



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 Winter 2017 newsletter

Happy New Year to all of our members, we hope you enjoyed a relaxing and healthy festive period. We start our first 2017 newsletter with a round up of 2016 and to share with you lots of news and events for the coming year.

IN THIS ISSUE:

A round up of 2016 • Quarterly question
Our annual Patient Day • HAE UK huddles
Our new website • Patient stories

THE QUARTERLY QUESTION:

Why do I sometimes have problems mixing up my C1-INH?

Oye Santana event Saturday 8th April 2017



Our star of 2016

hae day :-) 2017



A round up of 2016

2016 is not necessarily going to be everyone's favourite year, but for us it had some fantastic highlights.

It kicked off with the incredible Rick Talbot braving the icy seas off Llandudno to raise money for Lions and HAE UK (yes, alright it was Boxing Day 2015 but nearly 2016...). Rick and his wife Pam went on to raise a huge amount of money for HAE UK with the proceeds of his birthday party and Pam's Presidential year as the local Lions.

To ensure that we were functioning correctly as a Charity, HAE UK had to create a lot of policies, such as Child Protection and Fundraising, to suit ourselves and to comply with the Charities Commission rules. Our thanks to John Price who co-ordinated all of this.

To align ourselves with HAE International, we decided it would be a good idea to elect a Youth Ambassador and, after working our way through a fabulous shortlist, we (and the Trustees) eventually selected Alex Graham. Alex, her sister and her mother all have acute problems with their HAE but all three of them have been incredibly brave and proactive in managing their condition themselves.

May saw the HAE International Conference, this year in Madrid. It was the most illuminating experience, for Laura especially it was such fun to meet people she had only heard of and to actually feel part of the whole organization. The greatest news was that Laura's indispensable 'right hand' Rachel was re-elected onto the International Committee. We also were fortunate that our Youth Ambassador, Alex, was able to attend and join in with the young persons' track, which was the first time this had been trialled. Such a success and will be repeated!

Laura spent much of the Spring working with NHS England and the Immunology and Allergy Clinical Reference Group (CRG) to produce the new guidelines for use of C1-INH as prophylaxis. Laura also alerted NHS England to the problems surrounding the withdrawal of Stanazolol for those of our community who cannot tolerate Danazol. Thanks to help from the CRG, a policy was formulated to recommend Oxandrolone where

patients cannot tolerate Danazol. This was eventually released formally in July, along with the new NHS 'Clinical Commissioning Policy for Plasma Derived C1-Esterase Inhibitor for Prophylactic Treatment of Hereditary angioedema (HAE) Types I and II' to give it its full title. What was exciting about this new policy was that it recognized that peripheral attacks are disabling and should be treated, whereas the old policy was only for acute attacks or prophylaxis before dentistry and surgery for example. (Both of these developments were in our Summer Newsletter, on our Facebook group and on our website, but some people seemed to have missed out on the Oxandrolone announcement. Anyone who has unacceptable side effects from Danazol should contact laura.szutowicz@haeuk.org for more information.)

July also brought Laura's 12 month anniversary of having taken over running HAE UK, since the retirement of Ann Price in June 2015. We had no idea 12 months could go so quickly! Along with the work on the various policies, HAE UK had recruited two new Trustees (Tim Crouch, already on the Medical Advisory Panel) and Tom Pickering, who is a lawyer with a particular interest in Charity law. We are incredibly fortunate that Tom and his firm Travers Smith are prepared to give us the benefit of their expertise pro bono.

We are also fortunate that two more top class medical people were prepared to join our Medical Advisory Panel. Dr Scott Hackett, who is a Paediatric Immunologist in Birmingham, and Dr Tariq el Shanawanny, in Cardiff, both have particular interest in HAE and were very welcome participants at our Bristol Patient Day (even if Scott was in mourning over the Rugby results...)

All of a sudden Laura and Rachel were in Scotland! The first Scottish Patient Day opened to heavy fog, in Perth, on 1st October. Laura should have known, having Scottish ancestry – but wonderful Furkhanda had persuaded us it would be alright. She was right, and it was, especially after we got the heating sorted out.

