

HAE UK Spring 2021 *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 2021 newsletter

Warmer weather is on the way, many of us have had one vaccination at least and here in the UK we are slowly coming out of lockdown. It has been a long slow process, and at times it did seem to be never ending.

What has been wonderful is how many of you have carried on not letting the situation get you down!

We are even starting to get a little hopeful that we may be able to once again think about having a 'real' Patient Day. For anyone that has not yet seen our presentations from our 10 Year Anniversary Virtual Patient Day in November, they are absolutely excellent and full of information: www.haeuk.org/pd2020

Laura (HAE UK Chief Executive Officer)

10 YEARS OF hae day :-)

Help raise awareness step by step!

HAE Internationals activity campaign for this year is to step around the world in time for the 10th anniversary of **hae day :-)** on 16th May – and we need your help!

It's quite easy to take part. All you need to do is regularly record the time you spend on physical or wellbeing activities, on the hae day website www.haeday.org. They will then convert your activities into steps. You can record all your activity from the start of April.

HAEi's goal is to generate enough steps for a virtual walk that will take us around the world. As we go, HAE member

organisations around the world will showcase their history, achievements and hopes for the future. So, Let's Take the Next Step for HAE advocacy and see what we can achieve when we work together for people with HAE across the globe. See www.haeday.org to add your activities.



What are we doing at HAE UK?

As well as taking part in the HAEi activity campaign, we have created a **fun scavenger hunt** for you to take part in, a **zoom quiz** and an **exercise class with Mr Motivator!** More details over the page...



hae day :-> Scavenger hunt

Spend some time outside enjoying the fresh air and taking part in our fun scavenger hunt. Then add your activity to www.haeday.org and e-mail your completed sheet, along with your name and age, to support@haeuk.org by Sunday 16th May, for your chance to win a prize!

You can save a copy of the scavenger hunt sheet direct from the post on our closed Facebook group, or email rachel.annals@haeuk.org and we will send you a copy.

hae day :-> Fun zoom quiz

We will be holding another fun quiz via zoom. This will be fun general knowledge type questions, not a quiz about HAE, and there will be prizes to be won!

When: 8:00pm, Saturday 15th May 2021

How do I join? Details will be sent to all registered members during the week, so keep an eye out for your invite to join in!

Mr Motivator fun exercise session

Mr Motivator has invited us to join his live zoom Wednesday workout session, for fun movement to music, uplifting music and plenty of his trademark motivational advice! The workout lasts 45 minutes and is suitable for all ages and all fitness levels, with chair based alternatives for all exercises. Say Yeah!

When: 6:30pm, Wednesday 19th May 2021

How do I join? Details will be sent to all members early next week.



HAE HOME - Home-treatment record for patients

As patients start to return to face-to-face appointments, your clinicians may talk about the new HAE Home-treatment record.

HAE Home is a simple, easy to use and secure treatment and attack recording system for patients with HAE. It enables patients, using phones, tablets or PC's, to record their treatments and attacks (including the ability to attach images) as they occur. Treatment centres and

their clinicians are able to see this information in real-time, to help monitor, optimise and improve patient care. The system has been enormously successful and is already used throughout the NHS in Haemophilia and Immunoglobulin therapy.

This is a great system which will really benefit patients and clinicians and help them to work together to achieve the best care plan.

COVID VACCINATIONS

The UK is getting on well with their vaccination programme and many of our members have at least had their first vaccination. Most people have had no side effects, and one or two have reported mild reactions but in line with what has been previously stated. Please remember that any side effects must be reported either to your GP or HAE clinical team. This is also the same with any of your HAE medication, please report side effects to your immunology team as this is the only way treatments

can advance.

Many people have asked us about the Covid vaccinations and whether or not they should have one. The advice from our medical advisory panel remains the same – Yes, the covid vaccinations are safe for people with HAE. Unless you have had a previous severe reaction to a vaccination, it is definitely a good idea. If you have any queries please talk to your immunology team'

A FEW OF OUR AMAZING FUNDRAISERS

HAE UK is run solely on donations, which enables us to continue our work supporting HAE patients and their families in the UK.

Over the years we have received some amazing support from individuals taking part in events to raise money for HAE UK, as well as raising awareness. Here are a selection of recent fundraising events some of our members have taken part in...

