

## **Insect Stings – How it all started and how it ended!**



That's me in the yellow shirt!

I relish life.

I have a wonderful family, a successful life in business, and a comfortable lifestyle surrounded by good friends and neighbours. I am an enthusiast of all things - food and wine, sport, wildlife, computers, playing golf, having fun, sharing and caring with all.

I did not realise it then, but my life was destined to change in the autumn of 2000. I was to become one of a small minority of allergy victims who was hypersensitive, so sensitive that traditional medical treatment proved too dangerous.

### **Wasp Sting 2000**

Whilst walking from my car to my office I was stung by a wasp on the forehead and it was like being hit in the face with a brick. To say I was feeling ill was an understatement - I literally staggered into my office and fell into my chair with my head spinning. My workmates wished to call for medical assistance but I insisted that I was fine - embarrassed that a wasp sting could make me feel so ill. I was actually off work for about a week following that incident but just put it down to a bad reaction.

In 2001 I was referred by our doctor to a wonderful consultant immunologist who tested me positive by a blood test for an allergy to wasp and hornets - she recommended that I start desensitization, a programme of injections where controlled doses of venom are introduced gradually increasing each week. At the start of the treatment I would be dosed with 1/5000th of a wasp sting and by the 12th week would end up with the equivalent of 2 wasp stings. Recent studies show that this treatment works for between 96-99% of allergy sufferers. For once things were not to work out for me and I was to be one of the tiny percentage who do not respond to this treatment.

### **January 2002: The First Week's Treatment: No problems!**

The course started fine and the first dose of 1/5000th of a wasp sting was administered in hospital, I hang around for an hour to ensure no delayed reaction, and went back to work. Little bit of a headache but it looked like there was going to be no problem in sorting this allergy out.

### **January 2002: The Second Week's Treatment: First Anaphylactic Shock**

The next week I turned up again at 10.30 am very confident that I would be back in the office for a meeting later that morning.

Unfortunately this time I had an allergic reaction to this dose of wasp venom. The reaction is scary and can differ from person to person. For me it started with the throat feeling "tight" and a tingling in all my extremities. I then became very cold and my body trembled uncontrollably. Then I got the most amazing stomach cramps and have a real flavour of the female perspective of giving birth. It was seriously painful! The medical team were wonderful administering adrenaline, steroids, anti-histamine - I never normally even take aspirin! Within a few minutes I started to improve and whilst I was left exhausted I was not really any the worse for wear. I had a minor repeat later that evening and went back to hospital where the staff once again administered more drugs and sorted me out. We left at 1.45 am the following morning.

It had been a long day.

### **31 January 2002: Anaphylaxis and Resuscitation**

My third treatment was to take place on 31 January 2002 at 10.45 am. I returned to hospital and it was agreed that in view of my previous reaction we would go back to the initial dose and start again.

Due to my previous adverse reaction the medical team were taking no chances and drips, injections were at the ready and needles were inserted in my arms in anticipation of the need to administer drugs speedily. Within a few minutes of an injection equivalent to 1/5000th of a wasp sting I was in a bad anaphylactic shock which was so disappointing since I had been OK on this dose before. The first shock was treated and I was left to recover and monitored very closely which was just as well. At around 3.00 pm I went back into anaphylactic shock again, but this time in addition to a swelling throat, shaking body, and severe stomach cramps, I was struggling to keep breathing. I remember my heart pounding, the resuscitation team running in, and then for a period of time the time between hearts beat got longer and longer.

I was fully conscious of this and knew that I was entering the dying process.

To cut a long story short, I was brought back to a stable condition because I was in hospital under controlled conditions. and I shall always be indebted to the medical team for sorting me out when I needed them. However, the traditional route of desensitization has proven not to be a safe treatment for me and we still are searching for a treatment before the next wasp sting, which may be my last.

I launched InsectStings.co.uk on St Valentine's day 2002 in order to improve awareness of the dangers of insect sting allergies to encourage allergic and potentially allergic individual. to seek medical advice and treatment - it nearly always works with everybody else! I am worried that there are people walking around who may be as sensitive as me who could die because they were not aware of their allergy and had no remedial treatment available. They must be made aware of their problems and take the easy steps necessary to control their allergy.

For me it's different.

For the first in my life, I am not looking forward to summer but also have a real purpose in making sure that a trivial insect sting should not affect me, the family I love, and others around me. I am also fighting for all the fellow sufferers who do not even know it.

As I come to the end of February I look back at what has been a crazy month. It started with my recovery in hospital and ended with me looking into a future which looks rather bleak.

### **My Dilemma**

The dilemma is simple: I am so sensitive to wasp and hornet venom that desensitization simply seems to be too dangerous and even if tried, would not protect me in time for the arrival of these insects in the next few weeks. I am therefore left in a predicament - what sort of life do I lead?