The venue for the event was The Salutation Hotel.

THE QUARTERLY QUESTION

Why do I sometimes have problems mixing up my C1-INH?

Laura says "I am of Scottish origin on one side and have a lot of friends up there and when I said where we were going they said 'oh! Reeeeealyyyy!' in that way Scots do. Apparently for many years it was a 'house of ill repute'. However, it has cleaned up its image and it was super. If a little cold.....!"

We made a lot of new friends, with some 40 attendees, and excellent speakers: The wonderful Dr Rick Herriot, Immunology Specialist Nurse Mary Brownlie, Furkhanda, Nikki Pitt and Emma Parker made great presentations. We also had a presentation from Pippa Adams, whom some of you may remember interviewing you for her dissertation? Scotland also got to be the first UK showing of 'Special Blood', a film by Natalie Metzger which was premiered in Madrid.

Time galloping on, we find ourselves in Bristol for the Patient Day! We were very fortunate that the hotel we chose had availability for us to hold a small drinks/evening reception the evening before the patient day.

Success is a restrained phrase. Thanks to the Trustees, the Medical Advisory Panel and our trusty followers (you know who you are, the old lags staying in the bar till all hours!) this was a really good evening and definitely to be repeated. Less to be repeated is the sleepless night poor Rachel had worrying about the AV equipment which, although booked, had not turned up.... Rachel was up at 5am the next morning to try to resolve the issues but we were still let down.....

Anyway, that is another topic! Please see the article on the Patient Day over the page.

I hope this little overview of 2016 has reminded you of some good times.

Very many thanks go to our friends at BioCryst, CSL Behring, Pharming and Shire for their continued support, and also to Genetic Alliance UK, Rare Disease UK and the Specialised Healthcare Alliance who are invaluable allies and resources.

Here's to 2017!

The C1-INH products both use the 'Mix2vial' system which is a needless transfer system which normally works very well. It relies on the vacuum in the powder vial to draw in the diluent (water-for-injection)

1. Make sure the vials are on a clean, solid, smooth surface. Have ready the Mix2vial in unopened pack, sterile swabs, syringe(s) and your sharps box
2. Wash your hands thoroughly
3. Remove the plastic buttons from the powder and the water vials. Carefully swab with sterile swab
4. Keeping the Mix2vial in the pack, peel off the cover (blue end)
5. Keeping the Mix2vial in the pack and the water vial steady on the hard surface, swiftly and firmly push it onto the water vial. It will 'lock' into place
6. Now take off the pack, but take care not to touch the white end of the device
7. Turn it upside down onto the powder vial. Hold the vial steady on the hard surface and press the white end down onto the powder vial swiftly and firmly so it locks into place. The water will be drawn in by the vacuum in the vial.
8. DO NOT SHAKE! Gently swirl to make sure all the powder is dissolved
9. Unscrew the water vial by turning anti-clockwise and screw in the luer-lock syringe clockwise to draw up the solution.
10. Once finished your infusion, dispose of 'empties' safely.

Never try to use the Mix2vial 'in mid air', always have a solid surface for the vials to stand on as you need to be able to press down firmly.

This is a good video to watch if you need a 'refresher' <https://www.youtube.com/watch?v=csNumRfMyIU>

Our Annual Patient Day 2016, Bristol

EMPOWERMENT

That was the theme, and we did wonder how this was going to work. But the fantastic presenters and presentations made it all come true and we received so many comments afterwards about how 'energised' 'hopeful' 'optimistic' and 'inspired' people felt. So it seemed to have worked!

The first difference to the format was the suggestion, facilitated by the hotel, that we could hold an evening reception the night before. This worked really well and members of the team, the medical advisory panel, the Trustees and some 40 members all mingled over a glass of fizz, and later food, to get to know one another. We received lots of positive comments about the evening event that it will definitely be repeated.

