



HAE UK Spring 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 Spring 2017 newsletter

Welcome to the Spring Newsletter! This has been a busy year so far.....even though looking out of the window it looks more like Winter! One of the time-consuming tasks this year has been to ensure that the new website was up and running. As with all these things it sounded easier than it actually was and Rachel has been working incredibly hard to make it all come right. Read more later in this newsletter.

Laura has been very involved, along with various other organisations, in bringing home the facts about Rare Diseases to the Government and NHS. It is a constant battle to ensure that funding is kept in place to ensure the best outcomes for our members, and one of the points Laura keeps making is that keeping HAE patients WELL is a huge benefit to the country. We are constantly humbled by the stories of how hard so many of you strive to keep a 'normal' life. Because of the way things are, the NHS only counts the cost of treatment and does not rationalise the contributions a treated patient makes to society. Hopefully, we have some excellent champions now in Parliament in Philip Dunne and Ben Howlett as well as some other politicians. The House of Lords scored a big success in modifying a bill – see later in this newsletter – which hopefully will ultimately benefit patients.

IN THIS ISSUE:

Our new website • Presentations to clinics
Our annual Patient Day and Scottish patient day
Survey results • Quarterly question • Trustees

THE QUARTERLY QUESTION:

My C1 doesn't seem to get my swelling to go down....

Another thing we have been working on is that Laura now has a supply of various 'template' letters so that she can send in support for members who have to provide things like Education Plans for children at school; support in employment issues; or for members who are undergoing PIP assessment. Please contact Laura directly by e-mail: laura.szutowicz@haeuk.org or by phone 07975 611787 if you need to arrange such support.

We are very excited to be able to welcome four new Trustees who have joined the existing Trustee Board. They are all bringing different skills with them and will help to make us more active and efficient.

Rachel and Laura are well forward with arranging the two Patients Days, more later in this newsletter. And we also bring you the results of the Patient survey that many of you completed. So, read on, and we hope you enjoy the Spring 2017 newsletter!

CHAIR OF TRUSTEES

John Price, who has been a Trustees at HAE UK since it began, has taken the decision to step down as Chair of Trustees, he will still remain as a Trustee of HAE UK for the time being. We thank John for his dedication and hard work over the past six and a half years, we have come a long way! We would now like to welcome Ed Price as the new Chair of Trustees with immediate effect.

OUR NEW WEBSITE

We are really pleased that our new website is up and running. It is much more modern and user friendly which works better on tablets and phones too. It has lots of added features, such as a news ticker, calendar of events and member forums. We hope you like it.

If you have any suggestions for the website, please get in touch as we really want this website to be a patient friendly and useful tool for all HAE patients and the wider community.



HAE DAY :-) 2017 - TUESDAY 16TH MAY

Why not arrange a meeting in your GP practice or A&E?

Thanks to June Cole we now have available template presentations that you can customise to your own requirements and use in your local A&E or GP surgery.

If you would like this to happen in your area but are not happy about doing the presentation, we can assist. We will visit your area 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!

Or have a 'Huddle'?

We want to reach more HAE people so ask your clinic if they would like to hold a 'Huddle' for HAE patients. This is a low key social event, a meet up over a cup of tea and a cake to exchange news and views.

For more information contact Rachel or Laura: rachel.annals@haeuk.org or laura.szutowicz@haeuk.org



DIARY APP

For those of you who find keeping the daily diary a bit of a nuisance – can't find a pen, lost the diary, forgot to peel off the sticky labels – help may soon be at hand. This Summer will see the launch of a smartphone App which will make it all less of a chore and will help us to deliver to clinicians the all-important data on how often, how severe and how treated HAE attacks are. More information in our next Newsletter.

NEW TRUSTEES

HAE UK are delighted to announce that, following our request for more people to join the Trustees Board, we have four new Trustees to add to our existing five. The new Trustees are Dana Shapiro, Keven White, Rose Joseph and Sam Oxley. We look forward to working with the new team over the coming months. Read a little more about them below....