Should I leave the house for important events only? What sort of event counts as important? Should I just go for it and enjoy life regardless of my problem? What about my garden? How do I

earn a living? What about exercise and golf? Can we go on holiday? The questions are endless and at the moment I just don't have a clue what to do. The sight of my first wasp will be very scary - its easy to say be cool, but not when this little creature could cause me serious damage. Let's be honest - the next sting will kill me unless I am right outside a high quality A & E department. Its tough to admit, but I am staring death in the face for the first time in my life.

I am not scared of death at all. My faith and personal experience has fully convinced me that there is no reason for me to fear death. I just fear the pain of the anaphylaxis and the grief it will cause my fantastic wife and children - I pray that they are not around to witness my death which would be horrible for them.

It has taken me all of February to get over the physical shock of the anaphylaxis and whilst I still feel tired, at least I am eating and the 10 lbs I lost in hospital has started to return. I am also off the steroids which were making me feel very unwell and am now just stuck with taking anti-histamines which will at least reduce the allergic reaction a little bit in the event I get stung.

Mentally, I am coming to terms with what happened to me and the prospects for the future, but it is much, much harder for my wife than it is for me. She has to live with the consequences of my death, the sadness and the loneliness will be horrible for her and I grieve at that thought. Coping with two devastated children will also be very hard and I can only pray in advance that in the event of my death she will be strengthened and comforted by the Almighty. It is extraordinary that you can't have love on the one hand, without suffering on the other.

In the meantime, I am still searching for the treatment that will rid me of this horrible allergy. This website has been a great help and has had over 1000 visitors from all over the world in its first three weeks. I have had e-mails from all over the world offering help and support which has been wonderful. As yet, there is no traditional treatment that has been offered, and so I am going to try alternative medicines such as homeopathy and kinesis.

I am also thinking seriously about going to the press about my predicament and sharing my experience in the hope that it galvanises others into doing something about the amazing knowledge gap that exists about insect sting allergies.

## **APRIL 2002**

Well, the beginning of April has arrived and so have the first signs of Spring - including my enemy, the wasp! I have to say though that in some ways it is more comforting to have an enemy that we can now fight and direct our frustration against. We have been very busy putting up insect screens, looking for different forms of wasp repellents, and generally deciding what we can and can't do with our lives.

Of course that is not say that the medical journey has ended - I am now looking at having rush immunotherapy in Europe which is a form of treatment that we don't really offer here in the UK. Basically under intensive care conditions I will be injected with a really miniscule amount of venom which will be increased gradually every 30 minutes for a number of days until I reach a roughly satisfactory level. The danger is that I will have an anaphylactic reaction, but the safety is simply that I am there in intensive care with all the modern equipment and skills around me. It would however be enormously disappointing if it did go wrong since in many ways this is, I think, virtually the end of the road for orthodox medical treatment.

I have had fun during March and April looking for alternative therapies: I have tried homeopathy and kinesis: both methods of treatment are difficult to understand and rationalise but I feel a lot better now than I did, so who knows! I am also doing something which is definitely helping - visiting a gym and getting fit. I actually feel better than I have felt in years, which is quite ironic really.

The Insect Stings website gives me great pleasure - from a standing start on 14 February 2002 we are now attracting many hundreds of visitors each week - from all over the world. Some have joined the personal mailing list whilst others have kindly written to me offering lots of advice and thoughts. Shock and trauma is a hard thing to cope with but I feel the desperation of February,

and my writing then reflects it, has now been replaced by the traditional British stiff-upper lip that life must go on.

And thank goodness it does.

Life moves forward in strange ways.

For the first time in 25 years I am exercising seriously and as a consequence am not only feeling great but looking good too. People have been coming up to me and enthusing about the fact that I have lost weight and slimmed down - looking and feeling wonderful!

However, the reality is that underlying my physical well-being is this frustrating hypersensitivity that would mean that being stung by a wasp or hornet is seriously bad news. Sadly, every immunotherapist that we have contacted considers me a very high risk to be treated using immunotherapy and my hopes for treatment on continental Europe or the US have been thwarted by their negative responses.

My own consultant immunologist (or allergist!) is wonderful and is now going up what probably is our last medical alley. We first of all have to determine whether or not I have a blood condition called mastocytosis. Provided that result is clear, then she and her medical colleagues would be prepared to give me immunotherapy under intensive care conditions, and that way my tolerance to wasp and hornet venom could be improved.

I have to go through with this route because I want my life back again - I want to swim in the sunshine, garden with pleasure, walk the hills of England, picnic in the woods, take the children on holiday. I don't want to be a semi-recluse for half the year, and that is why the risk is definitely worth taking. My condition is life threatening and so is the treatment - catch 22! But I would rather go out fighting this condition in a dignified and controlled manner than getting stung on the backside unexpectedly in front of friends and family!