The 'day itself' dawned and poor Rachel had been up before dawn trying to amend some problems with the AV equipment.

The rest of us tucked in to an excellent breakfast and the day started with a brief introduction from Laura about the format to come. For the first time, we were able to welcome delegates over the age of 12, and there were over 100 members in attendance, plus the various pharmaceutical companies and other charity representatives.

Our first presenter was Dr Tariq el Shanawany, who gave a fascinating insight to new treatments for HAE which gave many listeners new hope of things to

come – and not too far in the future, either. Dr Tariq was followed by Dr Mark Gompels who presented on Sport and HAE, which was an inspirational look at how to manage HAE and still lead a full life. Dr Mark also asked attendees if they would participate in a questionnaire around HAE and heart problems.

Something we hope to be able to discuss further soon.

Just before the coffee break Dr Hilary Longhurst introduced the premiere of the short film 'Peripheral Attacks and Me'. This film was developed by CSL Behring and their partner Pegasus, following on from the interviews people gave at their booth at the 2015 patient day and Pegasus's subsequent follow up. We all had a chance to spot our local film stars (all of whom were present at Patient Day 2016!) CSL have used these interviews and the film to develop a whole campaign around encouraging patients and clinicians to recognise how disabling peripheral attacks are and how they must be treated efficiently and quickly.

For those of you not present at the day in Bristol, the film and other information can be accessed by visiting: www.peripheralattacks.co.uk

Our patient story after the coffee break was from Paul Carroll, our very own Iron Man! Paul's description of how he morphed from 'couch potato' to 'super fit' was a testament to a very special determination. You can read Paul's story on page 11.

We were very fortunate that Henrik Boysen from



HAE International could join us to give the HAE International perspective and 'HAE around the World'. Despite the vagaries of the AV system, Henrik's presentation was still very inspirational and very humbling when we realise just how poorly served many HAE patients around the world still are.

Dana Shapiro was our next patient presenter and her story of being determined to climb Mount Kilimanjaro (and her amazing photos!) was incredible. But like Paul, she started with baby steps.....walk home from work, then run a few yards, then walk.....gradually run a bit more until you are running five kilometers to and from work..... completely amazing! Plus sleeping with her C1 in her sleeping bag to make sure it didn't freeze. You can read Dana's story on page 10.

After a very good lunch we had the pleasure of Pippa Adams presenting her dissertation on the Lived Experience of Female HAE Patients, which many of our members were interviewed for. Pippa has produced a

really good piece of work which I am sure will be really useful for patients and clinicians.

Dr Scott Hackett, one of our Medical Advisory Panel, presented on HAE and the Family and then our Youth Ambassador Alex presented a short film she had made of all our 'Haero's'; all our younger members who are determined not to be defined by their HAE. Alex herself is a shining star; she achieves every goal she sets herself, whether it is to be a

black belt karate instructor or to get top results in her GCSEs. Alex and her team of younger delegates spent time in the afternoon designing 'emergency kits' which we hope will soon be available.

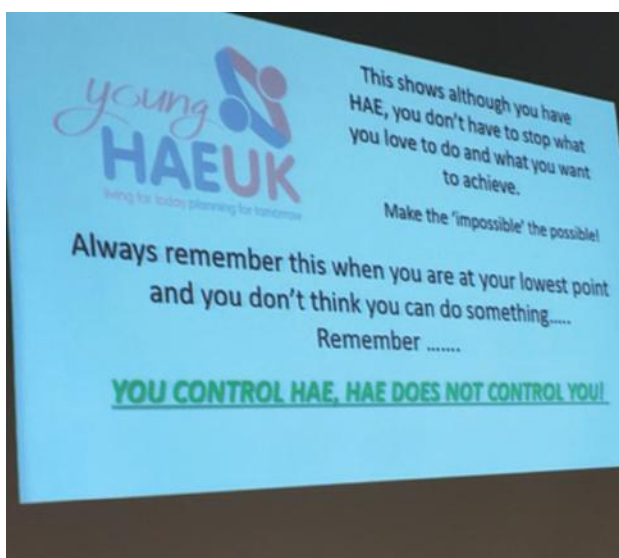
The break out groups were well supported and everyone enjoyed the opportunity to attend two.

