



Living for today....
Planning for tomorrow.

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 2016 newsletter

It seems no time at all since we were writing the Summer newsletter, we have no idea where the time goes. Some exciting things have happened for HAE UK since then, such as the first Scottish meeting, more of which later.

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NEW Clinical Commissioning Policy
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THE QUARTERLY QUESTION:

What age should I test my child for HAE?

NHS England Clinical Commissioning Policy for Prophylaxis with C1-INH

Very important news for HAE Type I and II patients was the release of the new NHS England Clinical Commissioning Policy for Prophylaxis with C1-INH.

This had been under scrutiny of the Allergy and Immunology Clinical Reference Group and was released for routine commissioning in July 2016. Under the terms of reference people suffering two or more clinically significant attacks per week, and who have not responded to oral treatments, are eligible for this prophylaxis. The crucial part of the statement is:

'A clinically significant attack is one which is i) potentially life threatening because it affects the head or neck or ii) causes pain or disability such that the patient cannot continue their normal activities. This may be due to disabling cutaneous swelling, sufficient to prevent the patient from undertaking normal activities

or severe abdominal pain which will not respond to oral analgesia.'

So it is being recognized that peripheral or abdominal attacks can be as disabling as the more dramatic laryngeal ones.

This is a great advance for HAE Types I and II and I know that several members are already benefiting from this new policy.

For the full version of the policy go to our website: www.haeuk.org

The CRG have also recommended that Oxandrolone be made available for people who were taking Stanozolol, which is no longer available.

Our first Scottish Patient Day, in Perth

Laura and Rachel headed North at the end of September, to Perth, where we held our first Patient Day.

The venue was the Salutation Hotel, the oldest Hotel in Scotland and with many historic associations, including to the Bonnie Prince himself. All in all it was a rip-roaring success!

We had 40 attendees, mainly patients and families, but also some nurses attended. The venue was very good, although parking was something of an issue and it also took some time to get the air conditioning turned off and the heating turned on! But the food and service was excellent, and the facilities in the meeting room were good too.

After Laura had welcomed everyone and given a brief resume of HAE UK and our work, Dr Rick Herriot started off with a superb presentation on HAE, the cellular biology involved, diagnosis, treatment and the 'forward view'. His was one of the best presentations we have heard, with lots of information, comprehensive explanations and plenty of humour! We are lining him up as a speaker to have in future at the Annual day.

Furkhanda gave a very good patient story presentation, then we had Pippa Adams who went through the study she undertook for her dissertation on 'The Lived



Experience of Women with HAE' which again was very well received. Pippa will also be joining us in Bristol.

Pippa was followed by Nikki Pitt, whose husband and daughter have HAE, who gave a wry, amusing and lively presentation on the family experience of HAE.

Lunch followed, during which we showed 'Special Blood'. This was the UK Premiere, which was exciting. It too will be shown in Bristol.

Our final speaker was Immunology Specialist Nurse Mary Brownlie, who presented on the role of

the specialist nurse in treatment and training for Home Therapy, and travelling.

After which, Emma Parker gave a good patient story on the difference home therapy had made to her life.

The day was wrapped up with a short question and answer session.

We gained 10 new members from the Patient Day, and there was great enthusiasm for another one next year.

Many people remarked how they had not met another HAE patient, other than family, so we hope we have given them some new connections.

HAE UK charity Christmas cards - COMPETITION

We received a few lovely entries to our Christmas card design competition. We are pleased to announce that Ethan Burrow and Aimee Burrow were both winners and will be receiving their prizes through the post very soon.

We will be e-mailing our members in the next week with details about how you can obtain small packs of these Christmas cards, to help support HAE UK.

Thank you to those who took part.

Our annual Patient Day - The Mercure Holland House Hotel and Spa, Bristol on Saturday 19th November 2016

Preparations for our Bristol Patient Day are well under way and we think we have an exciting, busy programme for you!

This year is the first time we will also be holding a social event on the evening before the Patient Day. This will be a 'meet and greet' and give all attendees who will be staying at the hotel, a great opportunity to meet up with old friends and make new ones, as well as allowing new attendees to feel more at home.

We still have a few spaces available for the Patient Day if you wanted to attend. Booking is via our website: www.haeuk.org/patient-day/ or by e-mailing: rachel.annals@haeuk.org



HAE Youth Ambassador

Since being appointed, Alex, our Youth Ambassador, has been positively brimming with ideas and is greatly looking forward to running some of them with her youngsters group at the annual Patient Day.

Recently, we have set up a dedicated Young HAE UK Facebook group so youngsters have their own forum to chat with one another, and we are working on various new projects with Alex. More in the next newsletter.

Save the date

One of our members, Ann Blake, and her husband Kevin, have lots of connections in the music business. Through their contacts, have set up a concert with proceeds going to HAE UK!

The event will be held on 8th April 2017 in the Winchester Guild Hall, and the group is OYE SANTANA

They are "the best tribute band I have seen" says one quote, and having gone onto their website and you-tube

we have to agree! So all you Latin Rock enthusiasts save this date for your diary.

This is such a generous gesture from Oye Santana and from Ann and Kevin to have organized it in the first place, so I hope there will be plenty of support. I'm booking my ticket!

More details about this fantastic concert will be available in our next newsletter.

THE QUARTERLY QUESTION - What age should I test my child for HAE?

This is a question we are often asked. The simple answer is, not before 18 months of age because, before then, results can be inconclusive.

Generally people start to experience symptoms around puberty, but there are a rare few who start to

have attacks much earlier, or sometimes much later in life.

If you have any concerns about undiagnosed children, it is important you discuss this with your consultant asap so they can arrange testing.

Fundraising

We have had some fantastic fundraisers recently:

- Declan McComb took part in a sponsored bike ride to raise money for HAE UK. This is the second sponsored bike ride Declan has taken part in in aid of HAE UK and he has raised an amazing amount.
- Rick and Pam Talbot nominated HAE UK as the Gnosall Lions charity and raised funds throughout Pam's Presidential year.
- Marion Lloyd, along with her colleagues, raised money for HAE UK by organising various small fundraising events at their place of work.
- Roberta Kendall kindly donated the profits from her tuck shop sales to HAE UK
- Furkhanda Haxton abstained from chocolate and all her favourite treats for a whole month and raised money for HAE UK.
- Some of our members have made one off donations or set up monthly donations to HAE UK via JustGiving or direct from their bank account. Each donation, however big or small, really helps us to continue our support to HAE patients in the UK.

We are so fortunate to have all you brilliant supporters! Thank you again to everyone fundraising and donating to HAE UK.

If you are interested in fundraising for HAE UK, we have just produced some Fundraising Packs. Please contact Rachel if you are considering fundraising and would like a pack: rachel.annals@haeuk.org

New clinical trial for HAE

A research study in patients with HAE is taking place, testing whether an oral, once a day, investigational medicine can reduce the frequency of HAE attacks over a 4 week period.

If you have Type I or Type II HAE and are interested in participating, please see the news page on our website for more information:
www.haeuk.org/news-events/

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 Trustees*

***www.haeuk.org • support@haeuk.org
laura.szutowicz@haeuk.org • rachel.annals@haeuk.org***