

Rachel's story

My trip to Washington DC

I don't let having HAE stop me from travelling, it does make things slightly more difficult, but with the right planning it is definitely possible.



In May 2014 I travelled to America with my husband and our 11 month old daughter, which in itself was a challenge, let alone also having HAE and the worry of having a bad attack whilst travelling away from home.

For this particular trip I spoke to my consultant a few months before I planned to leave the UK so he could help me prepare. He wrote a letter explaining about HAE and that I needed to carry my C1 medication on the plane with me, in my hand luggage. The letter also contained his contact details in case there was an emergency whilst I was on holiday. He made sure I had plenty of C1 medication to last for the holiday, as well as some extra just in case. I then arranged travel insurance for the three of us, which was a little more expensive due to me having HAE, but essential, I would never risk travelling without it.

Before we left the UK I also looked into which hospitals were close to where we were staying so I knew exactly where I needed to go for treatment if necessary. I am lucky that I am able to self treat so I rarely need to go to hospital for my C1, but you never know when the unexpected bad attack may mean you need to.

On arrival at the airport we checked in and I explained I was carrying medication in a cool bag in my hand luggage, which included needles. The flight to America was seven and a half hours which, with a toddler, was quite busy, but thankfully I didn't have any problems with my HAE and we arrived safely.

The holiday itself was fantastic, we visited lots of sites in Washington and New York, walking miles, but I didn't suffer any severe attacks. I did have to administer C1 twice throughout the trip when I suffered swollen feet and abdominal swells, but this didn't stop us from climbing the Rockerfellar centre, walking around Central Park and going on a helicopter ride over Manhattan, things I didn't think I'd ever get the opportunity to do. Although C1 no longer needs to be kept in the fridge, it cannot be allowed to get warm, so I did keep mine in a cool bag or fridge as much as possible for the duration of the trip.

We had a fantastic holiday and having my medication close to hand meant I felt confident I was in control, was able to treat as soon as I felt an attack coming on, and could just get on with enjoying the rest of the holiday.