



HAE UK Autumn 2023
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 2023 newsletter

I hope you enjoyed the 'Indian Summer' we have recently experienced – some sunshine for most of us at last!

We haven't sent out a newsletter for a little while, but we have been extremely busy, with lots going on behind the scenes, both with myself and Rachel, as well as the support from our team of trustees and volunteers.

In the last few months I have had lots of meetings and visits. I have just returned from the HAEi Conference in Munich (more later in the newsletter) and was delighted so many UK patients attended.

We also had our wonderful Patient Day back in May and are extremely grateful to Dr Sorena Kiani, Dr Patrick Yong, Christine Symons, Dr Scott Hackett, Nurse Specialist John Dempster and all the other participants. I think it fair to say we all learned a lot and also had a great day, especially doing our walk around the park just before lunch. Thank you to all who came.

As a patient advocacy organisation, we are here to

support you, the patients. We are always keen to hear what you most want to learn about, whether we are doing enough to share all the latest information with you, and, of course, are always here to help when needed. I am aware many of you have recently had home delivery problems for medication via the Sciensus company. Due to pressure by me on behalf of patients, we now have a dedicated HAE contact so if ever you have any issues with your deliveries, do get in touch direct: angela.metcalfe@haeuk.org

We have lots of exciting projects in the pipeline including updating our website, working with the University of Stoke on Trent on a project about HAE, continued engagement with pharmaceutical companies about the latest developments worldwide in treatments and medications, and most importantly sharing information and learning from you.

Lastly, please do join our closed Facebook group if you haven't already done so.

Angela



UK Patient Day

In May, we held our first in-person Patient Day for 3 years, due to the Covid pandemic. It took place in central London. We had some fantastic presentations and got to meet up with old and new friends, which everyone always finds helpful.

It was a glorious day, so before lunch we also

held a walk around nearby Russell Square Park, wearing HAE UK t-shirts, to help celebrate HAE Day which took place on 16th May.

Thanks for all who joined us, whether travelling from afar or locally, it is always great to see so many patients and family members together.



HAE UK Website

We are shortly going to start revamping our HAE UK Website. We want to be able to make it easier to find information on new medications and treatments currently being researched, new ideas and practices to support mental health and wellbeing, and to have access to all the latest research and trials currently taking place.

We will still have the patient stories, information for those newly diagnosed, travel information and, of course, more about how we can support you and advocate for all HAE patients in the UK.

If there is anything you would specifically like us to post or to include on the website, please let us know at support@haeuk.org



Patient Interaction

We have heard from many of you over recent months about how valuable it is to you to share your stories by meeting up with and talking to other HAE patients. Whilst we were grateful to all those who attended our Patient Day, many patients are no longer willing or able to travel to these events, some particularly being uncomfortable about staying away over night, so we are having a rethink about what else we can offer you.

We would like to run a series of workshops which we will hold via Zoom or Teams. It is thought that holding these in the early evening, just for an hour between 6:00pm and 8:00pm, would see a good

uptake in members taking part. Topics for these sessions could include 'Supporting my mental health and wellbeing', 'Should I take part in drug trials?', 'Getting the best support from my health care professional', 'Keeping an attack diary' etc. We hope to run the first of these towards the end of November, more details to follow.

We will of course still look to hold our patient days if this is something you, our members, would like.