Peter Kearney



Peter is not a HAE patient himself, but his two eldest daughters have HAE. In March, Peter set himself a challenge to run 4 miles every 4 hours for 48 hours! Not only was this a huge challenge, but it also left little time to sleep! Luckily the weather was on Peter's side and lots of his friends joined him along the way. Peter raised an incredible amount of money and is hoping his employers will select our charity to double his fundraising amount.

Furkhanda Haxton



Furkhanda, our Volunteer for Scotland, took part in the Kiltwalk which was run as a virtual event from the 23rd to 25th April 2021. She raised money for HAE UK again and we are very grateful to her for this and all the great work she does for us. Furkhanda walked the equivalent of a half-Marathon, but she did confess to having got some blisters!

The Kiltwalk is extraordinary in that, not only does 100% of money raised go to charity, but every amount raised is

increased by 50% donated by the Hunter Foundation.
www.thekiltwalk.co.uk/charity

Lucy Church



Lucy Church does not have HAE but has a relative who does. On 29th May, Lucy is going to do a 15,000 foot skydive over Salisbury in aid of HAE UK and her local church, St Andrews in Nunton. This is amazing of her! You can support Lucy via her 'go fund me' page:
<https://uk.gofundme.com/f/lucys-skydive>

Extra thanks

We'd like to thank each and every HAE UK supporter, from those who give one-off donations or regular monthly amounts, to those who take part in events to raise money, or sponsor those who do. We really appreciate all of your support.

HAE UK SHOP

We are ready to launch our HAE UK shop!

You will be able to order printed t-shirts, hoodies, sweatshirts and tote bags with different designs - choose from our popular Percy the Pufferfish, youth, standard or supporting us designs. All items are available in a range of HAE UK colours, in adult and child sizes.

More information will be sent out to all members on **hae day :-)** 16th May.

STRESS & ANXIETY

We were very grateful to Dr Mari Campbell for giving us her time and expertise in some Zoom meetings earlier this year. Mari is a consultant psychologist specializing in rare diseases and particularly Primary Immune deficiency at the Royal Free Hospital in London. She has worked with some HAE patients in the past and we are hoping to help her and her team set up a similar service in the Royal London.

Mari gave us an interesting insight into how stress happens, and that it actually is entirely natural, one of the 'fight or flight' responses that kept us safe from sabre-

tooth tigers and nowadays helps us to do that impressive presentation for our boss! It is when it runs away that it becomes a problem and the Covid-19 pandemic has become the modern day sabre tooth tiger of which we are nervous.....

Dr Campbell gave us many strategies for coping with and managing stress, and was extremely generous with her time and advice, providing us many other resources which we have been able to add to our website as a dedicated page on managing stress and anxiety. See: www.haeuk.org/advice-support/stress-anxiety/

VOLUNTEER STORY

Many of you will know our volunteer, June Cole, who pre-Covid was visiting A&E departments and GP surgeries to present to them about living with HAE.

June's great hobby is singing with the Rock Choir, and some of you may remember her organising a 'Flash Mob' in aid of HAE UK at the Westwood Shopping Centre in Broadstairs, Kent, back in 2018.



June shares with us some of the things she did over lockdown;

I sing in Rock choirs with many other people and suddenly overnight that stopped because of lockdown. The Rock Choir came up with the brilliant idea of organising daily singing sessions live via Facebook and weekly sessions, tutorials and virtual gigs via Zoom, which hundreds of people joined during the pandemic.



We also made recordings and a video which were used in aid of the Mental Health Foundation Charity to raise awareness and funds. We did this by recording from home individually using our phones to make a recording. Over 4,500 of us recorded the song 'Keeping the Dream Alive' in this way and then submitted our recordings to Rock Choir for all our voices to be included on a download single.

This single was released in December 2020 and went straight in at number 1 on both of the iTunes and Amazon download charts. This made everyone involved feel really uplifted!

These daily sessions and the recordings were great fun and a wonderfully joyous experience, keeping everyone's spirits up and helping their wellbeing while in lockdown, in addition raising awareness and funds for the Mental Health Foundation Charity.

Helping others

I also phoned my elderly relatives virtually every day to make sure they were OK and to see whether they needed anything. This was a great way to keep in touch with each other and help prevent loneliness.'

Many thanks to June for this inspirational piece. Who would have thought HAE UK could count a chart topping singer in our midst!

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

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