

Patient expert personal statement for the Multiple Technology Appraisal of Pharmedgen

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I have worked on the helpline of The Anaphylaxis Campaign, a charity supporting people with potentially life-threatening allergy, for 14 years and during this time have spoken with many individuals who have suffered severe allergic reactions to bee and wasp stings. A fair number of these have been bee keepers who have often been reluctant to give up their bee keeping. I recommend discussing the possibility of venom immunotherapy with an allergy specialist and pass on details of the BSACI website. Another of my roles within The Anaphylaxis Campaign is information manager. In this capacity I have acquired and read many research studies on anaphylaxis including a number on venom allergy.

I experienced an anaphylactic reaction to a wasp sting in my 20s. I can honestly say that this was the most terrifying experience of my life. I have also reacted to medication, but whilst the symptoms I experienced on that occasion were visually very distressing (severe urticaria and angioedema), they were in no way comparable with those experienced with my venom reaction. Within a few minutes of being stung I had collapsed and, according to a friend who was with me, was unconscious for several minutes, during which time I appeared to be “fitting” When I came round, the overwhelming memory I have was that I couldn’t breathe. I had to really struggle to draw breath and felt as if someone very heavy was sitting on my chest. People were crowding around me and I wanted to push them away or tell them to move to give me air, but couldn’t speak or move. I clearly remember being very clammy and feeling freezing cold. I pulled myself up to a sitting position to try to help my breathing but was still struggling. I had absolutely no idea what was happening to me, but knew it was something very serious and thought I was going to die. This I would certainly have described as an “impending sense of doom” – a term that has been used as a symptom of anaphylaxis. No-one called for an ambulance and eventually, after what must have been about 10-15 minutes, my breathing became easier. I was left alone to “recover” but felt unwell, tired and rather detached from reality for the rest of the day.

The incident left me with an absolute terror of wasps, creatures that it’s pretty much impossible to avoid at certain times of the year and in certain situations. Particularly distressing were occasions such as a camping holiday in Greece, sitting outside the tent eating crusty bread with jam on it and about a dozen wasps all trying to settle on the bread at the same time. Many an ice cream was thrown on the ground after being pursued by wasps trying to settle on it. I also had some close calls picking up windfall apples from my garden in the autumn. Wasps were frequently “hiding” in bruised, soft

and pitted parts of the fruit. The fear of being stung and the ever-present memory of the reaction was something I lived with almost constantly for many months of the year and for very many years.

Had I known about anaphylaxis and been made aware that immunotherapy was available, I would certainly have investigated the possibility of being treated.

Fortunately I wasn't stung again for some time. Many years later I read about anaphylaxis and realised that this was what I'd experienced. I went to the doctor who prescribed adrenaline (a mini-jet that was often prescribed prior to the introduction of auto-injectors). About 20 years after my bad reaction I was stung again. The fear I experienced, anticipating a repetition of the symptoms I'd experienced so many years before, is indescribable. I was barely able to "assemble" the syringe due to sheer terror. I waited with my adrenaline to hand but had no reaction.

I visited my GP the following week and told him what had happened and he referred me for allergy testing. The blood test was negative. It appears I am one of the fortunate individuals who outgrow their venom allergy if not stung for many years - "A substantial proportion of patients (20-80% in different studies) with a history of a generalised reaction to a sting have no such reaction to a subsequent sting—that is, spontaneous improvement is common" - Source: ABC of allergies; Venom allergy by Pamela W Ewan, BMJ VOLUME 316 2 MAY 1998.

My sister-in-law has kept bees for many years. She has been stung many times, but last year she began to develop allergic symptoms which became increasingly severe each time she was stung. Although she is a semi-retired GP she was not aware that venom immunotherapy was available. After I mentioned its availability to her she sought a referral to Addenbrooke's Hospital, where she is currently undergoing a desensitisation programme. She has just started on the maintenance phase of the treatment. She has commented that after 8 weeks of treatment she is now able to tolerate the equivalent of 2 full stings together, with only mild swelling. She told me that she had experienced some pain, described as being similar to a sting and also some fairly severe itching with most of the injections. She also said that even though the dose had obviously increased throughout the treatment she has undergone so far, the swelling and localized reactions had become less severe. She is absolutely delighted with the treatment and that she will be able to continue beekeeping.

Standard care for venom allergy without immunotherapy is understood to consist of antihistamines, adrenaline and avoidance. Antihistamines are unlikely to be effective for severe systemic reactions. Avoidance strategies can minimise but not eliminate the risk of being stung. Avoidance is effectively impossible. Adrenaline may not be

effective in all cases and being prescribed and having to take injectors wherever you go can be a psychological burden. Adrenaline eliminates neither the risk nor fear of being stung. Many people I've spoken to have not been given accurate medical advice on the emergency treatment of anaphylaxis, such as lying down if feeling dizzy and calling for medical help even if symptoms temporarily improve. Most are not aware of the possibility of biphasic reactions.

There is therefore really no effective comparator to Pharmedin.