

Living for today, planning for tomorrow

HAEUK

Newsletter

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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

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Dear HAE UK Member It's hard to believe but..... **HAE UK is 5 years old this year!**

Looking back

HAE UK started on a wet and windy weekend in October 2010. So much has happened over the past 5 years as you know.



(L-R) Henrik Boysen (HAEi), Ann Price, John Rixon & John Price

In 2010 so many of us had difficulties accessing the treatment we needed. Clinicians often had to apply for funding through 'Individual Funding Requests', which were very frustrating and time consuming.

HAE UK has worked with our wonderful HAE Clinicians and Specialist Nurses to improve the situation for us all.

We now have the NHS England Policy for the management of acute attacks of Hereditary Angioedema which sets out the basic services that will be paid for by NHS England and that we can all access.

We have the 2014 Revised UK Consensus Guidelines

which set out the aspirational standards that we are all working towards.

HAE UK seeks to support patients on a one to one basis to access the best treatment for managing symptoms.

We share information through our website and our new HAE Patient Information booklets.

We support each other through meeting up at Patient Days and through Facebook.

Things are getting better for our HAE Community.

Where are we now?

We are at a stage of change. The needs of our members are too great to be met by our present organisational structure. With this in mind we became a Charity in 2013, and now our Trustees are working to organise a structure that will meet the challenges of the future.

Ann will now be stepping down from her voluntary lead role with HAE UK, and we will be employing Laura Szutowicz as our new CEO to take us forward into the future.

Laura will lead all areas of HAE UK activities and will represent HAE UK with all stakeholders. Rachel will continue in her part time executive role supporting Laura as our events organiser and administrator and Furkhanda will continue in her voluntary role partnering Rachel in managing our HAE UK Facebook group.

So, it's 'Good Bye from Ann' and 'Welcome to Laura Szutowicz'....



Ann writes

It has been a great privilege for me to work with Rachel over the past five years to build our HAE UK support organisation. It's been wonderful to be part of our great HAE Family and to share experiences and friendships with

so many lovely people. Thank you for many great times together and for all that we have achieved together. Now it is time for me to step down from my role, and it's my great pleasure to introduce you to Laura Szutowicz who will be our new CEO.

I've asked Laura to say a few words about herself, and I know she is looking forward to meeting many of you in person at our November Patient Day.



Laura writes

I am very excited and privileged to take over from Ann as CEO of HAE UK. I have spent the past 20 years working in pharmaceutical companies and will be able to bring that business experience into this new role. Much of my

time has been spent in Immunology and Haemophilia so I do feel I am coming home.

Ann has left very large boots to fill (metaphorically!) and I will be trying my hardest to carry on the great legacy she and John have created. My future looks as though it is going to be very busy!

HAE UK Patient Day 2015

Laura will be leading our patient day on 7th November 2015, at Maple House, Corporation Street, Birmingham.

Invitations will be sent out at the end of the month when registration for the event will also open - Please reserve this date in your diary.

The theme for this year's day is 'HAE through all the changing stages of Life'. Our speakers will include Dr Aarn Huissoon, Consultant Immunologist at Birmingham Heartlands Hospital and Dr Scott Hackett, Consultant Paediatrician at Birmingham Children's Hospital.

This is an opportunity to learn from our HAE Experts and to meet up with many friends who know what it is like to live with our rare condition.

We look forward to meeting many of you there.

If you are planning on attending the patient day and would like to book accommodation for the night, the closest hotel is the Premier Inn which is a 6 minute walk (Premier Inn Birmingham City Centre New Street Station Hotel.)



Some of the attendees at last years' patient day in Cambridge

HAE Global Conference in Madrid, 19th-22nd May 2016

This exciting conference, which takes place every two years, offers the opportunity to hear from some of the world's top HAE specialists about developments in HAE management.

It is open to patients and their families, clinicians, nurses and research scientists – and this year there will be a separate track for young patients.

The organisers expect to have about 600 attendees present from all over the world.

More details about the 2016 conference will be available towards the end of the year.

We hope you will join us for a life changing weekend.



In 2014 10 patients and family members attended the HAE Global Conference in Washington DC, as well as Consultants and Specialist Nurses from the UK (above).

Fundraising - A huge THANK YOU to everyone fundraising for HAE UK

During our first five years HAE UK depended solely on the generous sponsorship of the pharmaceutical companies CSL Behring and Shire Pharmaceuticals. Both these companies continue to be very generous in their sponsorship – but we do now need to ask our members to consider fundraising for us – if they are well enough, and are able to help us in this way.

We will be putting information about fundraising on our website soon, with lots of stories from past fundraisers and information on how you can support HAE UK.

Advice, ideas and our fundraising leaflet can also be obtained by e-mailing Rachel: rachel.annals@haeuk.org

We want to say a huge thank you to everyone who has supported us over the past year. Every gift is much appreciated – large or small – it will all go to help HAE UK to continue our support and to help improve the lives of our HAE Family.

These are some of the people we would like to thank for their recent fundraising efforts: *(Please excuse us if we have not managed to include everyone who has been so generous)*

Marion Scott & the All Sorts Club held an event



Rose Joseph held a Cuppa & Catch Up event with friends

Rose and some of her friends baked cakes and Rose held the get together on hae day :-) in her garden in the sun

Ruby Davenport (with the help of her mummy Faye) organised and took part in a 3 mile sponsored walk with lots of friends, 'Ruby's Walk for HAE'

Ruby is a wonderful ambassador to share with other children how she copes with her HAE – and has a great life – just like all her friends. You can read about Ruby's Walk for HAE overleaf.

