



# Reader's letters

## Have your say...

● *Dr. Tom Warner (The Dystonia Society Medical Adviser)*

### Mercury fillings

Further to Janet Baird's letter (*Iridology. Winter Issue 58*), I know of no proven link and there appears to be nothing published on mercury fillings and dystonia. This is a very contentious subject, I know, and these fillings have been linked with many problems, some neurological. However, most of the reports are anecdotal. There are, however, several published papers involving a potential link between dental trauma (ie. having a dental procedure) and subsequent development of oromandibular dystonia. This has nothing to do with fillings, of course.

**Editor's note:** *The recommendation from the British Dental Association is that you should not have fillings removed unless they need to be renewed, as removing fillings prematurely can damage the teeth and lead to more extensive dental treatment. They do suggest that should fillings need to be replaced then they should be changed to non-mercury containing fillings.*

● *Alan Tamlyn, Cardiff*

### Cheque mate!

I recently had a cheque returned to me (not to mention a quizzical letter from the payee) which declined payment on the grounds of my signature being 'inappropriate'. This I determined, meant it did not match my 'standard', therefore acceptable signature.

My initial thoughts were mixed. It was nice to know that someone was taking the trouble to protect my interests by checking that my signature was valid. On the other hand it never occurred to me that my writer's cramp might be a cause of a problem. In this case an embarrassing one. The matter has now been resolved but it raised an interesting point. I wonder if anyone else has had this problem?

**Editor's note:** *Stickers are now available from the UK Office. Please call us on 0845 458 6211 if you would like to request some.*

● *Barbara Weller, East Grinstead*

### Right to hear

People with sight loss have a right to 'hear' what is going on in the Society and should have access to the newsletter and other material produced in the format of their choice. I am concerned that the current format discriminates against people with sight loss, as the newsletter is only available in written form.

I think other members with sight loss or visual impairment should contact the Society to support this request, as I feel that there must be others who would also benefit from this.

**Editor's note:** *The Society is able to produce larger print versions of the newsletter (A4 page size). We are currently reviewing the feasibility of producing the newsletter as an 'MPEG' computer file. Previously, we produced a tape cassette. However, this delayed the newsletter by two months and was very expensive. We welcome members comments.*

● *Carroll Ashton, Lancashire*

### Confidence returning

After 15 years of botulinum toxin injections for blepharospasm, the benefits lessened to the point where I felt I was back at square one, with only the coping strategies I developed over the years to keep me from becoming a recluse.

I was recommended by my optician to contact ophthalmic surgeon, Mr. Brian Leatherbarrow at Royal Manchester Eye Hospital, to discuss my future treatment and suddenly I had a light at the end of the tunnel.

After a lengthy discussion, it was agreed that I would undergo an operation to remove most of the eyelid muscle causing the spasms (orbicularis myectomy), together with skin tightening, as a day case under local anaesthetic. There were no promises of a successful outcome but at 62 years of age I was not ready to give up my golf and voluntary work and I didn't want my grandchildren to remember me only with sticky tape holding my eyes open.

My right eye was operated on in May and the left in October 2007. What a transformation (after the bruising had settled). My eyes are now wide open without spasm, and the facial contortions are gone. I can see birds flying and have discovered the high shelves in Tesco, where previously I could only look down. *(continued on page 37)*

## Reader's letters... *continued*

In a few months I will be assessed to see if I need the occasional injection to support my new vision (my lower lids were not operated on), but hopefully this will not be necessary. After 15 years, I no longer hide from a camera or dread unfamiliar experiences. My confidence is coming back and I am putting all my energy into making up for my lost years.

**Editor's note:** See page 7 for the medical views of Mr John Elston and Dr Marie-Helen Marion.

● Clive Vare, Slough

### The Sun should apologise

I suffer from dystonia and have botulinum toxin injections in my neck every three months. Like many thousand of others, including children, I have read the front page story in the Sun newspaper about the number of deaths in the USA from botulinum toxin. I think it's well out of order as it clearly puts fear into a whole lot of people who depend on the injections but will now worry that it will kill them. It is quite clear that the reporter did not research the story properly and she should have asked the Dystonia Society who could have put her right. The Sun should apologise for causing this scare but I bet they don't. Even if they make a hefty donation, it still won't make up for this piece of scaremongering.

**Editor's note:** A statement outlining our view on this subject is featured in the Society News pages..

● Sheila Blacklock, Hexham

### I have torticollis

I have had dystonia for over six years now and I could tell a different story to Derek Thompson's (*Charlie Fairhead's Hell*, featured in the *Sunday Mirror*, December 2007). I wrote an article for my local paper to help raise awareness and it seemed to do the trick in my village at least, but for me dystonia was a living hell in every sense of the word. I am very pleased that Derek's dystonia doesn't appear too bad. He is one of the lucky ones.

I am now classed as stable but there are no guarantees that I will stay that way! I have torticollis and have numerous injections every three months. For now I am able to live a fuller life, albeit with certain restrictions. I feel very strongly about dystonia and want to help others as I have experienced it first hand and 'got the t-shirt', so to speak.



Please send all your letters to: The Editor, 1st floor  
Camelford House 89 Albert Embankment, London SE1 7TP

I personally think dystonia has to be tackled positively as many sufferers need help now – some are in the dark place I was. I am not sure where you would begin to help them as there is so much to be done, especially in making more doctors and people in the medical profession aware of this condition. Dystonia takes over every aspect of your life and for me the pain has been immeasurable and drugs didn't seem to help. Let's hope there will be more awareness of the plight for dystonia sufferers this year.

● Anna Rose Coldwell, Minster

### Congratulations

I must congratulate you on the new Dystonia Society newsletter. It is such an improvement to the old one and I am delighted to see such a lot of research has been done. I have had laryngeal dystonia for 34 years. It took 15 years to diagnose the condition and I have been having injections for 20 years. I am now rejoining the Society. Thank you.

● Patricia Slingsby, Somerton

### Happy Ending!

Some stories do have happy and successful endings. In response to my letter published in the Winter 2006 issue (DVLA and blepharospasm), I was contacted by Val Wells, the Service Development Manager, who discussed my condition and my driving license having been revoked by the DVLA.

After forwarding supportive letters from my GP, opticians and hospital consultant, I finally received paperwork from the DVLA to apply for my driving licence – and lo and behold seven months later I have finally had my driving licence re-instated. Freedom once again – to shop and visit friends locally! I can't thank Val Wells enough for the support in helping me to achieve this.

**CORRECTION:** We featured Judy Reeves in 'My Story (Issue 56 Summer 07) and she provided readers with an update on her condition (Issue 58 Winter 08). We inadvertently omitted the word 'more' from her letter on page 34 as it should have read "... I am more able to voluntarily control my neck."

**PLEASE NOTE:** The views and opinions expressed in Reader's Letters are not necessarily those held by the Dystonia Society.