

## **BLEPHAROSPASM IN AUSTRALIA**

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Secretary/Webmaster  
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It was in the late 1980's when I first realised something was wrong with my eyes. Back and forth between my general practitioner and several ophthalmologists and neurosurgeons I went, all to no avail over a two year period. Finally an ophthalmologist recognised my condition and put a name to it: Benign Essential Blepharospasm (BEB).

There was no Internet in those days so it was a case of several visits to the State Library in Perth, Western Australia. I soon discovered there was very little about BEB in the literature at that time.

A few years later a friend told me she had been talking to someone who had the same condition as I had and so began a collaboration with Lesley which has taken us from a small local group to the national support group that we are today .

It was the availability of the Internet that really opened up a wealth of information about Benign Essential Blepharospasm. Although we had not yet met, both of us had discovered the BEBRF online. I used to post on the Forum in the early days and Lesley had decided to contact the support group in Melbourne, Victoria that she had found on the website. Sadly this group has now disbanded. She obtained their newsletter and subsequently found the name of a person with BEB in Perth who knew of another and slowly discovered she was not alone with this condition.

Lesley decided to try and set up a support group here in Western Australia. She contacted the BEBRF and was sent a lot of information in the form of pamphlets, booklets, and a set of audiotapes from their annual conference. This contained sessions from neurologists, ophthalmologists and sufferers of blepharospasm, also Question and Answer sessions that were very informative. The first support group meeting was organised for May 2004 but was not advertised sufficiently and it attracted only 5 sufferers and their partners/carers.

Lesley and I had met by this time and we decided to try again and another meeting was organised for November 2004. This attracted 12 sufferers and 8 carers from far and wide in the State. This was a very encouraging response and it was decided to set up a website, print flyers and brochures.

Our next local meeting was in May 2005 and this was also the year we incorporated our group: BEB Western Australian Support Group Inc. We found that as most of our members were elderly, many did not have computers and so were unable to access online information. This meant most of our contact was via mail. We had no funding at this stage so approached a local group who generously gave us \$500 for expenses.

Later that year, our group was also involved in a television current affairs segment on BEB. Several of us were interviewed about our symptoms and the trouble we had in getting a diagnosis of this condition.

In November 2007 our members were privileged to be invited guests to a segment on Blepharospasm at an International Ophthalmic Conference held in Perth, Western Australia. This was certainly a plus to know that more awareness was being given to this condition. There were ophthalmologists from around the world in attendance.

As our membership continued to grow we decided to hold our meetings at Citiplace Community Centre at the Perth Railway Station which is convenient for most people to access. We hold our AGM in April and an end-of-year function in November. We endeavour to have a guest speaker at our meetings and these have included ophthalmologists, an optician, a clinical psychologist, pharmaceutical representatives, and a chiropractor. We have about 80 local members in Western Australia and many more website members from all over the country.

We also produce a twice-yearly Newsletter which is mailed to those who have no Internet and emailed to those who do. We have been fortunate in obtaining some funding in recent years from pharmaceutical companies. One of our current activities is to create a database of all doctors in Australia who treat Benign Essential Blepharospasm. This will be particularly useful for our travelling members as well as for enquirers looking for a doctor in their locality.

When the website was first established in 2004 it did not take long for people all over Australia to get in touch. We had a registration form so people could join the website and they had the option to allow their email address to be available so that other sufferers could contact them for support and advice. We had registered members from all over Australia. We acted as a referral centre and forwarded enquiries to a contact person in the relevant State.

In 2012 Lesley decided to step down from her role as Chairman and became our Member Liaison Officer. We elected a new Chairman. John Yeudall was diagnosed with BEB in 2010. He is a professional company director having served on the boards of numerous public and private companies for the last ten years. Most of his earlier working life was living and working in the Middle East both in the private and public sectors. For ten years he served as Australia's Senior Trade Commissioner to the Middle East including a three year term as Australia's Consul General in the UAE. He lives in Perth, Western Australia and also serves on the Board of RANZCO Eye Foundation.

It has become apparent over the last few years that more and more people in our membership demographic now have access to the Internet and obviously this will increase in the future so it was decided to make the website the focus of our primary aim of promoting knowledge and understanding of Benign Essential Blepharospasm in Australia. There are no actual support groups in the other States of Australia. As this state of affairs does not look like changing (at least in the short term) we decided to take on the mantle of a national support group website, hence the change of name to Blepharospasm Australia: [www.blepharospasmaustralia.org.au](http://www.blepharospasmaustralia.org.au).

The website offers lists of doctors in each State and Territory, and lists of support groups or contact people; we hope the latter will expand as more people become aware of the website and will step up and form a group in their own State or at least become a contact person for that State. We also have a section devoted to beneficial aids such as eye drops, sprays and gels for dry eye, and FL-41 lenses which are proving popular with some members. Another feature is a section devoted to Case Histories where members describe their journey with BEB from symptoms to an eventual diagnosis. There is also a list of links to useful websites including the BEBRF.

Our registration form for membership of the website also asks for the name of the treating doctor and the form of treatment used (Botox, Dysport, Xeomin or Other) though this is optional. We do hope people will supply this information as it would be very useful in adding to our knowledge of how BEB is treated in Australia. As far as we know, pharmacological treatment of BEB is very rarely used here.

Our website has a Certificate of Compliance with the Code of Conduct HONcode for health online information - <https://www.healthonnet.org/> and we are a member of Ophanet - the portal for rare diseases - <http://www.orpha.net/>.



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