During all my treatment one recurring question has been - do I have this wretched mastocytosis. I have had various urine/blood tests which say no, but these are apparently not definitive. So the next step is a bone marrow biopsy to find out if I have systemic mastocytosis once and for all - if I do then I just cannot take the risk of an desensitization since anaphylaxis is almost the inevitable result.

Well, I just had the biopsy (28th May) and it takes a week or two to get the results.

## **JUNE 2002**

It has been a glorious month in England. The weather for once has been kind.

The Queen celebrated the 50th anniversary of her coming to the throne. There was a wonderful procession and fireworks in London - as well as great celebrations around the nation including a splendid tea party in our local town. There has been Royal Ascot (a horse racing week which is part of the British social scene), the tennis at Wimbledon, picking the first home-grown strawberries - well it certainly should make one feel a bit more positive about the world.

On a local level the children have their sports day and the schools have their summer fairs and parents' days. Our village is celebrating the 100th anniversary of the church by having Songs of Praise on the village green, music recitals, flower festivals.

I can participate in only very limited ways in all this excitement because of the threat of being stung - a sting is so life threatening that it just isn't worth risking life to go to a child's sports day. Or is it? When does the restrictions of this allergy become so invasive on the normal quality of life that it does become worth risking spending an afternoon in the sun? Life is immensely precious but when you have been used to the "good things" of life it is immensely frustrating not to be able to enjoy them anymore. I can only look forward to a normal life with the onset of the British winter - something I have never really done before!

On the medical front, I received the news on the biopsy which was excellent - I do not have systemic mastocytosis which means that immunotherapy remains a viable option provided that we start at very extraordinarily low doses of venom indeed (almost saline, as my medical consultant describes it), the treatment takes place in intensive care conditions (needed to hopefully save my life in the event of another anaphylactic event) and all the medical team are happy with the treatment and associated risks.

I feel compassion for the medical team who are there to help their patients - and yet I am asking them to undertake a treatment which has a real possibility of threatening my life. If all goes well, then everyone will say how brave I was to take the treatment but the real courage actually comes from the medical team making a positive decision in the first place. If I die, notwithstanding my own strong wishes to have the treatment, fingers will be pointed and mutterings will go around about how the doctors should have been more prudent and cautious, should not have been swayed by the patients misconceived wishes etc.

Is it worth my risking my life by having treatment or should I just carry on having a restricted lifestyle during the wasp season (around 8 months of the year)? The problem is that wasps are everywhere and I would rather take the lower risk gamble of having a chance by taking the treatment rather than the higher risk strategy of living with such sensitivity to wasps and hornets, and having the inevitable sting one day.

If I do not take the treatment I have condemned myself, my wife and family to a very limited future - if I do take the treatment then at least there is a chance of reducing my sensitivity and having a normal life again.

As I have said before, I would rather be remembered for going out fighting.

## **JULY 2002**

Whilst there is still the glimmer of a possibility that I may be accepted for treatment I remain "sensible" about how I live my life - aware that if I do get stung for living "normally" my wife will understandably never forgive me.

It is frustrating. I am a "modern" man and was making a beautiful salad and thought what would finish it off beautifully would be some nasturtium flowers - totally edible and so pretty! I popped out into the garden, looked around carefully, picked them and came back into the house. The salad was served up and my wife then realised what I had done - she was not amused and she was right, I suppose. There is no point risking life to improve the presentation of a salad. It is the old dilemma rearing its ugly head - quality of life to me is all important, not quantity. It is the flowers in the salad that makes life a little bit special and yes, I would risk my life again for that special thing. However, it is also selfish because my wife wants me around for as long as possible - if she could, she would tie me down and forbid my doing anything outside at all.

Medical progress this month has been frustrating. The hospital have still not decided whether they want to treat me or not - it is a difficult decision for them. The treatment could kill me and yet the alternative is a limited life with the probability that a wasp sting would do it instead - then everyone would say how disgraceful it is for them not to have given me a chance! I am keeping absolutely everything crossed that they sense and give me the treatment I urgently need.

I am hugely gratified by the website - we had around 23,000 visitors in July and I responded to several hundred e-mail enquiries from concerned visitors who wanted to find out more. The site has also begun to cost me money as the web traffic has grown and I have therefore decided to open a shop dedicated to ethical and natural products which may help my visitors. It would be great if the shop could generate something towards the running costs of the site which is costing quite a bit of money each month.

I have also been approached by a TV production company interested in my dilemma and story - it is very early days but if it can help improve awareness of insect sting allergies then I am happy to take part. So much of my e-mail correspondence revolves around family doctors ignorance about insect sting allergies and so I hope that in my own way, we can help them too.

Finally, we thought our house was wasp proof, but one got into the shower room the other day. Everything had netting on it except for - the extractor fan.

It has now!

## **AUGUST 2002**

The school holidays are upon us in August and like most children mine understandably want to go on holiday with their dad like so many other children do.