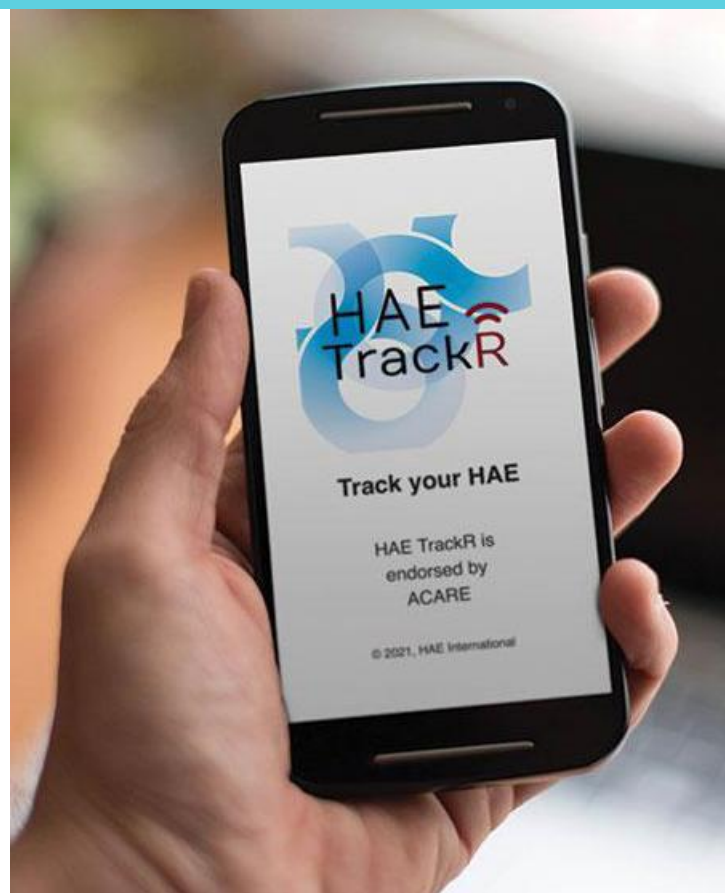
If you have any suggestions for our online sessions or in-person patient days, please drop us a line at support@haeuk.org

HAE TrackR App

Developed by fellow HAE patients at HAEi, HAE TrackR is an easy-to-use electronic diary designed to record your HAE treatments, attacks, and the impact HAE has on your life. HAE TrackR also has a reminder function for medication, and extensive reporting.

HAE TrackR is a secure, product and company neutral app, where all data gathered is the sole property of the user. Only you can share the data, if you want, with your HAE team, which can be really helpful in managing your treatment and care plan.

The app can be downloaded from the App Store and Google Play. www.haetrackr.org





HAEi REGIONAL CONFERENCE EMEA MUNICH 1-3 SEP 2023

HAEi Regional Conference, EMEA - Munich

Over 40 patients, caregivers, medical professionals and industry from the UK, travelled to Munich to take part in the first HAEi Regional Conference EMEA (Europe, Middle East and Africa). In total there were over 600 people from the region.

It was a very busy and educational two days, where we heard presentations from some of the world's leading HAE specialists and regional patient advocates, listened to stories from some incredible HAE patients from the region, and

got to meet other HAE patients and their family members.

The event concluded with a fantastic "Octoberfest" where everyone ate dinner together, danced and celebrated the end of a great weekend.

HAEi Regional Conferences take place every six months, alternating between regions. The next EMEA conference will be held in August/September 2025.

HAEi Youngsters – the next generation



HAE Youngsters

Whilst in Munich we saw the incredible work the HAEi Youngsters Team were doing. We were lucky to have some youngsters from the UK participating in the youngsters track and we would love to start to grow our UK youngsters team too.

There is an exciting opportunity for youngsters to join the HAE International LEAP programme. HAEi LEAP supports members of our HAEi Youngsters' Community and Member Organizations.

HAEi LEAP is an educational program, developed by HAEi, that allows young people to learn new skills and develop as individuals, and advocates.

So if you are a youngster with HAE, please get in touch with us to find out how you can work with the HAE UK team and/or join the LEAP 2024 programme.

Join us!