June Cole led one of the breakout groups which was one of our most popular, discussing how to put together your own presentations to give to GP surgeries and A&E departments. June's slides are just being reviewed by the Medical Advisory Panel so that we can make them available for other interested people to use to educate their own local hospitals and surgeries.

The active part of the day closed with a lively Question and Answer session and then we were able to show the film 'Special Blood' by Natalie Metzger. Rachel and I first saw this in Madrid and were able to work with Natalie to screen it here in the UK. Natalie has subsequently won the

'Best Woman Film Maker' Award at the Chandler International Film Festival and California Womens' Film Festival Best Documentary with this film. (She is also about to shoot something with JeanClaude van Damme in a submarine, lucky girl!).

We have been overwhelmed with good responses to this day and definitely the evening get-together must be repeated. So looks like the Patient Day is becoming a weekend!





Star of 2016

Our stars of 2016 are Rick and Pam Talbot. Rick and Pam have been fantastic in supporting HAE UK by fundraising when taking part in events, making HAE UK the Gnosall Lion's chosen charity during Pam's presidential year as well as requesting donations in lieu of gifts at Rick's birthday party. They have both put a lot of effort in to supporting us throughout 2016, which is why we chose them as our star of the year.

There have been many other fundraisers during 2016; members taking part in half marathons, bike rides, walks and more, and we would also like to extend a huge thank you to you all too.

If you are thinking of taking part in an event to raise money for HAE UK, or would like some inspiration in setting up your own challenge, please e-mail Rachel and she can send you one of our Fundraising Packs.

HAEi Committee Meeting, San Diego

Rachel, in her position as committee member for HAE International, travelled to San Diego in November for her annual committee meeting.

It was two very busy days of presentations and meetings and included a visit to the HAEA Angioedema Centre San Diego, meeting with Dr Bruce Zuraw, Dr Marc Riedl and Dr Sandra Christiansen. A few of the things discussed over the weekend were:

- The 2017 Camino Walk; following on from the very successful 2016 Camino Walk, HAEi and AEDAF suggested repeating the event and walking part of the trail. If you are interested in taking part, it will take place between 13th and 17th May and you can find out more information by contacting HAE International or Rachel.
 - HAEi Youngsters Summer Camp; this will take place on the weekend of 3rd to 6th August 2017. This is an exciting opportunity for youngsters with HAE and/or their siblings to get together. Details for this event haven't been finalised yet, more information will be available from HAE International soon.
 - The HAE Global Conference 2018; plans for the conference are well under way and the exact date and location will be announced by HAEi on hae day :-)
- 2016



Before flying home on the Sunday, Rachel, along with a few of the other committee members, took part in a HAE in Motion San Diego, a 5k fun run organised by HAEA. Rachel said it was great to get to meet so many of the American HAE patients taking part to raise awareness of HAE and it was nice to finally be able to enjoy a little of the 24 degree November sunshine!

Our fantastic volunteers

HAE UK has some fantastic volunteers who help us throughout the year. Furkhanda Haxton helps manage the HAE UK Facebook Group, supporting new members and pointing them to Laura and Rachel if they need one-to-one support. Rose Joseph works alongside Rachel and Ann Harding on the fundraising team. June and Peter Cole have been working hard at raising awareness in their local hospital and GP surgeries and are using their

experience to help us encourage other members to do the same. We also have many other members who help us out, especially at our annual patient events, there are too many of you to mention.

We really appreciate the time and effort our fantastic volunteers dedicate to helping us throughout the year. If you have skills you would like to volunteer, please contact Laura.

'Special Blood'

Special Blood is the documentary about HAE produced by Natalie Metzger, who is herself a HAE patient. The documentary follows the lives of four HAE families in America as they tell their personal stories.