Sadly, it is not so easy this year as the traditional holiday of the English family involves going to lovely warm climates and exposing our pale bodies to sunshine. This dramatically improves the likelihood of my being stung by stinging creatures and so for this year they went alone on their holiday to the English south coast. This means that they left me behind, well stocked up with food and the necessities of life to survive a week without them. I love them dearly and it was great when they got back, but secretly - I quite enjoyed the peace and solitude for a week!

The website got about 28,000 visitors in August - that is a lot of people who have been stung or hurt by wasps and bees. A number of those have written to me personally and I am so thrilled that I have been able to help a number of them - it is so gratifying when they write back and thank me and it is so exciting to be there for them too.

The prospect of treatment becomes more and more real as time progresses - and I hope that during September we may get the good news that my treatment can start. As the time gets nearer, it becomes less and less attractive. I am fit and healthy at the moment so why should I risk my life on this treatment? Simple. I just feel I have to give it a go because it is things like the summer holiday that are important to life. The alternative of being stung at some undetermined time in the future is not a prospect I would want to consider. The probability is that my wife and children could witness my death from anaphylaxis and that is a prospect for me, and a legacy for them, that is unacceptable.

I have been told that the wasps and bees are at their worst in the Autumn - dozy and aggressive. My life continues to be restricted as a result though we have found that during the day I can go swimming (indoors), tenpin bowling, cinema, museums, and similar indoors places. It is frustrating that in England at least my condition is not rated as a disability and so I get no favoured car parking status. This is fine as long as my long suffering wife is happy to drop me off, but in essence it means that I can no longer go alone to the hairdresser, dentist, wherever without having to take the risk of being stung, and dying as a consequence. My independence has, to a considerable degree, been taken away from me.

Still, I have made it through the summer and there is only a couple of months for the wasps to disappear and then.....we can breathe again until the coming Spring!

## **Winter 2002**

So I have survived the first Spring, Summer and Autumn as someone that is hypersensitive to wasps and hornets - I was not stung and there were few occasions when I even got close to being stung, thanks to my wife Penny who was highly vigilant for any unfortunate insect that got even close!

Despite every effort I have to admit huge frustration - I have been unable to get treatment for my problem and whilst there is still the possibility of treatment I must hang on to that slender thread of hope for as long as possible. I am now beginning to enjoy the freedom of being outside again and loving every moment of it. What joy there is in simply going for a walk, visiting the shops, going to public events... just being normal. How I dread the fact that in a few months time I must start my internment in my self constructed prison - just to avoid the minor possibility of being stung and the overwhelming probability of death to follow in that event.

It is for that reason that I still have to search for a cure and no stone will go unturned in that quest.

In the meantime I look back on 2002 as the most extraordinary year of my life - bar none. It was the year in which I "died" and came back to life and it was a year when my lifestyle changed dramatically. I have had the immense privilege of greeting around 250,000 visitors to the website in the first year of launch and the excitement of receiving e-mails from people seeking advice, giving advice, encouraging, discouraging.....everything you can imagine!

It is a huge, wonderful world and despite the differences between individuals, cultures and nations, it has been truly inspiring to know how so many really good, kind, and caring people there are out there.

What a great pleasure to hear from them all.

### **SUCCESS AT LAST!**

After a year of searching, in February 2003 we have finally determined upon a method of treating me which, whilst not risk free, offers me a serious chance of ridding me of this frustrating hypersensitivity.

I shall be starting a course of immunotherapy treatment in February 2003 under the watchful eye of the intensive care team to make sure that in the event of an allergic reaction then medical assistance is there to get me through the anaphylactic shock. The treatment consists of very small but increasing doses of wasp venom until eventually I reach two wasp stings and am desensitised and able to tolerate wasps as well as the next man! The treatment will take place under intensive care conditions and I will have to stay in the Intensive Care Unit for 24 hours after the injection. Remember that if you are going through immunotherapy yourself the great probability is that you will never need these type of precautions - so don't let my experience in any way put you off immunotherapy which does work for the great majority really well!

We went to visit the intensive care unit in January 2003 to get a taste of what is to come. Whilst it is hugely impressive and gives my wife and I enormous confidence that I should walk away from the treatment, there is no doubt that it is a scary place. Various tubes and wires will be attached to me as I lie in bed surrounded by lots of beeping and flashing machines - it will be no picnic and the stress of waiting to see what is going to happen will be very unpleasant. If there was ever a time to start smoking.....!

If things go well then I will visit hospital for an injection every week for what we estimate will be between 25 and 40 weeks - a long time, but by the end of the Autumn 2003 we will have won the battle. If I suffer another anaphylactic reaction during the treatment then that is that insofar as immunotherapy is concerned. Treatment will stop. I will just have to face life as hypersensitive to wasps which would be a bitter blow because it does have serious implications on life style and the quality of my life as well as my family's.

