Business as usual!
Christina Smith

Christina Smith is in her tenth year of fighting the effects of blepharospasm and now, finally, she has an effective treatment at last.

The owner of a successful business in the City of London, Christina first noticed something was not right when her eyes began to blink excessively and her eyelids did not open properly. “Initially, I was diagnosed with dry eye symptom and started using eye drops which really just made my eyes sore and led to conjunctivitis,” said Christina. “Finally, I was referred to the ophthalmology department at my local hospital and after various tests, including an MRI scan, they diagnosed me with myasthenia and started treating me with a very strong course of steroids.

Not only did this not work but they forgot to lessen the prescription and I suffered an overdose. Although the specialists were very nice and convinced they had diagnosed correctly, it was only when they referred me to their ‘boss’ that he categorically stated my condition.” It had taken some two and half years for Christina to receive the correct diagnosis, learning a brand new word – ‘blepharospasm’.

Christina has botulinum toxin injections every three months but also paid to have an eyelid lift. “The injections were just not working and I believe the weight of the over stretched skin from constantly propping my eyes open did not help,” commented Christina. “My specialist felt it would be worth having the operation but knew the NHS, and indeed my private insurance, would not cover it because it would be considered cosmetic. However, it was worth every penny and my injections are now effective, although they hurt more as the skin is more sensitive.”

Luckily for Christina she did not have to give up employment since she has her own company. But she wryly notes that had she been an employee, she would have lost her job as she would have been unable to function properly.

“I run an employment agency and my role is to interview candidates for my clients and I could not do this,” explains Christina. “In the early days, it was a very difficult. I found even walking down the street very hard. The devastating effect of dystonia nearly led me to sell my business to a competitor for a very low price, as I was feeling very demotivated and depressed. Luckily, I changed my mind at the last minute.”

“I could not drive and at school I was known as the parent with the eye problem who had to prop her eyes open at parent meetings and events. It really does knock your confidence. I also found it difficult to join in conversations in larger or noisy groups as in those circumstances lip reading is very important and eye contact in any conversation is very important.”

“But family and friends have been brilliant. My husband effectively became my carer when I was out and about, guiding me when I was walking and driving me everywhere. I could not go anywhere on my own. Even my three young children used to take it in turns to hold my hand and guide me.”

For Christina, post the operation, everything seems to be improving. While there is no cure for her blepharospasm, there is a form of normality in her life. As she observes, “I still need the injections every three months, and think I always will do, but my eyes are open! I still have to focus my muscles around the eyes but sometimes I’m able to drive and I can now attend meetings without feeling and looking very strange.”

“I run a successful business in the City, have a big social life, a supportive husband, and while the first years of dystonia really knocked my confidence and ability to function, I’m now very positive and upbeat; I can see the light at the end of the tunnel!”

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