The HAEi Youngsters Comm



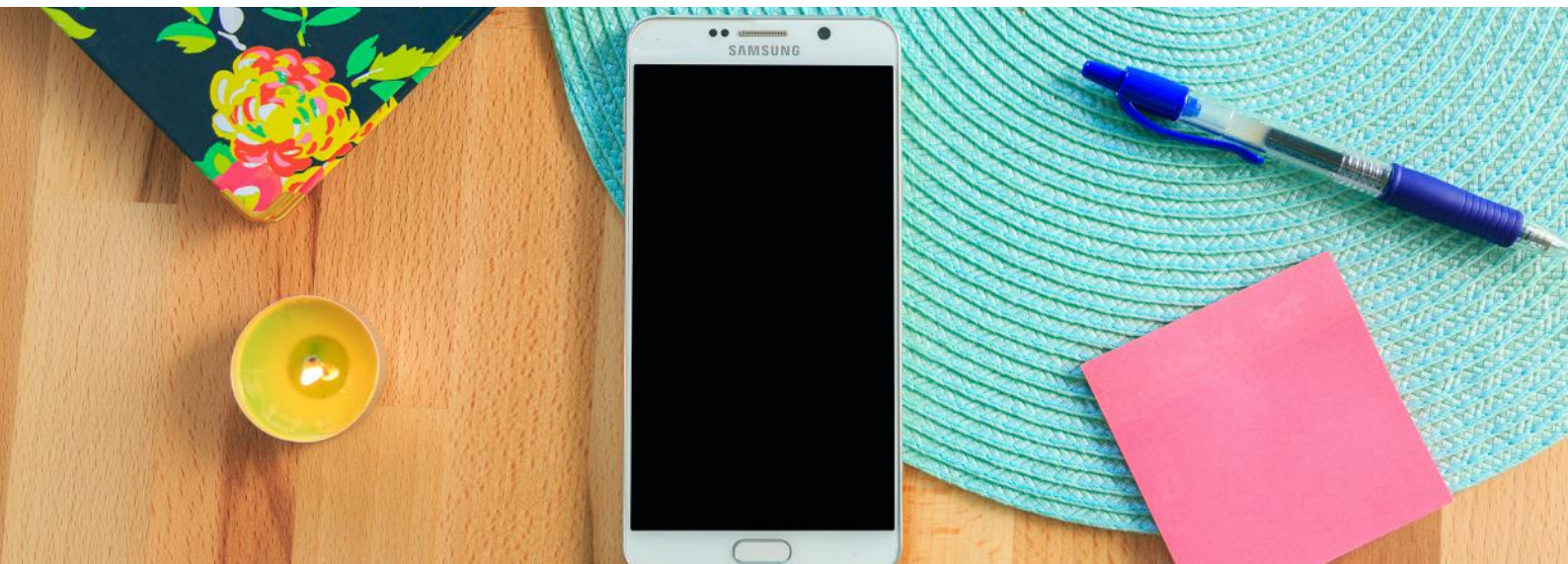
Raising Awareness In A&E and GP Practices

We are shortly going to undertake a large mail out, sending a letter and poster to every single GP Practice in the UK, as well as all A&E Departments.

We would also like to send each member a few copies of these posters, asking you to perhaps ensure your GP Surgery has one on display, maybe putting one up in your local A&E Department notice board, and indeed displaying

in any other public spaces such as libraries, supermarket noticeboards or anywhere else you think could reach people and raise awareness.

Please therefore check that your postal address is up to date on our secure patient database. You can check this by requesting a link to update your details. Please email rachel.annals@haeuk.org



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. You can also contact through our closed Facebook page.



New Treatments and Clinical Trials

Over the past few years there have been lots of new HAE treatments developed, with many more in the pipeline. We are fortunate to have six modern therapies to treat HAE in the UK, and there are clinical trials taking place for many more.

If you are interested in taking part in a clinical trial, please first speak to your HAE team and they will

be able to advise if you fit the criteria to participate.

If you are currently taking part in a trial, or have done in the past, thank you. New drugs can only be developed with the help of people like you, and will really benefit both patients in the UK, as well as worldwide.



Sharing your story

Whilst we are updating our HAE UK website, we would like to include more patient stories and experiences. If you would like to share your own or your family story, please get in touch with us support@haeuk.org

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

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