**Date**

**Diary**

**Do remember that this is an exceptional and unusual form of immunotherapy - for most people it is done without any major precautions other than being near the hospital emergency room. My previous response to immunotherapy required a lot more caution and care.**

The treatment is basically the same each time.

I arrive at the hospital intensive care unit (ICU) at 7.30 am and after changing I am put onto a drip and wired up to machines that measure blood pressure, heart rate, blood gases and am then ready for an injection of venom at 8.00 am. There is lots more equipment around for intubation, breathing, emergency syringes, nebulisers - you name it and it is there!

Introduction

There are a number of people very close to hand - the consultant anaesthetist, the consultant immunologist, and a number of intensive care nurses who have different roles in the event that full life support is required. It is very reassuring but rather strange having so many people so worried about my health!

There is also me and my wife Penny whose presence is more important to me than anyone! Following the 8.00 am injection it is then a waiting game. Various measurements are made every few minutes and accurately recorded - the nursing is "one to one" which is intensive for them and strange for me too. I have never been so closely scrutinised for so long.

If nothing happens then I leave the next day.

Week 1

12 Feb 2003

1/5,000,000th

of a sting

I am pleased to report that all went really well and smoothly. I started with a dose equivalent to 1/5,000,000 th of a wasp sting or 0.00000002 of a gram of wasp venom and - I had no allergic reaction. The staff in the ICU were brilliant and helped me get through the all the fears and worries in one piece. It was a big psychological victory and I am looking forward to next week's injection!

Week 2

19th Feb 2003

1/500,000

Yet another successful stay in intensive care with a small dose of venom equivalent to 1/500,000 of a wasp sting - I had no allergic reaction to the venom. Whilst success so far is great news I am still at a dose of venom equal to 1/100th of the dosage that people normally start their immunotherapy - so at the moment whilst progress is fine the path ahead continues to be daunting but achievable.

Week 3

26th Feb 2003

1/100,000

of a sting

A five-fold increase in the dose of wasp venom to 1/100,000 th of a wasp sting went fine - no allergic reaction, just a headache and general feeling of tiredness. I am now getting into the rhythm of being in intensive care - it is amazing how quickly one adapts to this strange way of life. I claim to be the only patient in the intensive care unit's history who arrives and leaves in a vertical position and under his own steam!

Let's hope that this record is maintained in the coming weeks and months.



Week 4  
5 March 2003  
1/50.000  
of a sting

This week was a dose of 1/50,000 of a wasp sting which is 10 times weaker than the normal starting dose for immunotherapy and once again, other than the flu-like symptoms, there was no obvious reaction. This is going well and I can only be hugely encouraged that there is some light at the end of this tunnel. The intensive care staff are very professional but also great fun - they gave me a signed card for my birthday and intensive care must be the strangest and most memorable place in the world to have a birthday.

Give me the Seychelles, Mauritius or Barbados next year!

Week 5  
12 March 2003  
1/25,000  
of a sting

Some weeks treatments are better than others and this week was hard work. Not only did I feel rough after the injection (1/25,000 of a wasp sting) but I also for the first time started to question myself - was it the stress of the situation that was making me feel rough or the venom injection? Either way we have agreed that provided I am feeling sort of OK and stay within site of the intensive care unit I will come off the monitors during the afternoon and be free to move about. That will hopefully make me feel a bit happier about my situation and more cheerful about things.

Very sadly, my neighbouring patient, a delightful gentlemen whom I had got to know quite well over the last few weeks, died during my stay this week. I suppose that for an otherwise reasonably fit chap like me, it is no surprise that get these occasional "moments" of gloom.

Back at home I am nevertheless still looking forward to next week and controlling my allergy one day.

Week 6  
19 March 2003  
1/12,500  
of a sting

This was an altogether happier week when I moved around and was not wired up all the time to the monitor - this was great and gave me the independence and freedom that had got to me last week. Its not much fun asking to be unplugged every time you want to visit the men's room! The higher dose of venom (1/12,500th of a wasp sting) had the same sorts of effect as last week: a sore head and general tiredness. I can put up with that provided control of the allergy is getting nearer which I am beginning to believe it is!

I am going to attend the funeral of the charming gentleman who died last week in the neighbouring bed. He was one of the "good guys" and I guess he would have done the same for me. A true gent and it was a privilege to attend his funeral.

Next week is worrying because the venom dose is very nearly the equivalent of what nearly killed me last year - whilst I am no coward, I am also no hero. It will be a challenging day!

Well - we must be making progress because I had no violent reaction to the venom injection like the one experienced 15 months ago at very nearly the same dose of venom (1/6,250th of a wasp sting). Just the headaches and flu like symptoms again.