Some of our members were lucky to see the premier of Special Blood at the Global Conference in Madrid, others at one of our two patient days in 2016.

We are hoping to be able to arrange further



screenings throughout 2017. If you are interested in seeing Special Blood, please contact Rachel so we can look at the possibility of arranging a screening in your area, maybe in conjunction with a 'huddle' (see over the page for more information on these).

Peripheral Attacks and Me

We are pleased to be able to share with you the short film, Peripheral Attacks and Me.

This film, made in partnership with CSL Behring, aims to raise awareness of the impact peripheral attacks can have for the HAE patient and their quality of life, and the importance of speaking with your consultant if you have concerns about your treatment.



You can view Peripheral Attacks and Me film here: www.peripheralattacks.co.uk

Coming up in 2017...

Oye Santana - 8th April 2017

One of our members Ann Blake, and her husband Kevin, have helped organise a fantastic tribute event in Winchester. **The brilliant Oye Santana event will take place on Saturday 8th April at the Guildhall, Winchester at 7:30pm. The event is suitable for all ages and tickets can be purchased from their website: www.oyesantana.com/gigs or by telephoning the box office on 01962 840820.**

Oye Santana are the best Santana tribute band in the world and this event will be a fantastic evening. This event has been organised as a fundraiser so some of the proceeds from ticket sales will be donated to HAE UK too.

It would be really great if we could get a crowd of HAE UK members together to join the event. Please e-mail Rachel if you are interested in going and we will see you there!



HAE UK website

Our website is currently undergoing a rebuild, into a more modern, more user-friendly format. Until the time that the new website can go live, the current one is 'frozen in time' so although the majority of the information on it is still current, we cannot update it with the most recent developments. Therefore, if anything such as a new product launch or new

guidelines published happens before the new website is available, we will e-mail this news out to you all. Similarly, if anyone has any queries about medications or treatments, please e-mail laura.szutowicz@haeuk.org or rachel.annals@haeuk.org and we can help you.

HAEi youngsters summer camp

HAE International are really excited to introduce their new youngsters summer camp. This is the first event of it's kind and will take place between 3rd

and 6th August 2017. HAEi are still in the planning stages of this exciting event but more details will be available soon.

hae day :-) Many faces one family

16th May is the annual **hae day :-)** reaching out to all of the world by raising awareness of HAE among the general public and medical community



Ideas to help us raise awareness in the UK are always welcome. Any contacts you may have with local newspapers, radio, TV or other media could be great. Some people have

even managed to get awareness raised nationally, like Kirsty who bravely went on the Jeremy Kyle Show with her mum to explain about her condition. Please e-mail Laura or Rachel with any ideas you may have.

You can find out more about **hae day :-)** on their website www.haeday.org

HAEi/AEDAF Camino Walk 2017

After the very successful HAEi/AEDAF Camino Walk on the legendary Camino de Santiago in northwestern Spain during the days leading up to the HAE Global Conference 2016 in Madrid, quite a number of people have expressed an interest in repeating the experience in May this year. Consequently HAEi and AEDAF is organizing a Camino Walk to commemorate the global awareness day for **hae day :-)** in 2017.

If a sufficient number of people sign up to fill one bus – or more – we will follow the well-known



format: departure by bus from Madrid on Saturday 13th May, three days of walking with 15 to 20 kilometers per day on average, and return to Madrid on Wednesday 17th May. The third day of walking,

when we would arrive at Santiago de Compostela, would appropriately coincide with **hae day :-)** in 2017.

Returning to Madrid on 17th May we would give the people who plan to attend the 10th C1 Deficiency Workshop in Budapest, Hungary plenty of time to go there for the beginning of the event.

HAE UK huddle

What is a 'huddle'? Basically, a huddle is a small gathering of HAE UK members in a given locality. Whether you have HAE or are a friend or family member, we will welcome you all to meet over a cup of tea or coffee to chat, catch up, exchange news, views, discuss problems and more importantly solutions.

