



Living for today, planning for tomorrow

HAEUK

Newsletter

ISSUE EIGHT
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HAE UK is an Association of HAE Patients, working together to improve the situation for all HAE Patients in the UK

Dear HAE UK Member

We hope you are well. It's been great to hear from so many of you by e-mail, on the phone and via Facebook over the past few months, we gain so much support and help from each other.

So much has been happening over the last six months. Let's start with the most recent:

2nd HAE International Patient Conference in Washington DC

A group of UK Clinicians, Nurses and Patients flew across 'the pond' to meet up with lots of HAE experts and fellow patients from around the world in Washington DC, America.

The conference was well attended, with over 450 people from more than 30 countries coming together to share in their experiences and to meet other patients from the worldwide HAE family. It was so exciting to hear about progress in HAE management and new medications that are undergoing trials.

Also, it was an emotional roller coaster hearing presentations from other countries about the level of access they have to treatment. We realized that in spite of our struggles, HAE patients in the UK have a lot to be thankful for. Very many countries have minimal access to HAE medications and in Africa, Eastern Europe and Russia there is no support at all.

Rachel Annals has now been voted onto the HAEi committee and will be working internationally alongside Henrik Boysen, Tony Castaldo, and the other committee members from around the world. There is a lot of work to be done on a global level and we look forward to hearing how things progress in the future.

HAE UK Membership

Our HAE UK membership has continued to increase. We now have over 260 members.

Please encourage any family members who have HAE to register with us. This helps us to know where HAE patients are and it helps us to have a strong voice nationally to continue to improve access to treatment for all HAE patients countrywide.

If at any time you wish to unsubscribe from receiving our newsletters and e-mail information, please e-mail Rachel and she will remove your details from our mailer: rachel.annals@haeuk.org



To read lots more about this brilliant weekend, see the most recent HAEi newsletter http://www.haei.org/sites/default/files/public/201403_Newsletter.pdf



HAE Awareness Day 2014

Thank you to everyone who supported HAE Awareness by sending their 'smiles' across the world.

Also a huge thanks to CSL Behring who worked with Izzy Richards to raise awareness of HAE in the media and on their own website.

Izzy has been a fantastic ambassador for HAE patients by using her story and photos in an interview with The Mail online and in a ten minute broadcast on Radio Norwich. Izzy will also feature in a half hour documentary on the Discovery channel. We will let everyone know dates and times for this program as soon as they are available.

Thank you so much Izzy.

Visiting HAE Centres

Jen Harrison and Ann and John Price were invited to meet HAE families at the Alder Hey HAE clinic in April. Thank you so much Jen for arranging this. We hope to attend this clinic again next year.

Ann Price represented HAE UK at the UKPIN Steering Committee meeting in April. We look to work closely with UKPIN in the near future to support HAE patients throughout the UK.

In May, Ann Price gave a presentation at the Immunology Nurses Annual conference in Birmingham. HAE UK works closely with our wonderful Specialist Nurses in the HAE centres around the country.

Rachel and Ann will be attending a few other HAE clinics in the next couple of months, so we look forward to seeing some of you there.

Ongoing projects

HAE UK are still working on a few key projects such as the Emergency A&E Cards, a HAE Patient booklet and our updated HAE UK website.

The big update of the website is taking some time as we will be including a lot more useful information - we hope to re-launch soon. If anyone has any suggestions for important additions to the website please e-mail: rachel.annals@haeuk.org

HAE UK Family Day

Who would be interested in meeting up with other HAE families to give the younger generation a chance to get to know other young people with HAE?

We are thinking of arranging a family day but need to know how many of you would like to join us?

It would just be an informal get together for a picnic or similar, on a weekend, somewhere central, outside with plenty of space to play. The day would not involve any presentations, consultants or nurses and not be an official HAE UK event, but a friendly, relaxed afternoon getting to know other HAE families.

We plan to hold this day towards the end of the school holidays, so dependant on interest, we will have more information about this day very soon.

If the day is a success, we hope to make it an annual event.

Please e-mail Rachel as soon as possible if you are interested: rachel.annals@haeuk.org

Trials for new HAE medications

Thank you to all the HAE UK members who have taken part in trials for new HAE treatments over the past year. These trials are essential in the process of making new medications available to the HAE community.

Hopefully there will be new trials coming up in the next few months, and it would be great if our members could check to see if they meet the various criteria for volunteering to help in this very important work, which will be a huge benefit to all HAE patients in the future.

Sponsorship and fundraising

Over the past four years HAE UK has greatly appreciated sponsorship from CSL Behring, Shire and ViroPharma. We are now looking to also raise funds ourselves to facilitate our services to HAE patients.

We would like to thank Barrie Hurley's company Viridor for their generous donation of £500

Ann Harding cycled from Cambridge to Chelmsford in June and raised £1,025 for HAE UK. Thank you so much Ann, and everyone who sponsored her and helped her to exceed her sponsorship target.

Ann said:

"I was asked by an ex-colleague to do a 55 mile bike ride for the National Autistic Society, I agreed but only if I could pay the entrance fee and donate the rest to a charity closer to my heart.

I did a few 20 mile bike rides to prepare but I can tell you after 30 miles of riding up hill and in wet conditions I was ready to give up. To keep going I had to remember all the A & E visits, operations, tears and fight to get my daughter Sian treated. Sian supported me by keeping me topped up with water and jelly babies and jokes about how stupid I looked in my helmet.