Dana Shapiro

Dana is a candidate for a Masters in Innovation, Creativity and Leadership at Cass Business School at City, University of London. Prior to returning to education,

Dana worked in finance, auditing and bank regulatory reporting for almost a decade.

She was diagnosed with HAE in 2003 in the United States, and moved to the UK in 2012. She became involved in HAE UK in 2014 when she fundraised in preparation to climb Mount Kilimanjaro.

Dana joined the HAE UK Board of Trustees in 2017 to help people with HAE take control of their lives, improve their well-being and reach a higher quality of life. She looks forward to creating a stronger association with the medical and research communities to improve both knowledge and treatment of HAE patients with the long-term goal of finding a cure for HAE.



Keven White

Keven has lived with symptoms of HAE for at least 40 years and has several family members affected, including his son and daughter, both of whom have HAE

attacks. Keven is grateful to HAE UK, both for inviting him to become a Trustee and for raising the profile of HAE nationally and internationally, which he's sure has contributed to the better management of our challenging rare disease.

Keven is a career nurse, much of it spent in Oncology and Specialist Palliative Care, the latter as a Macmillan Nurse for 13 years. His current role is that of Acute Oncology Nurse Practitioner, offering clinical help and support to individuals living with cancer who are admitted to hospital with problems associated with their cancer or its treatment.

Keven's spare time is taken up with his quest to maintain a midlife crisis - riding motorcycles, acquiring the occasional tattoo and listening to rock music. He draws the line at pink sweaters!



Rose Joseph

Rose is a Sales Administrator for a BMW dealer and has worked in the Motor trade for over 30 years. She lives near Southampton and is married to Leyon. Rose has

HAE type 1 and was diagnosed at 18 after suffering symptoms from the age of 5, she manages her HAE with a low dose of a prophylactic drug and keeps emergency treatment at home for self administration. Her only other known relative with HAE was her late mother.

Rose likes to live life to the full and enjoys many sporting activities including cycling and running; she doesn't let her HAE hold her back.

Rose is very excited to have been selected to be a new HAE trustee and looks forward to working with the board of HAE UK to raise awareness and develop services for the betterment of all HAE patients.



Sam Oxley

Sam was born in 1969 and diagnosed with HAE Type I in 1972, after a long family history. She lives in Oxfordshire and is married with two daughters, who are also

diagnosed with HAE Type I.

Sam has a very positive attitude and actively encourages her girls to follow their dreams and not let having HAE stand in their way - Sam and her youngest daughter Alex, take part in full contact Shukokai Karate, with Alex achieving her 1st Dan Black Belt.

Sam has had a previous career in Sales, Marketing and Operations Management and retired from full time work a few years ago to project manage a house build.

As well as Karate, Sam loves to travel and spend time with her family and animals. She is also passionate about mental health support for patients with chronic long term illness, which she hopes she can help and support HAE patients with.

PATIENT DAYS 2017

We are pleased to announce that our patient days have been booked for 2017.

Our Scottish patient day will be held at the Grand Central Hotel, Glasgow, on Saturday 30th September
Our Annual patient day will be held at the Mercure St Paul's, Sheffield, on Saturday 18th November.

More details about these events will be circulated to all of our members in the next few weeks, this will include details about booking your place. We look forward to seeing you there!

'YOUR MENTAL HEALTH WITH HAE' SURVEY

If you haven't already taken part in this survey, please do consider it. It will only take a little of your time and could really help to understand the effects of living with our rare disease. The survey is being conducted by Pippa Adams, a student at Teeside University.

You can contact Pippa Adams through our Facebook group or contact her direct via e-mail: n3060059@live.tees.ac.uk

POLITICS

Laura has spent a lot of time over the past six months helping and advising over the presentation of the case for Rare Diseases to Parliament.

