



HAE UK Spring 2024  
**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 2024 newsletter

### Today, 16th May, is **hae day :-)** 2024

To help raise awareness of HAE, we will be posting on social media throughout the day. If you could, please share so that we may obtain as much exposure as we can on all social media platforms.

Also don't forget to continue adding all your activities to [haeday.org](http://haeday.org) and help the UK total in travelling around the world to raise awareness of HAE. All activities count, from walking and swimming, to knitting and reading.

## UK Patient Day 2024 - save the date!

We are excited to announce that we will be holding our 2024 patient day on Saturday 14th September in the beautiful city of York.

The event will see some of our HAE healthcare professionals, patients and family members, and industry representatives come together to share

information and learn more about HAE.

More details and invites to the event will be sent to all registered members in the coming weeks. So save the date, and keep an eye on your emails for your invite to join us.

# The Power of Partnership

We are delighted to share with you some great developments in raising awareness of HAE, not least of which is the The Power of Partnership: Shared Decision Making in HAE.

This was a collaborative project with BioCryst, one of the pharmaceutical companies that makes a medication to treat HAE, and was two years in the making. Interviews with members and patients, with health care professionals and development of resources to help you to achieve better shared decision making with your health care team. It is very interesting reading and very informative.

You can find the full report, the Patient Diary, the Monitoring your HAE Questionnaire to complete every time you have an appointment, and a post attack form to help you remember how each swelling episode affected you on our new website [www.haeuk.org](http://www.haeuk.org). We cannot stress enough how important this information is for you to keep and to share with your consultation.



This report was also discussed on BBC Three Counties – thank you to P for your interview you were brilliant, and also on BBC Radio Staffordshire where K spoke very openly and honestly about managing her condition. As soon as the links become available (vagaries of the BBC!) then we will post them on the website.

## A&E awareness teaching video

Angela Metcalfe, our HAE UK CEO, has just completed the filming for our PhD Student in Clinical Psychology's A&E awareness teaching video. Sarah Oleluyi is at Staffordshire University, and this wonderful teaching aid features stories from patients, as well as interviews with Dr Patrick Yong and Dr Lavanya Diwakar. The video discusses patients experiences of visits to A&E and both doctors advise on the course of action that should be taken when a diagnosed patient presents for emergency treatment.

We hope that it highlights strengths and weaknesses with the system, where things need to change and talks about the necessity for rapid intervention.

Sarah will be taking this video to various hospitals around the country and hopefully it will also be launched nationwide, as well as given as an education aid to the various medical colleges.

We will post the links to the videos in the next few weeks on our website.



## Immunology and Allergy Nurses Annual Conference

Angela was delighted to have attended the Immunology and Allergy Nurses Annual Conference conference on Monday 13th May, to deliver literature and speak at the meeting.

There was a specialist session on HAE with health care professionals, and two patients under Addenbrooke's Hospital in Cambridge spoke about

their journeys living with HAE and about the treatments they are currently undergoing. This was a real insight for some of the nurses in the room who had not yet worked with HAE patients.

Angela did, of course, thank them all for the work they do looking after HAE patients and their families.

## HAE UK Roadsweeper



Yes, it's true, HAE UK have their very own branded roadsweeper! Our HAE UK Chairman, Ann Harding works for Quattro plant and very cleverly managed to persuade the company to 'wrap' one of their new roadsweeper's with our details. It also marks a milestone for Ann's daughter with her treatment – more to follow in due course – which has a phenomenal potential for patients. Thank you Ann and Quattro Plant.



## Doctor Sorena Kiani video

On Rare Disease Day, on Thursday 29th February this year, we were proud to mark the day with a new video with Dr Sorena Kiani in London, explaining what HAE is and how different treatments work.

We know that living with a rare disease, such as HAE, can be challenging, and hope that this video

will be a helpful resource in your understanding of the disease and explaining it to friends, family, and coworkers.

You can watch the full video here: <https://www.youtube.com/watch?v=SOpNjFy8jrs>



## Contacting us

We are always here to support you with anything related to HAE, but we cannot give specific individual medical advice, as this must be done through your HAE medical team.

You are welcome to contact us for support via our telephone line 07975 611787 or email address: [support@haeuk.org](mailto:support@haeuk.org). You can also contact through our closed Facebook page.

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