGENCY BOX - COMPETITION

Alex our Youth Ambassador, is running a competition. The idea is to create a design to be printed on special emergency boxes. The box is designed to contain a supply of acute attack medication and any letters, 'who to contact in an emergency' information etc, so if you were to have a severe attack you could just grab your box and head to A&E. This would also work well for children to keep in their first aid room at school. For more information please contact Alex: alex.graham@haeuk.org

★ SECOND SCOTTISH PATIENT DAY - 30/09/17

Our first Scottish patient day last year was very successful, with attendees keen to have another. So we have arranged this year to hold it at the **Grand Central Hotel, Glasgow, on Saturday 30th September.**

Registration and coffee/tea will be from 10:00-10:30am followed by presentations from clinicians and patient experiences, lunch, and then small breakout sessions in the afternoon. The final agenda will be available nearer the day.

You must register to attend this FREE event. **Registration is open now. Visit: www.haeuk.org/patient-day-glasgow**



★ ANNUAL PATIENT DAY - 18/11/17

Our Annual patient day will be held at the **Mercure St Paul's, Sheffield, on Saturday 18th November.**

We are finalising the agenda at the moment and have some excellent speakers lined up. We will also be having small breakout sessions in the afternoon to enable you to get together and discuss more specific things. The day will start with registration and coffee/tea from 9:30-10:00am and the day will finish at 4:30pm. Lunch will also be provided.

On the evening of Friday 17th November we will also be holding a social get together for those of you who will be staying in Sheffield ahead of the patient day the following day. This will be a drinks reception where you will have the opportunity to meet and socialise with other patients and family members in a relaxed environment.

You must register to attend this FREE event, **registration is open now. Visit: www.haeuk.org/patient-day-2017**



QUARTERLY QUESTION

I am travelling abroad this summer and am a little worried about what to do with my medication. Can you help?

- Firstly, discuss with your immunologist in advance of your holiday, ask him or her to provide you with a letter which briefly explains HAE and the medication that you need to carry with you.
- Get in touch with Rachel (who is an HAEi executive committee member) Rachel may be able to put you in touch with a HAE representative in the country you will be travelling to, or advise of the nearest hospital to your destination.
- Ensure you have plenty of medication to last your trip, as well as an extra dose in case you are delayed returning home. It is **really important** you carry all of your medication in your hand luggage, along with the letter from your immunologist, so you can keep it with you at all times. This is to ensure it doesn't get lost with hold luggage and you have it to hand in case of an emergency!
- When you arrive at the airport and enter security, make sure you take your medication out of your bag so it can be scanned separately.
- C1 and Icatibant must be stored below 30 degrees, so if you are travelling somewhere hot and do not have air conditioning, it would be best to keep the medication in a fridge or cool place.
- And most importantly, relax and enjoy your holiday!

★ OUR FIRST HUDDLE - LONDON



We are really pleased to confirm we have now booked our first HAE UK Huddle!

Huddles are designed to get local people with HAE to meet with others in their area for support and friendship. The Huddle will take place on Friday 25th August from 5:00pm to 8:00pm at the Regent's Cafe in Regent's Park. If you live in the London area it would be really great to see you!

This will be a completely social event with no presentations taking place; come along and join Laura and Rachel for a chat, a drink and a slice of pizza! Please e-mail Rachel if you will be attending so we can ensure we order plenty of pizza for everyone!

If you would like to hold a Huddle in your area, please contact Rachel and we will look at arranging this with you.

GET TO KNOW YOUR IMMUNOLOGIST



Dr Mark Gompels is a Consultant Immunologist and Allergist at Southmead Hospital in Bristol and Musgrove Park Hospital in Taunton.

Mark qualified in 1986 and has worked in London, Newcastle and Bristol, starting as a consultant in Bristol in 1999. He has been interested in HAE since his arrival in Bristol, when he found that there were significant problems in the diagnosis and treatment of patients with HAE. He was responsible for compiling and publishing the first UK HAE Guidelines, still widely cited and more recently he has been involved in updates and International guidelines. He is currently a medical advisor to HAE UK and Clinical lead for Immunology. Mark also has a keen interest in HIV care and looks after and conducts research for both HAE and HIV patients.

Mark has HAE clinics at both Bristol and Taunton, managing a large number of patients. Patients are encouraged to adopt the most suitable forms of therapy that allow them to have the most fulfilled and productive lives.

Outside of work Mark is actively involved in a busy family life with his five children. He likes to cycle and swim for relaxation, and has taken up training guide dog puppies!

WE WILL PRESENT IN YOUR GP PRACTICE OR A&E

This is a great opportunity to raise awareness of HAE in your local area. If you would like this to happen in your area, we can assist. We will visit your GP or A&E and give an introduction to HAE, diagnosis and treatment. All we ask you to do is to find out when the departmental or practice meetings are and if they would like to learn more about HAE. Then give us the contact details and we will arrange a meeting and presentation. We would like you to come along too! Please e-mail Laura with your details.

ADVICE LINE

We will soon be running a trial of a HAE advice line. This will be an opportunity to phone and speak to an immunology nurse about anything that is concerning you. We are recruiting a team of volunteer nurses who will be available for short one-to-one conversations at a set time each week. More details will follow.

DIARY APP

In the Spring newsletter we trailed the launch of the diary App for recording your treatment and attacks. This App is now available to download from www.myhae.co.uk; click on the relevant App store and download the app. Please note, the App is intended for use on iPhone 5, 6 and 7, and the most popular Android phones, but it will not work on a tablet or iPad.

PATIENT RESEARCH

We have been contacted by Oracle Fieldwork who are carrying out a study into the experiences of people with HAE. This study will be conducted by telephone interview and they are looking to interview five people aged 9-17 years and five people 18 years old or over. The interviews are conducted to strict protocols, especially in the case of the younger people, so you need have no worries about disclosing information to them.

If you would be interested in taking part, please contact Stella Frost on 0161 284 889 or e-mail: stella@oraclefieldwork.com as soon as possible. Stella will be able to send you all the information you will need to decide if you wish to take part. Details also available on the news page on our website: www.haeuk.org/hae-news

PERIPHERAL ATTACKS ANIMATION

The Peripheral Attacks video www.peripheralattacks.co.uk has been made into a quick and easy to follow animation. It is now available from our website – **see the news ticker!** Use it on its own or with the longer video to show your GP, nurse, school or employer, as a way of helping them understand more about HAE.

If you have any suggestions or ideas for our next newsletter, or a question for our Quarterly Question, we would love to hear from you. Please e-mail us.

*With our best wishes from
Laura (CEO) & Rachel (EO)
and the HAE UK team of Trustees*

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