Hereditary Angioedema has greatly affected Sian's life and without HAE UK who introduced me to the wonderful Hilary Longhurst and Nurse John Dempster, her life would have been very different now. Although she still gets attacks and has to inject 3 times a week, she holds down a full time job and has a good quality of life. HAEUK helps in areas where patients are still not getting treatment and supports families with this rare life threatening illness."



We have recently set up a justgiving charity page: www.justgiving.com/haeuk/ so people can now fundraise to support us as well as make a one-off donation or donate on a regular basis if they wish.

We have had a few members decide to take part in sponsored events and have set up their own pages to raise money for us already:

Rose Joseph will be taking part in a 60 mile sponsored cycle ride on 14th September.

Rose writes:

"Back in January my colleague and I decided we wanted to get fit & start cycling and wanted to do something for a charity personal to us. Thankfully Ness & Jo decided that they wanted to support HAE UK too, since then the team has grown and we have 7 members all cycling for HAE UK.

"Our ride is a 60 mile circular route around the New Forest on 14th September. Since January I have started a training programme, I do spinning twice a week at the gym, attend body tone classes & cycle at least twice a week. So far our longest distance has been the 44 miles that we achieved over the Easter weekend.

"Last week we were in Sweden and cycled most days and had 2 rides around a lake, which was a 28 mile ride with a starting temperature of 8 degrees. I am hoping that by September I will be fit enough to enjoy the ride at the ripe old age of 51. If anybody would like to support me by sponsoring my ride for this fantastic charity you can donate at www.justgiving.com/Rose-Joseph"



Sam Jones will be running the Cardiff half marathon on 5th October to raise money for HAE UK. Sam is not a runner so this is a big challenge for her. You can support Sam by visiting her justgiving page:
www.justgiving.com/Samantha-jones

Sam says:

"On October 5th 2014 I will be running my first half marathon in Cardiff. I have HAE and it affects me and the people close to me, but I don't see it as a negative, it's something that makes me unique. Although it can become scary, it's always a good conversation topic especially with anyone involved in medicine or hospitals - not many people can say they have to explain their condition to a doctor!"

"My main reason I decided to do this run is to raise awareness of HAE, as we all know it's such a rare condition and there is very little public acknowledgement."



"To help my fundraising and help spread awareness, I have made a just giving account and have written a short paragraph about HAE and added some personal photos, which was hard for me to do as not many people have seen me during an attack. There is also a personal reason I'm running this race, which is to prove to myself that I won't let HAE stop me from doing anything I really want to."

Thank you so much for everyone who has helped raise money for us to-date, it really will help us to help you. If anyone would like to support us by arranging a sponsored walk/run/swim/cycle/cake bake/silence or any other type of event, please get in touch with us and we will do all we can to support you - We can advertise your event, send you sponsor forms and arrange a branded t-shirt for you to wear at the event if you wish.

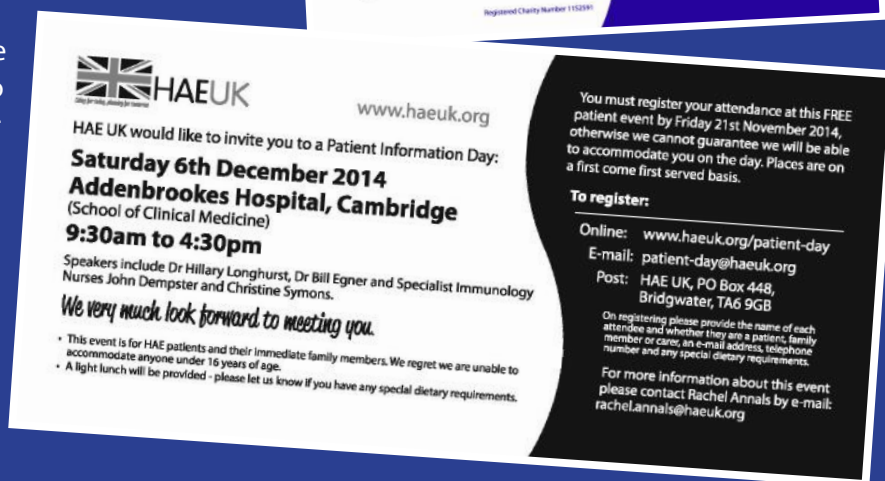
HAE UK patient day 2014

HAE UK changes to location of the venue for our meeting each year, so that in the long term we are able to serve the needs of everyone in the UK. In addition to this, many hospitals are offering local patient meetings for their HAE patients.

This year we have had to change the date of our meeting from November to December due to the availability of our important speakers. We are pleased to announce that this year's patient day will be held on 6th December in East Anglia.

As usual, we expect places to be filled quickly for this event, so to secure your place please register your attendance by visiting our website:
www.haeuk.org/patient-day

For more information please e-mail Rachel: rachel.annals@haeuk.org



Patients in the North West of England will be having their own Primary Immunodeficiency (PID) and HAE patient day at the Haydock Park Racecourse in November. This meeting is being hosted by the North West Immunology Centres for patients who attend their clinics. 'North West patients' will receive invitations directly from their clinics soon.

Thank you to everyone in our wonderful HAE family for supporting each other like we do. We very much look forward to seeing as many of you as possible in November or December.

Our very best wishes, from

Rachel, Ann, John and Barrie