



# HAE UK Autumn 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 Autumn 2017 newsletter**

Welcome to the Autumn Newsletter! We had a very successful Patient Day in Scotland last month (full details in our next newsletter) and are now looking forward to the annual Patient Day on 18th November.

At the end of August we held our first Huddle, at the Regents Park Cafe. It was a glorious evening and we made two new friends, Paul and James. Neither of them had ever met anyone else with HAE before and so it was great to be able to introduce them to 'old hands' like Marion, Jimmy, Stevie and John.

Laura and Rachel also took the opportunity of being in London to visit four A&E departments; St Marys Paddington, St Thomas', the Evelina and UCL, to speak to the 'nurses in charge' and deliver educational information for them to use in training about HAE in the department. We hope this will help to raise awareness of HAE and plan to continue visiting A&E departments around the UK in 2018.

## **NEW CHAIR OF TRUSTEES**

Over the Summer John Price stood down from the Trustee Board. We would like to take this opportunity to thank John for all the help and support he gave over the years. Working very much 'behind the scenes' he gave HAE UK a very strong base from which we can work to go forward in the future. Our new Chair is Ed Price.

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#### **Our annual Patient Day in November**

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### **THE QUARTERLY QUESTION:**

Should I have the flu jab?

## **ANNUAL PATIENT DAY**

There are still some FREE places available for our annual Patient Day on 18th November in Sheffield. For those of you staying the night before we are also holding a welcome drinks reception again and an opportunity to meet up before the actual day. You can still register via: [www.haeuk.org/patient-events/patient-day/](http://www.haeuk.org/patient-events/patient-day/)

## QUARTERLY QUESTION - Should I have the flu jab?

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This was a question that cropped up at the Scottish Patient Day and the consensus was it cannot be a bad thing to get as much protection against possible infections (which can trigger/worsen HAE attacks) as possible. But remember the flu jab only prevents against certain strains of flu, so you can still get it but hopefully not as badly as if unvaccinated!

Remember that even minor infections can trigger attacks of HAE, but also if you notice a change in your attack pattern, e.g. more frequent attacks, worse attacks, it can be a symptom of some underlying problem, so if it continues for any length of time please discuss it with your care team.

## PIPPA ADAMS - MY MASTERS DEGREE

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In January 2017 HAE UK sponsored my Masters Research Project. My research was investigating the Psychological Wellbeing of patients who have Hereditary Angioedema.

The sponsorship money was used to meet members for interviews and attend two international Health Psychology conferences. I attended the International Society of Critical Health Psychology Conference at Loughborough University where I presented my undergraduate research, I also attended the European Health Psychology Conference at Padova, in Italy where I presented both my Undergraduate research and my Masters research project. This was beneficial in raising awareness for the condition but also for feedback on my work.

I recently submitted my undergraduate work for publishing, attending conferences provided great feedback and this feedback helped me with my master's research.

I would like to thank HAE UK for their support and opportunities that they have provided, especially the support in recruiting participants and raising awareness for the research. Also thank you to all the participants who took part in the research, I look forward to sharing it with you soon. I am also pleased to announce that I passed my masters with a 2:1.

## GET TO KNOW YOUR IMMUNOLOGIST

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**Dr Scott Hackett** is a Consultant in Paediatric Immunology, Allergy and Infectious Diseases at Birmingham Heartlands. MB ChB, DTM&H, FRCPCH, MD

Dr Hackett leads the nationally accredited paediatric immunology service, based at Birmingham Heartlands Hospital, covering the West Midlands. This is the only dedicated paediatric immunology service for the whole of the West Midlands. Scott sees and reviews the vast majority of HAE children in the West Midlands. Children with unexplained angioedema are also regularly seen either in his immunology or allergy clinics or by his two allergy/immunology nurse specialists. Dr Hackett has recently become the chair for the RCPCH Immunology, Allergy and Infectious Diseases training CSAC and with colleagues hope to get paediatric allergy services accredited as has happened with immunology services and is happening with adult allergy services.

Scott's interests include birding, mothing (especially Warwickshire micro-lepidoptera), conserving the rare butterflies and orchids on his local nature reserve and has now taken up trying to make electric guitars.

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