

HAE UK Autumn 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 Autumn 2021 newsletter

The UK has seen some changes over the Summer as the Covid19 vaccine rollout gathered pace and the weather improved. Children are now going back to school after the Summer holidays, and many members are taking up the reins of life before the pandemic.

HAE UK are also seeing some changes in the Trustee Board and management this Autumn.

Sadly, I am stepping down as Chief Executive of HAE UK. I have enjoyed every minute of my six and a half years in the role, mainly due to the terrific support of the Trustees and the members, and particularly due to Rachel who has

been my right (and probably my left) hand! We have had some memorable times and I have great memories of all the various patient days and getting to know so many members.

I hope I shall still see some of you at meetings and I know that you will all give the same tremendous support to my replacement Angela Metcalfe. Angela brings a wealth of knowledge, both of business and of the Third Sector, and I am sure will steer HAE UK to a great future.

Laura

OUR NEW CHIEF EXECUTIVE OFFICER

HAE UK have successfully recruited a new CEO, Angela Metcalfe, who started in the role at the beginning of November.

Angela joins HAE UK from both a commercial business background and working together with CEO and Director level within an autism charity, as well as for a Charitable Foundation. She understands the frustrations that can exist with accessibility to support, especially around

medical needs and mental health. Her main focus will be to raise awareness of HAE, to help develop better sharing of information about the illness within the UK Rare Diseases Framework that is currently under development, and to grow the training programmes in place throughout the NHS.



Angela says "It is an absolute privilege to have taken over as CEO from Laura who has served the charity so well for the past six and a half years, and I am sure you join me in wishing her well for the future.

Whilst I don't have a clinical background, I have many years of experience in business and working for other charities, particularly in the field of autism, so I hope to bring an additional perspective to the way in which HAE

UK can support you, the members and your families.

I would love to hear from you if you have ideas as to how we can better keep you informed and up to date with new treatments and advances in medication: you can contact me at: support@haeuk.org"

Angela

HAE UK PATIENT DAY

Last weekend would have been our 2021 Patient Day, but due to the ongoing pandemic, we reluctantly decided not to hold our event this year. Whilst everything is slowly getting back to normal, cases of Covid are still high and people are still nervous about travelling and meeting in groups.

Last year we held our 10 Year Anniversary celebrations virtually, and all the fantastic videos are still available for you to view on our website. Why not take another look: <https://www.haeuk.org/pd2020/>

We look forward to planning a great Patient Day for 2022 and seeing many of you there.

CHANGES TO HAE UK TRUSTEES

Ed Price, who took over as Chair of Trustees when his father, John Price, stepped down in 2017, has himself now sadly resigned.

Ed is a very senior civil servant in the UK and has steered HAE UK to grow and improve our service to patients and families affected by HAE. Ed spearheaded the development of exciting initiatives such as the Expert Nurse Training Course, improvement of the website and general comms, expansion of the Medical Advisory Panel, the Young Advocates (including the wonderful Percy the Pufferfish!), the merchandise shop and several exciting Patient Days including the last one in 2020. Owing to Covid this had to be virtual but is an amazing resource available on our website.

Ed is a talented violinist and plays in a London orchestra and we do hope he will occasionally come to Patient Days and catch up with us all!

We thank Ed for all of his time over his period as Chair of Trustees for HAE UK



We are delighted that Ann Harding, despite her demanding career as Road Services Director of Quattro Plant Ltd, is to step up as Chair of Trustees. Ann has been involved with HAE UK since the start in 2010 when the organization was started by Ann Price. Until that time, she had

spent much of her time fighting repeatedly in a battle for diagnosis and treatment for her child, Sian, now 30. This is a short resume of what made Ann so driven to work for HAE UK

Sian says; "My mum noticed from birth I was always ill. My stomach was swelling; I was vomiting and in excruciating pain; totally dehydrated. She would rush me to A&E and it became the norm for me to be there twice a week. The doctors didn't know what was wrong with me. They thought it was appendicitis, maybe some form of cancer. They kept pointing to blanks. It felt like someone was stabbing me in the stomach; like somebody is grabbing and twisting my insides. It was unpredictable and would happen anywhere; foot, arm, four times the size. Then one day I was lying in the children's ward on a drip and getting pumped full of steroids, and a Chinese doctor was on call. He came to see me and said he had seen this same illness in another country he had worked in. By fluke he just said, 'Test her for this', and they found out what was wrong."