One of the results is the paper '**Delivering Equality and Access - Making the UK a Rare Disease Leader**' which is on our website, and also supporting the case against the Government Bill '**Health Service Medical Supplies (Costs)**' which was a bill to limit the cost of any new products coming to market to a ceiling which would make it very unlikely that new HAE products, for example, would get authorized. The Bill went through the Commons with a Government majority and went on to the Lords, where it was heavily amended (in our favour), batted back to the Commons where again the Government defeated the changes and returned it to the Lords. Again, the House of Lords made many amendments which will make the Bill much more Rare Disease friendly, and it was due to go back to the Commons when the Election was called!

We were in despair thinking all was now lost and we would have to start again, but the great news is that the Government has decided to accept the amended Bill (mainly to avoid an embarrassing row in the lead up to the election?) and in the words of one commentator "The Government has now accepted – in primary legislation – the importance of considering, and consulting upon, the impact that exercising its powers may have on patients".

OYE SANTANA

Thank you to those of you who joined us at the Oye Santana event on 8th April at the Guildhall, Winchester. It was a brilliant evening of music and, after Laura's short presentation, we hope many people left with a little understanding of our rare condition.

A huge thank you to Ann and Kevin Blake for organising this event, and to Oye Santana for supporting us and kindly donating to HAE UK.

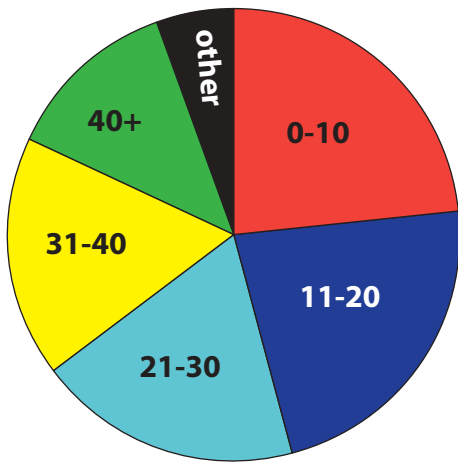
OUR SURVEY SAID

Thank you to everyone who completed the surveymonkey survey on our Facebook group a couple of weeks ago. The results have been shared with the medical advisory panel (MAP) and now you.

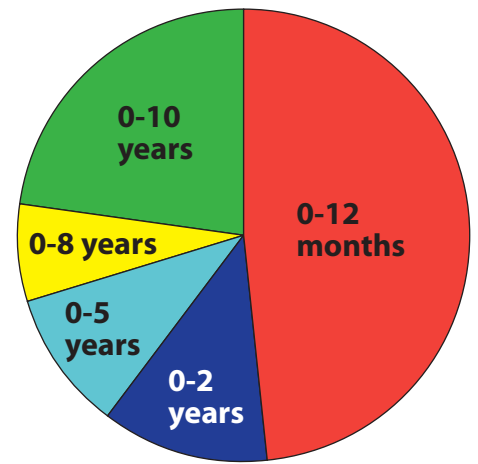
The MAP were pleased to see that, on the whole, time to diagnosis is getting much shorter and, as per the 2014 Consensus Document, most patients are seen in Immunology clinics. Some of the answers have raised more questions! So to drill down and get even better results the MAP are advising on some further questions, so look out for another monkey coming your way soon.

128 people took part in the survey. Below are the results from some of the questions.

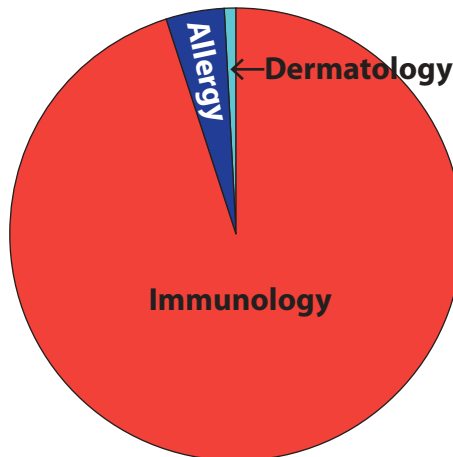
What age were you at diagnosis?



