

Case study

Howard Jenson

*Howard Jenson is a member of the West Yorkshire Support Group. **Dystonia**matters! met up with him in March to learn more about his dystonia.*



● Howard Jenson

"I have benign essential blepharospasm with apraxia of eyelid opening. I'd been noticing for some time my eyes had become sensitive to light and also the tendency for them to blink a lot. This gradually became worse towards the end and before I finally got the correct diagnosis, I was effectively blind. My eyes would close for indeterminate periods, perhaps only seconds, but nevertheless both scary and potentially dangerous. I simply could not control the blinking to the extent that my wife had to become my guide and protector when outside.

I insisted I was referred to the local eye hospital. On both of my visits I saw a 'member of the team' ie. not the Consultant, and was told I had blepharitis, which is basically an infection, for which I was prescribed a course of antibiotics. Needless to say there was no improvement. I was then told my eyelids were drooping and offered surgery to adjust them. The surgery took place and, of course, I was no better.

I then swallowed my principles and paid to see the consultant who insisted I had 'Dry Eye Syndrome' and would have to live with it. He ignored my repeated question regarding the excessive blinking other than to declare it was as a result of the dry eyes. I knew I did not have dry eyes and started to try and work out logically what could be the cause of the condition. By this time my quality of life was pretty awful. I then told him that my GP had sent me for the X-ray and CT scan and that I had also seen the neurologist. At that point he changed his mind about my diagnosis, declared it to be blepharospasm and referred me to another ophthalmologist who did botulinum toxin injections. I now receive four botulinum toxin injections around each eye. The botulinum toxin is meant to numb the muscles that are causing the spasms to take place. So far I have had four sets of injections and each has had a different response. I don't feel the correct regime has been found yet. Currently my left eyelid is drooping which means vision in that eye can be problematic. My eyes themselves are fine, it's the eyelids that are the problem."