Ann continues; "You have no idea what it's like seeing your child so ill. It breaks your heart; it just isn't fair. Sian was very sick and I felt in a helpless situation. We were going A&E a lot, at any time... Christmas, birthdays. She would be vomiting and swelling and they'd put it down to a stomach bug or allergy. It's so hard to diagnose. At one point they thought it was appendicitis and when they took her down for

the operation they found nothing wrong with her appendix. I knew something was wrong and I was not going to take no for an answer. I was relieved when she was diagnosed but there was no help, and still a long way to go. The first step was to get hospitals to recognise HAE, as many hadn't heard of it. Sian was given open access to a children's ward which meant the nurses and doctors knew her and knew what was wrong with her and we could visit without having to repeatedly explain the history to an A&E doctor or nurse. But even so she's had a lot of operations. I would wait until she was in surgery before I cried; I never wanted her to see me upset. Great Ormond Street was fantastic. The doctors and nurses were amazing, but sometimes I didn't know whether she'd survive. I didn't think she would ever have a job. I just tried to keep being positive about it and keep moving ahead. My mum helped me. If Sian was in hospital I'd stay with her, but I was a single mum juggling a job to pay the bills. I did have a tough time. Sian has a four years' older sister, Keighly, who doesn't have HAE. Keighly was a ballroom and Latin dancer; she was amazing and came second in the UK. But I was managing family, work, house, travelling, bills and my children all the time. I just kept facing battle after battle and I felt like I had nowhere to turn."

Sian was finding life even harder as she went through adolescence; "It came to a point where my veins collapsed from being used too often when I was 12 or 13, so they put Hickman line into my neck, a line that comes out the side you can feed drugs into. After a while the Hickman line got infected so I was back into hospital to have another Hickman line operation, then a 3rd one got really badly infected and I was in hospital for 3 months. Eventually they took it out, but by this time I was 18. There was a lot of back and forth because I was now an adult and had to go to adult hospital."

After the Hickman Line was removed, the veins had a chance to recover, so Ann pushed for Sian to become the first person in the UK to be trained to self medicate.

Sian "It changed my life! I never thought I'd be able to do it myself, but now I inject myself every three days. Since I was 18 I have been doing it in my veins. I mix a powder and liquid in a glass vile, and then put it into a syringe. I put a butterfly needle into the vein over 20 minutes. I have my one good vein that never lets me down. I've done it in an airplane, I've done it in a car, you name it! My medication is delivered to my home and they send me what I need, prescribed by the hospital."

HAE UK are very fortunate to have such an energetic and driven Chair of Trustees! Ann's final comments; "It's not a question of whether I want to do it; I'm doing it because I need to. I want to help people not have to suffer. They need help to live a normal life. I'm a fighter and I don't take no for an answer. You tell me what's more important than a sick kid."

The last word must go to Ann's boss, John Murphy, Quattro MD; "Ann Harding has every possible quality needed to make this Chairmanship a success. She is tenacious, passionate and driven; a warrior both as a mother and a Quattro employee. Her vital yet unenvied and difficult thirty years experience combined with a dogged determination will lead her through any challenge. The Quattro Group congratulates her and I'm extremely proud to support her leadership of HAE in any way I can. Never has a person been more right for a job.

HAE UK is also sorry to say goodbye to two other Trustees who have generously given their time to use over the past years; Sam Oxley, herself with HAE and mother of our karate black belt trainer Youth Ambassador, Alex. Sam has many family commitments and we are sorry to see her go but thank her very much for all her help and support over the years. And thank you also to Tom Pickering, who came in as a Trustee in order to provide us with legal advice as he was a solicitor specializing in charity work. He has married, had a baby and changed jobs since then, so is very busy, but he has been of great help to us since he came on the Board.

We are very excited to welcome June Cole onto the Board of Trustees! Many of you will be aware of June who is a keen singer and, as part of the Rock Choir, has been involved in a chart-topping record. She also organised a 'flash mob' with the Rock Choir in a busy shopping centre to raise funds and awareness for HAE UK. June is also a passionate educator and advocate, and is our key person for presenting about HAE in Emergency units.



The second new appointment to the Trustee Board is Simon Mumford who is a lawyer and Partner for Pinsent Masons LLP. Simon will be able to provide legal support to HAE UK if needed.

FUNDRAISING AT CHRISTMAS, AND BEYOND

Did you know that you can shop on Amazon and eligible purchases will generate a donation to HAE UK at no cost to you?

You'll pay exactly the same as without a donation and Amazon will fund the HAE UK donation for you through their AmazonSmile programme.

Visit: smile.amazon.co.uk and search for **haeuk**

You can also register with [easyfundraising](https://easyfundraising.org.uk) and nominate HAE UK as your chosen charity.

By doing this, each time you make a purchase online with one of the 2,700+ participating retailers, a small donation will be made to HAE UK, with no cost to you! Retailers include Amazon, John Lewis, Argos, eBay, Next, ToysRUs, Tesco and many many more.

You can register at: easyfundraising.org.uk

NURSE TRAINING PROGRAMME

HAE UK have designed a course specifically about Hereditary Angioedema, which is either a comprehensive introduction to HAE for a nurse new to Immunology, or a refresher for those who are more experienced.

We encourage all nurses to take a look at completing the course, which can be accessed via our website, or you can contact us for more information: support@haeuk.org

BIG CHRISTMAS QUIZ

Our Zoom quizzes have been very popular over the past 18 months, and we will be hosting our next one in a few weeks time. This will be our Big Christmas Quiz....so find out your Christmas jumpers, get ready with a glass of your favourite Christmas drink and nibbles, and join us

online for the fun quiz. As always, there will be prizes to be won!

More details will be circulated to all members in the next couple of weeks.

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

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