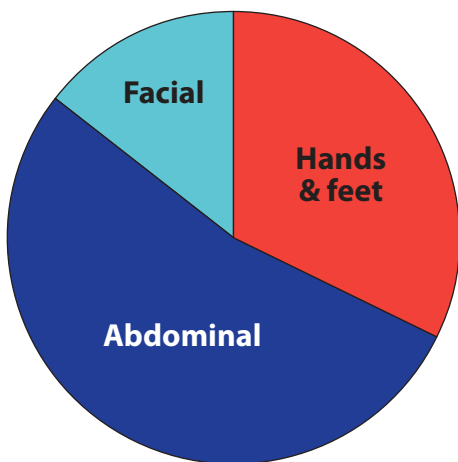
How long did it take for a diagnosis?



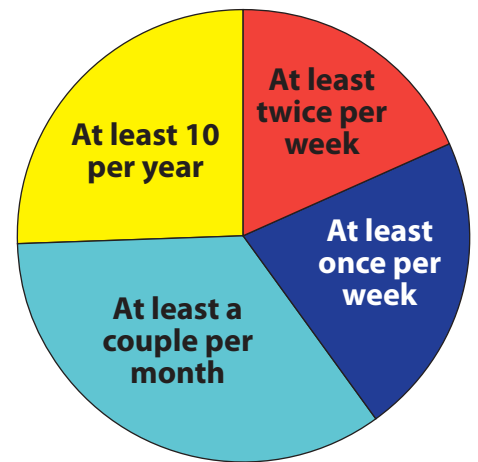
Which hospital unit do you see for review and treatment?



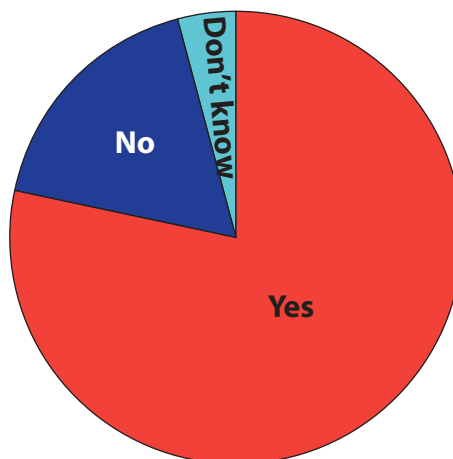
What type of swellings do you have most frequently?



How frequently do you have swellings?



Do you think your HAE is well controlled?



THE QUARTERLY QUESTION

My C1-INH doesn't seem to get my swelling to go down....

Firstly, remember the action of both C1-INH and Icatibant is to STOP the swelling and prevent it getting any bigger. However, it will not act to disperse swelling that is already there. That has to be done by your natural circulation. So **treat as soon as you can** Please don't ever hang around waiting to see if it gets better, stop the swelling in its tracks.....

Then, there are simple things you can do to help your body disperse the fluids.

- Keep hydrated: Odd though it may sound, keeping hydrated is a good way to help your body get rid of the excess fluid. Drink fresh still water (not too cold) or put a little flavour in it, but try not to drink anything very sweet or fizzy because this will not hydrate you. Tea and coffee have slightly diuretic effects so they are also not good for hydration.
- Gentle exercise: Go for a walk, quite a brisk one, to get your circulation going, or a swim?
- Gentle massage of the swollen area will help, remember to massage towards the heart so if it is a swollen hand gently stroke from the finger tips towards the wrist.
- Alternate warm and cool packs on the area; a flannel soaked in warm water laid on the affected part and then a bag of frozen peas wrapped in a towel. Repeat several times to get the circulation going.
- Don't wear restrictive clothing

HAEi YOUNGSTERS SUMMER CAMP

The first HAEi Youngsters Summer Camp is taking place in Frankfurt, Germany from 3rd to 6th August 2017. This is an amazing opportunity for our HAE UK youngsters to have fun and meet up with other HAE youngsters from around the world. The trip is fully funded, including travel and meals, sessions at the hotel and a possible excursion.

If you are interested in finding out more please contact Rachel: rachel.annals@haeuk.org

DON'T FORGET

The Peripheral Attacks video www.peripheralattacks.co.uk is a very useful, quick film to show your doctor, 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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