



HAE UK Spring 2020
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 2020 newsletter

Our last newsletter was full of optimism and excitement about the Marathon runners, the Go-Kart Challenge, the up-coming HAE International Global Conference in Frankfurt. There had been some news about a virus spreading around China and Asia.... And now we find ourselves at least in 'lockdown', whilst many members have had the letter suggesting they shield for 12 weeks.

We may have lost some of the excitements with the decision to cancel the Global Conference but we still have plenty of optimism. As I write, the Government have announced that they have smashed their target for testing and the awful daily figures are now showing a sustained decline. Some of the best scientists in the world are in Oxford and they are working with a promising vaccine. To date, we have had fewer than a dozen

members who have contracted Covid-19 and they have all recovered successfully. Many of our Immunologists who look after the HAE patients have been seconded to Covid-19 wards, two of them have contracted it but are recovering and one is back at work.

Our HAE Clinical Network are still available to us to answer any questions we may have, and they were the first to issue the advice that **there was no evidence to show that having HAE puts you at more risk of contracting Covid-19, or of having worse outcomes, than someone who does not have HAE.** This advice was also repeated by the HAE International medical advisory board.

Laura (HAE UK Chief Executive Officer)

HAE UK ZOOM MEETINGS

We have been very busy with setting up a Zoom meeting system so we can hold virtual meetings with all of our members. These Zoom meetings have been great fun and we hope the other participants have enjoyed them and found them beneficial too!

We would love to hear your suggestions on topics for future meetings, whether these be Q&As, presentations from HAE consultants or specialist nurses, exercise or relaxation classes, youngsters only sessions or a childrens story time perhaps. Please e-mail your suggestions to support@haeuk.org

HAE DAY :-) 2020



Around the globe on 16th May, HAE organisations, patient groups and patients will be celebrating the global HAE day – also known as **hae day :-)**

Whilst sadly the Global Conference has been cancelled, we've lots of exciting activities for you to participate in during lockdown to celebrate and raise awareness.

Before hae day :-)

Global walk for HAE

The annual **hae day :-)** aims to raise awareness worldwide and once again HAEi are arranging the HAE Global Walk – allowing everyone to take part in a truly worldwide HAE event no matter where they are. From 1st April to 31st May 2020 you can help to raise awareness of HAE by counting your daily steps..

All you need to do to be part of the HAE Global Walk is to walk any distance you would like, wherever you feel like it, on your own or together with others, and add your steps to the global total by visiting **haeday.org**

So far people around the world have walked nearly 4,000 miles in total, with the distance growing every day.

#7daysofhae

In the week up to **hae day :-)** on 16th May, we are encouraging everyone to wear a HAE Awareness label on their shirts whilst going for their daily walk. Your label can be as creative as you like, a standard label is at the end of this newsletter for you to print at home if you wish. Please take a selfie of yourself on your walk and share on social media, with the hashtags **#7daysofhae** and **#haeday** We can then see your labels and you enjoying your walk - let's hope it's a fine day!

If you do not use social media, please send photos to us so we can share and create a montage of amazing walkers raising awareness for HAE.

On hae day :-)

Silly Saturday

On Saturday 16th May we will be holding 'Silly Saturday'. We would love to see photos of you and your families wearing your silliest outfits, wigs, hats, inside-out or back-to-front clothes. Use your creativity and show us your silliest outfits!

Please share your photos to social media with the hashtags **#sillysaturdayforhae** and **#haeday** to help make people smile, whilst helping raise awareness of HAE.

Again, if you do not use social media, please send photos to us so we can share on your behalf and we can also create a montage of silliness.

We will be issuing prizes to the silliest outfits and you can post as many different outfits as you like. We can't wait to see them all.

Quiz time

At 8:00pm on Saturday 16th we will be holding a fun Quiz via zoom.

The quiz will include a variety of different, fun topics, you can take part as individuals, couples, families or housemates. **There will also be individual and team prizes to be won!**

Invites to join will be sent to all registered members early next week.

We would like to say a huge THANK YOU to all HAE UK members who are keyworkers, and to our wonderful HAE consultants and Specialist Nurses, all of whom are working incredibly hard to help keep us safe.

With our very best wishes

from Laura (CEO), Rachel (EO) and the HAE UK team

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HAeUK

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Planning for tomorrow.



Walking for HAE

hae day :-) 16th May 2020

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