Ann Harding also held a Cuppa & Catch Up event with friends

Ann held this event on hae day :-)



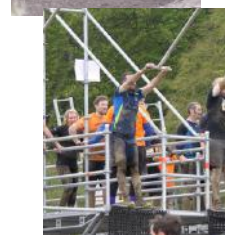
Declan McComb took part in a sponsored bike ride

This 55 mile ride, on 13th June, took in the picturesque villages around the Chelmsford area



Jeevan Bahra took part in the Tough Mudder London 2015

This 12 mile military style obstacle course tests mental as well as physical strength and involves diving into ice water filled ditches, jumping through fire and crawling through mud. Jeevan exceeded his target sponsorship by 294%



Tej Agheda organised a 'Dress Down at Work' day

Tej wanted to raise awareness about HAE and hae day :-)

In addition to the fundraising events, we have also received individual donations:

- one off donations through JustGiving and via our Text Donate number 70070
- monthly donations from members and friends
- donations in memory of loved ones
- lots of small donations from large retailers through easyfundraising.org.uk

Ruby and HAE Type 1 - Ruby's Mum Faye writes

Like many HAE patients with no known family history, Ruby suffered tremendously before her diagnosis, with swells and stomach problems from being a toddler. By the time she was 5, she was spending more and more time off school due to sickness and the visits to GP and hospital began. Luckily for Ruby, we had heard of HAE as, ironically, her classmate suffers from the disease. The similarities between Ruby's symptoms and her friends were very similar and this was how we finally got the correct diagnosis, not too long after Ruby's 6th birthday.



Ruby is very severely affected by HAE, experiencing swells every few days without treatment. Due to the frequency and severity of Ruby's swells, her consultant decided that she would benefit from home therapy, just 2 months after her diagnosis. I was trained how to infuse her with 500u C1 Inhibitor, twice per week. This initially worked, however, after a year on this treatment she started to have more breakthrough swells so the dosage was doubled. Again, this worked for a while but recently, Ruby had to have the dose increased to 1000u 3 times per week.

Ruby's diagnosis of HAE has also led to my own diagnosis of the illness in November 2014, aged 45! I too had many 'mystery' illnesses during my childhood.

Ruby has a fantastic outlook on life. Although she is shy by nature, she is happy, loving, very caring and loves to win! She is a football fanatic and an avid Manchester United Football fan. Despite mine and her dad's concerns, Ruby was adamant that HAE would not stop her from participating in sport. She has recently won a certificate for swimming and has received numerous awards for football -



most recently from Stockport County FC who have sent her a complimentary family ticket for receiving player of the season award during after school football coaching.

Excitement is Ruby's main trigger for HAE attacks, so we have to try and time her infusions to coincide with football matches, swimming day and any other events she is excited about such as birthday parties, sleepovers, trips out. Ruby also insisted on attending all of her school's educational visits off site. The school was very concerned as to what they would do if Ruby had an HAE swell during an outside visit. To eliminate as much risk as possible and to ensure Ruby can attend all trips, I go with them and take C1 Inhibitor with me.

Ruby is excelling at school and has surpassed all targets set, apart from attendance. Unfortunately, due to HAE her attendance falls below the national average. Ruby does try to do everything that every other 9 year old child would do and when HAE knocks her down, she gets straight back up and gets on with living and enjoying

life. Last week I was contacted by school who told me that her face was swelling at an alarming rate. They asked me to collect her immediately. I was able to collect her from school and infuse her within 40 minutes of the phone call. Ruby insisted on going straight back to school as soon as the swelling started to subside.

Ruby is eager to learn how to administer her own C1. She already knows how to prepare the mix and has inserted the butterfly needle in my arm on several occasions. Although Ruby is very young, I feel that the knowledge alone that she could perform her own infusions would give her so much more freedom and peace of mind.

Ruby's Walk for HAE

To celebrate **hae day :-)** on 16th May, Ruby wanted to do something to help raise awareness of HAE and we also thought it would be a good idea to raise some funds for HAE UK at the same time. A sponsored walk seemed like a great idea.



We (Ruby, her dad and I) spent the run up to HAE Day bombarding Facebook with simple facts about HAE. I also posted photographs of Ruby whilst she was experiencing HAE swells. Most of the photographs were taken as evidence for doctors and not intended for posting on a social networking site. I think that the visual

shock of seeing Ruby looking so sick in contrast to her usual happy self was enough to generate great interest.

I received numerous private inbox messages and mobile text messages from people offering support and making comments like "I knew that Ruby had an illness but I had no idea how poorly it made her - no-one would ever guess if they saw her happy face". I received one message from an old school friend who is now a paramedic. She read all the information I gave about HAE and then did some investigations of her own and she made sure that all her colleagues were aware of HAE.

I also have many other friends who work in

hospitals and many who work in schools who all shown great interest and shared HAE posts to help raise awareness and funds.

The donations on the 'Just Giving' page came flooding in. Although the project was titled 'Ruby's Walk for HAE', we had lots of help from friends, family and HAE UK. Dozens of people walked with us making it a thoroughly enjoyable day. Ruby's classmate, Sienna, also has HAE and she, along with her mum and one of her sisters also walked with us, as did a wonderful young family from Bolton who read about the event on Facebook.



We generated lots of interest en route and collected over £170 whilst walking.

We set a target of £200 but that was smashed within the first few days.

The total of the donations currently stands at over £1,281.73.... which is a massive 640% of the target initially set. The total continues to rise and we have promises of several more donations.

We also received an on-line certificate from 'Just Giving', as out of 65,838 fundraisers in the UK, Ruby was in the top 3% of fundraisers during May.



We wish you all a good summer and we look forward to seeing many of you at our annual Patient Day on 7th November.

With our best wishes from Ann, Laura and Rachel