Week 7  
26 March 2003  
1/6,250

I have got to know the nurses so well in ITU - they are a brilliant team and they lift my spirits during my tough hours with them. It is also nice when I can do the same and meet some of the other patients who are going through the trauma of intensive care - I was able to meet two this week and hopefully cheered them up and reassured them that they would get through their particular problems. I shall look those patients up again next week when hopefully they will be in the "normal" part of the hospital. Very therapeutic!

of a sting

I am a patient in ICU but am not "ill" and sometimes cannot help but wonder what I am doing there. This week I saw my first wasp in the garden this year (23rd March) and remembered just how important it is that I sort my allergy out and how potentially dangerous both the treatment or a live wasp sting would be for me.

I have no choice but to proceed onward to Week 8.

The dose this week was equivalent 1/1,250 of a wasp sting - a five fold increase on last week and - no nasty reaction just the normal one I have become accustomed to of a major headache and general feeling of tiredness. Not very different to a hangover, I suppose. I was pleased to visit my hospital friends from last week and I found they were successfully over their operations and going home shortly - great!

Week 8  
2nd April 2003  
1/1,250

I must admit that this week's treatment was a positive experience and I have now set in my own mind the possibility of going to watch the tennis at Wimbledon in July. It may be a fantasy but it is a target well worth pursuing - I will probably end up watching it on the TV but we have nevertheless got the tickets for my wife and I to use in around 10 weeks time.

of a sting

I have so much support from my friends, website visitors, the Intensive Care Unit, the doctors, the nurses - I feel that if I don't succeed in this treatment that I will be letting lots of people down.

This responsibility is a heavy burden and I am now really motivated to get myself sorted out.

A dose which was twice as much as last week - success yet again! Other than the headaches and tiredness after the dose, all went well - my confidence is increasing by the week.

Week 9  
9nd April 2003

I have been doing some mathematics and it seems to me that if the dose doubles each week then in about ten weeks time I shall be at the target level. However, one adverse reaction and the treatment either stops altogether or we have to go back to a smaller venom dose - either way, I would not make Wimbledon fortnight. We have a careful balance of being prudent about the dosage and me wishing to get to Wimbledon. Too large a dose and I could have anaphylaxis, too little a dose and I miss Wimbledon. It is a good thing I am not the prescribing physician!

of a sting  
1/625

We had a great week at home - I completed my pond project in the garden of putting in a little waterfall and hopefully that will attract the frogs and toads. Penny, my wife, was standing sentry duty by my side watching out for flying objects and she killed three before they found me - our garden is now almost becoming too dangerous for me to enjoy - as the weather warms the wasps come out to play and I have to stay indoors.

I could not help but smile on waking up in the Intensive Care Unit this morning and seeing .....snow falling outside. This is rare in southern England in April - but I feel that the somehow I am currently on a roll. - a few more days in the garden....!

Another milestone has been reached! If one wasp sting is the equivalent scale of a year (so half a wasp sting gets you to June 30th, quarter wasp sting to 31st March etc) then as of week 10 I have finally moved off January 1 and am now on January 3! This is progress and whilst there is still a way to go - well I cannot help but feel optimistic that things are going to be OK.

Week 10  
16th April 2003

That being said, the headache and particularly the tiredness seems to be getting worse after each dose - I seem to spend most of my time in hospital asleep at the moment. Its strange, I walk in feeling fine and wide awake and then bang, I feel like I have been on a wild night out - of course wild nights out are all memories nowadays (!) but it is the same sort of awful aching head.

1/100th  
of a sting

The nurses in the intensive care unit keep my spirits up - they really are a wonderful bunch and I will definitely miss them all when my treatment is over. Lots of different people from all over the world who all share a common quality of caring for people in their charge with great sensitivity and humour. I feel very lucky to have found such a great team to share my adventure with.

I am now really looking forward to the Easter Holiday weekend and my treatment next week. Happy Easter!!!

For the sharp eyed my treatment this week was held on a Saturday not the usual Wednesday - the intensive care consultant's flight back from his Easter holiday was delayed due to the SARS problem in the far East.

Week 11  
26th April 2003  
1/50th  
of a sting

In any event the treatment went well and this week was the equivalent of 1/50th of a sting or 1 microgram of wasp venom. For the non-scientific a microgram is 1 millionth of a gram - a full wasp sting contains 50 micrograms of venom - so whilst the dose is still small in size we are definitely moving nearer our destination. We have now worked out the plans for the future and it would appear that we have around 9 weeks of treatment left (if all goes according to plan) and so I should just about make Wimbledon after all!

This week I just had the usual hangover after the venom injection which stayed with me all day Saturday and into Sunday - a small price to pay for the freedom that the treatment will give me very shortly.

We just have to stick with it and I am looking forward to next week when the venom dose more than doubles!

Another successful hospital stay with the biggest jump in the venom dose yet and no anaphylaxis - we seem to be on a roll here, and whilst the doses are increasing at aggressive rates it seems my body is coping with them all just fine.