The huddle could also be organised in conjunction with an HAE clinic. If you think you could help to arrange a 'huddle' in your area, please contact Rachel to discuss further.



Scottish patient day 2017

We'll be visiting Scotland again in 2017. Ideas of possible venues in the Edinburgh or Glasgow area are welcomed, ideally they need facilities for about 60 people, with good parking and within easy reach of a mainline railway station. Please e-mail Rachel if you have any suggestions.

Details about this event, including how to register, will be available in the next newsletter.

Annual patient day

We will be heading north for our annual patient day this year. We are working on the details at present and look forward to sharing these with you in the next newsletter. Because of the success of last years' weekend, we hope to be able to offer another social evening too, so we hope that many of you will join us to make this years' patient event even bigger and better.

More details, including how and when to register, will be available in the next newsletter.

Training for the climb - A Kilimanjaro prequel by Dana Shapiro

After I decided to climb Kilimanjaro, I knew that I needed to start exercising to prepare. Since joining the working world, I struggled to find a way to incorporate exercise into my lifestyle in a long-term way. I have always hated the gym. I tried taking classes over the years but never stuck with them. Generally, instructors in group classes encouraged participants to do exercises with more repetitions, heavier weights or in a deeper stretch than felt comfortable for me. For example, I tried a yoga class, and we held the downward dog pose – it is when you support your body on all 4s with your bum up, so your body creates a V-shape. We kept returning to that stretch throughout the class. Before the class finished, both my wrists were swelling, and my shoulders began to swell shortly after. Explaining to an instructor that simple exercises can make my body swell was embarrassing, and sitting out through half of a class seemed like a waste. The benefit of taking a class



was lost in the HAE that followed.

I started training for Kilimanjaro by simply walking. It was November, and I spent a few weeks walking further than I normally did on the weekend and evenings. I brainstormed how I could incorporate working out into my normal daily routine so it did not feel like such a burden to my schedule. I needed to find a way to make exercise part of my life instead of

something else on my to do list. My office was 6 kilometres from my flat, so I decided to use my commute as my workout.

I started by walking home from work one day. I was surprised at how sore my legs were the next day. I rested a few days, and tried again. On the weekend, I found a route that was about 5K in the streets around my house, and started to add a little bit of running when I felt able. I started walking home from work at least 2 times a week,

and started a weekend workout at least once for a couple weeks. Then I started to walk/run into the office in the morning. It was February, so the cold was good preparation for Kilimanjaro and also good motivation to run more in order to stay warm. I was highly motivated by the idea of climbing Kilimanjaro, and that was enough to get me out of bed and into my running kit. I just had to get myself out of the house. Once I was en route, I had to arrive to work - even if I was not running – and that was enough to keep me moving. It was not until the beginning of May that I could run the entire distance without stopping.

If you google workout trainings online, many programs say that you can learn to run a 5K in 8-10 weeks. For me, it took about 25 weeks. I was competing with only myself, and I was the judge of my own success. The key to keeping myself going was through positive mental attitude. Even when I needed to stop running and resume walking, I would tell myself, "You are doing great!" or "You are doing more than sitting on the sofa!" It felt strange to give

myself positive reinforcement while working out, but it was especially important when I was intentionally slowing myself down in order to preserve my health. I treated myself like a toddler learning a new skill – every little step forward was a win.

I managed my HAE with C1 infusions as normal, and did not experience any swellings directly related to running. My goal was to continue to workout over a long-term period of time, not to achieve an individual best record. I was never in insurmountable muscle pain from overdoing it. I comfortably increased from basically doing nothing for years to walking, from walking to running, and from running every other day to running for multiple days in a row. About a month before I climbed Kilimanjaro, I achieved my goal of running for at least 30 minutes for 14 days consecutively. For me, I managed my way to fitness by: having strong motivation, making my workout something I could not avoid instead of something extra to do, going at my own pace and giving myself positive reinforcement.

My HAE story by Paul Carroll

My name is Paul Carroll and I have Type 1 C1 Esterase deficiency and this is my story.

