

## **"YOU HAVE ARRIVED"- MY GPS GUIDE TO THE LAND OF DYSTONIA**

by Harriet Berkal

Ah the BRAIN- such a broad terrain and tricky to navigate through. So much so, in fact, that Dystonia often doesn't even show up on its map. Getting to the dystonia destination is half the battle and for me the process took a good two years.

Most of us expect certain adjustments to our bodies after we reach the age of 50. So when I started to experience severe dry eyes and extreme sensitivity to light, I thought the worst of it would mean that I could no longer wear contact lenses. But that turned out to be just the beginning of my medical journey.

There was more happening to me than meets the "eye". I went from one ophthalmologist to another, travelling to Houston's Alkek Eye Center at the Baylor College of Medicine to Toronto's Herzig Eye Institute, seeking relief, as it was getting more and more difficult to keep my eyelids open.

No one seemed to know what was happening and all I ever heard was that my eyes were very dry, likely due to hormonal changes in mid life. I was given every eye drop from Restatis, which elevated my blood pressure to dangerous levels, to having a procedure called lipiflow; sort of a hot soothing spa treatment on your eye lids to melt the oil clogging your myobian glands. Nothing helped. The mystery continued, as did my frustration.

It was hard to hide from others, as they noticed that when I spoke, my eyelids would be open and when I listened, they would close while I would struggle to keep them open. In hindsight that should have been a red flag to me that I was dealing with a neurological issue. Hindsight is 20/20 unlike my vision.

Finally, I went to try out one more doctor in Toronto who tried to fit me with a sclera lens (the kind they wear in horror flicks)- which fits over the entire eyeball, where they attempt to fill it with eye drops. This lens is intended to keep out wind and air that would aggravate my eye. Dr. Barbara Caffrey, who is an optometrist in Toronto, was stunned at how little moisture I had and how fast my evaporation rate was under 3 seconds. She referred me to Dr. Consky for a consultation.

A few weeks later, I received a call from his office asking why I would

be coming all the way to Toronto for botox shots in my eyelids? This was perplexing- botox? Why would I require botox shots for dry eyes? I told them I would contact ophthalmologists in Winnipeg to seek out this service. That proved to be quite enlightening, as no one in that field in Winnipeg administers botox shots to the eyelids. I contacted Consky's office again and indicated that not one eye doctor here provides that therapy. They quickly informed me that Dr. Consky was NOT an ophthalmologist but rather a neurologist and that I had a condition called Non Essential Blepharospasms, (BEB) a form of dystonia. It is a neurological disorder, where they presume the basal ganglia part of your brain is misfiring and hence the eyelid muscles lose control.

I finally had a diagnosis to this bizarre illness, and was referred to Dr. Borys a neurologist at the Movement Disorders Clinic in Winnipeg.

It turned out I was not alone. The average diagnosis for BEB (benign essential blepharospasms) is three years. Clearly, there is a massive disconnect between the medical specialties, i.e. ophthalmology and neurology.

Who goes to the Movement Disorders Clinic besides those suffering from Parkinson's disease? Well, anyone with Dystonia for one and there are a variety of areas it challenges the body. Here is a sampling:

- 1.) **Benign Essential Blepharospasms** (BEB) which is a focal form affecting the eyelids and brows,
- 2.) **Cervical Dystonia**, (spasmodic torticollis) which causes the head to shake from side to side and can affect the shoulders,
- 3.) **Spasmodic Dysphonia** (laryngeal dystonia) affecting the vocal cords,
- 4.) **Oromandibular Dystonia** (cranial dystonia) with symptoms including forceful contractions of the face, jaw, and/or tongue,
- 5.) **Hand Dystonia** (writer's cramp) targeting the fingers, hand and/or forearm,
- 6.) **Torsion Dystonia** (PTD) -primary torsion dystonia) which appears to affect the entire body. They have identified the

gene for this one, which can begin in early childhood or have adult onset. Its severity can range from involvement of a single muscle to generalized contractions of the limbs, neck or facial muscles. It can progress over a 5-10 year period.

- 7.) **Musician's Dystonia** – Task specific,
- 8.) **And my favorite – Psychogenic Dystonia** – one that is secondary to psychological causes i.e. it's all in your head, or perhaps in some other part of your body, etc.

I have always been proud of my Jewish heritage, but it was fascinating to learn that Ashkenazi Jews and those in the Amish/Mennonite communities have a disproportionate amount of torsion dystonia being genetically passed down from generation to generation.

The other various forms of dystonia affect not only Jews but also others from a variety of ethnicities. Dystonia has been estimated to affect only 1-3% of the population. So, it's not a very sexy disease and is remiss in having it's own telethon, and/or wide exposure within the community.

How to you acquire dystonia? It can be genetic (mostly on the torsion variety of dystonia) but also it can be brought on by physical trauma and there appears to be a stress related component to this illness.

Dystonia affects both men and women and all age groups but commonly the age of onset is between 40-60. (Other than Torsion Dystonia.) Women are more prone to it.

There is a support group in Manitoba, where I have recently acquired the role of Chairperson and my job involves educating the public about this illness, where there is a general lack of knowledge. As a result, there which is a serious lack of research monies.

What our group has discovered through our exchange is that:

- 1.) There appears to be a very strong stress related component to this illness, whereupon some individuals go into remission after retirement.
- 2.) We believe there is a correlation with hormonal change. Two

individuals in our group have experienced remission over a five-year period from taking oral estrogen supplementation.

- 3.) Blepharospasm is related to Hashimoto disease, which coincidentally I was also diagnosed with. They aren't sure why but I'm assuming it's hormonal.
- 4.) Many of the individuals in our group suffer from TMJ where they grind their teeth and two of us have travelled to California to be fitted by a neuromuscular dentist who believes that many movement disorders are related to skeletal misalignment. <http://tmjconnection.com/> (scroll down to the video gallery and watch the amazing work this dentist is doing to help those with Parkinson's, dystonia, etc. He is definitely on to something. Both of us obtained temporary relief from the mouth guards but sadly it didn't last. If we needed any dental work, the mouth guard would then become misaligned. Some neurologists I have interacted with refer to the dental splint as "snake oil". But if you have seen and felt the difference with your own eyes, perhaps an open mind would be helpful.
- 5.)
- 6.) We have all had to become advocates for ourselves and recently one person who was not getting any relief from the botox shots, was sent to an Ophthalmologist/ Plastic Surgeon, who utilized a different technique and template in administering the botox and she got results for the very first time.

The ride to Dystonia can be bumpy. There is no present cure except for the treatment of deep brain stimulation (DBS), which can be risky. It has helped many individuals who qualify for this 8-hour invasive surgery into the brain with electrodes, which are then connected to a pacemaker.

If you suffer from Dystonia, know that there is support out there for you. We welcome new members to attend our meeting, held four times a year. The next meeting is Saturday, September 13<sup>th</sup> at 1:00 p.m. at the St. Boniface hospital. Please feel free to contact me at:

haberkal @gmail.com for further information. And in the spirit of the New Year, the Manitoba Dystonia support group is receptive to accepting any donations that will further research into helping us find a cure.

#### References

<https://www.dystonia-foundation.org/what-is-dystonia/forms-of-dystonia>

<http://www.jewishfederations.org/page.aspx?id=45016>

<http://tmjconnection.com/>