Week 12  
30th April 2003  
1/10th  
of a sting

Intensive care is an amazing place. An elderly lady who has been there for many weeks and required continuous ventilation during her stay had, I must be honest, been written off by me. Not only did I think she would not make it, but I was privately wondering whether just keeping her going was worth the cost and the suffering it was apparently causing her. Well, I walked in this week and there she was sitting up, conscious, looking quite chirpy and breathing for parts of the day without assistance. I even had a chat with her for the first time! I feel quite ashamed of my judgement and have learned just how naive I am about the tenacity of the human spirit and the skill of the medical profession. Still it was great news and has pleased me no end. I am looking forward to watching her progress over the weeks ahead.

So, I have a definite feeling of bouyancy at the moment - though can only be cautious about the future since I understand that the probability of a bad reaction starts to increase from now on for just normally allergic people. There is no reason to panic but also no reason to celebrate just yet - despite the fluttering in my stomach that indicates we are winning the battle!

We walked into hospital this week and realised that we were famous - the hospital quarterly newsletter had included an article about me, the allergy and the treatment and we were feted as celebrities - our picture was also included so there is now no escape!

Week 13  
7th May 2003

The treatment went fine though with one big difference - the injection hurt for the first time just like a wasp sting. Instead of being just the usual small scratch, it was a small scratch and then a continuous stinging for a few hours afterwards. We must be getting near our destination so it is all hugely encouraging. However, it did hurt and in view of the fact that treatment requires me to go to a 2 sting dose of venom, I guess it'll hurt even more as each week moves forward. It will be just like deliberately placing a wasp on your arm and asking it to sting you not once, but twice. Ouch!!

1/5th  
of a sting

Who cares - fact is that this whole course of treatment looks like it is beginning to have an end after all and whilst there are still seven weeks of immunotherapy left, which I am not look forward to, the prize at the end is having my life back.

Definitely worth all the stings on the way.

By the way, my elderly lady continues to make good progress but she is still on the ventilator and so can't talk back. I joked with her that it was probably the first time in her life that she hadn't been able to get the last word in - and she laughed back at me, and stuck up her thumb which indicated that I was dead right!

This week went well - in fact the best week yet with hardly no headache and just a stinging arm. I took some of the Pyrethrum spray from our on-line shop and it worked really well. Truly practicing what I preach!

Week 14  
14th May 2003

2/5th  
of a sting

I will admit to being tired of it all at the moment. I just want to get to the end of the treatment sooner rather than later and get back to a sensible life again. It is hard work sharing accomodation with the very ill and this week was no exception. In addition to a full complement of patients with alarms going off and more hustle and bustle than usual, my elderly lady was deemed fit enough to be taken off the ventilator and the result was that she had to be put back on it again since she had very serious breathing difficulties. Does this mean she will be condemned to be tied to a ventilator for the rest of her life? I don't know, but all I know is that the whole situation makes me feel very sad for her and the situation she and the doctors are now situated in. Don't get me wrong, an intensive care unit is an extraordinary place and the people that work it are wonderful - genuine heroes! But it is amazingly hard work for someone who is fully conscious and completely fit to be a patient. I am not ill but just have a condition - it is sometimes hard for me and the unit to remember that.

On a happier note, the charming widow of the gentleman whose funeral I attended in the middle of March came to visit. She was very touched that I came to the funeral and I was equally touched that she came to visit me and the unit. It was brave of her to come back and we were all very happy to see her again.

What you expect never seems to happen - this week was physically trying and hard work with the sting hurting more, my head clanging, and general feeling of being shattered. Once again like a hangover with no party beforehand!

But, once again it is another week behind us, and one in which we were able to celebrate my wife's birthday with a cake in the intensive care unit. No candles to blow out because of the dangers of all that oxygen though! The elderly lady opposite me seems to be getting better after all the traumas of last week but the issue still remains as to how to wean her off all this life saving equipment so that she can live a sensible life again.

Week 15

21st May 2003 As for me, the major good news is that there was no anaphylaxis which means that I am well on the way to being cured which is fantastic. The website is getting very busy again and the e-mails are increasing daily which is great. My business is very busy and so there is little time to do anything when I am not in hospital but catch up with all the work.

3/5th

of a sting

All is going well so it is odd that I can't help feeling fed up and "cranky" at the moment. Perhaps it is the thought of next week's injection which makes me feel negative at the moment and the fact that I feel more and more tired. We British are meant to have a stiff upper lip but sometimes even the stiffest lip has the odd tremble.

On to next week when I hope I shall be a bit more positive!

What a difference a week makes - it was a very positive week with a very modest reaction to the increased dose of venom and generally a very comfortable stay. I came home feeling relaxed and very ready for the fray! It was particularly great to see my elderly lady walking around the unit without the ventilator - perhaps she is feeling more positive too and I am just catching her vibes!