I was diagnosed after in 1995 at the age of 18. My brother was admitted to hospital with a throat swelling. I had the condition along with my Mother, Sister and Brother. Post diagnosis I don't recall back to having attacks but mum recalls occasions where I did get swellings.

I was prescribed Stanazolol to be taken daily, and the types of attacks I have generally suffered are in the Feet, Hands, Groin and Abdomen. I now take Danazol (200mg per day) and I have Firazyr as emergency medication.

I have been married for 12 years and we have 3



children, Louie 5, Amelia 8 & Mia who is nearly 10. Louie has Type 1 and has suffered quite badly over the last few years with multiple hand and feet attacks and a throat swelling. The girls do not have HAE so that is great!

I work full time in Manufacturing Senior Management and have experienced multiple periods of high pressure where at times I have been working up to 60 hours per week.

I have always tried to manage pressure but this is not always easy. I did go through a period where I had 12 months of attacks and this was directly an effect of work. I started a new role and my previous attack was 2 years prior. I started to do less exercise and was more stressed. As a consequence I suffered more attacks..... I took action though and changed

my role in the business. I think this is an important point. If you can attribute things in your life that cause you issues, take action and change them....

I was always pretty fit growing up playing a combination of football and tennis but in my late teens I spent the next decade or so partying. I had a great time spending most of my weekend's DJ'ing or clubbing. My diet was very poor during this time, I was over 15st and smoked 15 cigarettes a day.

I did suffer a number of attacks throughout that period of my life with 1 hospitalisation. These attacks were abdominal, and in my feet and hands.

I have always found that fitness and strength have helped me in my management of HAE. I got into running after getting bored walking the 2.5 miles home from work. I had a little jog and it didn't kill me so I decided to run a bit more. I have since gone on to race circa 20 Half marathons and 5 marathons. I did get the odd swelling in my feet upon taking up running and I guess this is something else I have learned. Don't rush, your body can take time to adapt to new situations and if you get a little set back don't let it put you off....

I did start to get knees issues from running so I thought it would be good to mix up my training so I thought I'd take up Triathlon. I entered a Triathlon and I couldn't swim a length of the pool without stopping. I joined a tri club who put on various training sessions over the week. My first spin class was great but after I suffered a groin swelling, and I thought oh what had I done! But much like my running experience I carried on once the swelling

had gone. I didn't let it put me off.

Over the next 4 years I raced Sprints, Olympic, Half Ironman and full Ironman distance which is a 2.4 mile swim, 112 Mile Bike and a 26.2 mile run, all in one day. I have completed 2 full Ironman races now and all this after having a knee operation in 2013 too. I didn't let that stop me either....

I do think I am addicted to taking part in events, this is where I get a real buzz and I have to push boundaries. Over time issues reduce and now I don't get any HAE type attacks when I run or cycle. I've learned how to adapt to new situations and reduce the trauma effect of trying something new.

Keeping fit definitely helped me in a number of ways; with work it was an outlet for me, and a way of getting rid of excess adrenaline. I have found it an excellent way of clearing my mind and processing the day. I am physically strong so this makes me less susceptible to traumas. I also have Ulcerative Colitis, an inflammatory bowel disease. Some symptoms are similar to HAE and I feel that UC can interfere with HAE too. This is another complication but it is something that just needs to be managed.

So what have I learned? I keep an eye on my immune system, if I have colds etc I am very careful. If I have hard training sessions or periods I make sure I get enough rest. Most importantly don't give up on your dreams! They are achievable and a positive attitude and a measured approach has taken me on some amazing adventures.

Paul

If you have any suggestions or ideas for our next newsletter, or a question for our Quarterly Question, we would love to hear from you. Please e-mail us.

*With our best wishes from Laura (CEO) & Rachel (EO)
and the Trustees*

***www.haeuk.org • support@haeuk.org
laura.szutowicz@haeuk.org • rachel.annals@haeuk.org***