Week 16

28th May 2003

4/5

of a sting

The weather has turned lovely again and I have suddenly realised that I have got my life back again because next week I will be taking a full wasp sting worth of venom which means that if I get stung in the field then I should not have any problems. However the target dose is two wasp stings worth of venom - wasps can sting twice and there are some pretty big queens out there so it is better to be safe than sorry!

The first day of Wimbledon is looking far less of a problem and it should be on Monday 23rd June 2003 on No 1 Court - I know there are a few weeks to go but I can't help but feel positive about the whole situation at the moment.

If all goes well my final immunotherapy treatment will be on Friday 27th June 2003.

We have finally made it - after 17 weeks of hospital visits, frayed nerves, headaches and tears, we have finally reached the landmark of one wasp sting only to remind ourselves that the conclusion of the treatment will be in three weeks when we reach two wasp stings. But I am confident that there will be no problems getting to this landmark.

It means that I am basically cured of this condition and now able to go and do the ordinary things that ordinary people do all the time without thinking about it.

Week 17  
4th June 2003

There are another three weeks of treatment and I will be keeping this diary until then, at which time I will close the diary for good - I originally set up this website as a resource for others and now I want to concentrate on that side of things rather than talking about my particular condition, which is/was very rare anyway.

1 wasp sting!

Keep coming back for the next few weeks and see a picture of me at Wimbledon, an ambition that seemed almost impossible four months ago now looks as though it will be readily achieved.

I have got my life back again and I am amazingly grateful - just how do you thank the doctors, nurses, family, friends, web correspondents who have got me to where I am today?

Something to think about during next weeks treatment!

A change to the treatment this week - instead of one injection of venom I now am given two. This is good news as these injections do sting and to have them given in two separate locations hurts a bit less! I had no reaction to the first injection at all (0.6 of a sting) though had the usual headaches after the second injection was given. I slept most of the day but all went well for another week.

Week 18  
11th June 2003

The best bit of news this week was that the "elderly lady" who has been "up and down" for the last month or two is now definitely on the up and up. She is able to talk through her tracheostomy valve and she is more than a character! In fact I can see that she is a very strong personality and quite a fighter. She is doing really well and she may well make a full recovery yet.

1.2 wasp stings!

As for me, well my work is getting busier just at the right time and when I am not in hospital most of my time is catching up with earning a living. It is a good thing that they do not allow mobile telephones in hospital or else I would be on the phone/e-mail continuously when I should be resting.

I can't believe that there are only two more weeks left!

The penultimate week went so smoothly - two doses of venom on each arm and I went to sleep for most of the day and felt fine.

It is all turning into a great success - everyone increasingly confident each week that there will be no anaphylactic reaction and none the more confident than me. My body's reaction does seem to be changing as the weeks progress with the intense flu-like symptoms now replaced just by sleepiness. If, in future years, I can't sleep then I shall go out in the garden and get stung.

Week 19  
18th June 2003 My "elderly lady" has now left the intensive care unit and is in a normal ward and seems very happy that she is going "home". However her old home is not practical for her any more and so life will have to change massively for her - her former independence will have to be sacrificed which is very difficult.

1.6 wasp stings!  
For me, I am lucky - it seems I have got my life back and I feel as elated about it now as I felt depressed about it last year. I shall be going to Wimbledon on Monday 23 June 2003, a few days before the **last treatment session on Friday 27th 2003.**

I will then make my last diary entry and draw a line on what has been an extraordinary period in my life.

Log in and see a picture of me celebrating at Wimbledon!!

Yes - I made it to Wimbledon before my treatment which this week takes place on Saturday. For once the grey start to the day was soon replaced by beautiful sunshine - a day of great celebration for me and Penny!

Wimbledon







It is often said that the journey is more exciting than the arrival - and today's treatment of a wasp sting in each arm went very straightforwardly with no problems at all - in fact I got out of hospital earlier than normal because I was feeling so well!

I had arrived at my destination with a sense of anti-climax - of course I was thrilled to be there but relief was far more the order of the day than celebration!

I have finished the "step-up" programme and now start the maintenance programme of an injection every month, for how long I don't know but certainly a few years. The threat to life is comparatively tiny compared to what it has been over the last 20 weeks.

Week 20

27th June 2003  
2.0 wasp stings!  
This is my last diary entry - so thank you, dear reader, for your interest in my situation and the general cause for people who have severe allergies. My fervent hope is that everyone with severe allergies will find a cure for these dreadful conditions. They are so life-limiting and soul-destroying. They generate far less concern from those who do not suffer than other illnesses but are all the same absolutely dreadful problems to have to face on a daily basis.

I have been so lucky and have so many people to thank that I will be posting a separate web page shortly. In the meantime, I now have my life back again and have to start working out what to do with it.

I just know my priorities and values have changed so much over the last 18 months that, quite literally, life will never be the same.

I consider myself very blessed to have been given my life back, and a life which has become so much the richer and finer as a result.

David Glaser, 28th June 2003

