

BLEPHAROSPASM BATTLERS

New South Wales Support Group Newsletter

Summer Addition

December 2006

Welcome to the very first edition of the BEBNSW newsletter.

Next meeting:

The Benign Essential Blepharospasm and other related disorders NSW Support Group (BEBNSW) meets biannually at: Burwood RSL Club
96 Shaftsbury Road
BURWOOD NSW 2134

The next scheduled meeting is on: Thursday 19TH April 2007.

How your support group works:

BEBNSW is a non-profit making support group for people suffering from blepharospasm and related dystonia disorders. It is open to all, charges no fees and dues – you just come along and join. The advantages of belonging to BEBNSW is that you get to meet other sufferers of this ailment, giving you the opportunity to compare notes, share insights and hear about the latest information on treatments along with coping strategies. The experience of most sufferers of this type of dystonia appears to having been strengthened by the mutually supportive ambience of our group.

Write to us?

Blepharospasm Battlers newsletter welcomes written contributions from BEBNSW members and other recipients of this newsletter. Feel free to submit any. Due to limited space please keep your contributions as brief as possible.

Contacts:

If you are interested in joining our group, or would like to make a submission to the newsletter, please contact either:

Steve Bradley (Co-ordinator)
Mob: 0408 232 338
Email: tangles30@bigpond.com.au

Steve Greaves (Editor) on
Tel: (02) 4625 3624
Email: stevegreaves30@hotmail.com

A Coping Strategy...

When suffering an attack of the all too familiar symptoms, such as eyelid flutters, squinting etc, gently bow your head slightly (so your chin points towards your neck) whilst continuing to look at something about eye level or higher. This will cause your eye pupil to elevate towards the top of your eye socket. Without any effort you will most likely find that your top eyelid (the bigger of the two) rises in sympathy. Immediately afterwards you should feel a welcomed relaxation in your eyelid muscles and a cessation of the attack. If the symptoms return soon after, repeat the exercise. I have found this to be a great aid in controlling the symptoms. It costs nothing and can be used anywhere. – ED.

Dystonia Australia:

Dystonia Australia offers some very useful and helpful information for those who have Blepharospasm and kindred dystonia complaints. You can access this information by contacting Dystonia Australia either by letter or email. The contact person is Nicola Dawson who is the National Co-ordinator of Dystonia Australia.

Address: PO Box 570, WESTMEAD NSW 2145
Email: nicolad@med.usyd.edu.au
Website: www.dystoniaaustralia.org.au

Help from cyberspace:

The following websites may be of interest for members, supporters and friends of BEBNSW:

Blepharospasm Australia:
<http://www.bebaustalia.org.au/index.html>

Another excellent source of information can be found from a leading American website:
www.blepharospasm.org

The bulletin board/chatroom can be found at
<http://www.blepharospasm.org/forums/beb/>

Interstate support group contacts include:
VIC: efo33132@bigpond.net.au (Elizabeth Foster)
QLD: loralby@westnet.com.au (Rae & Al)
S.A. janetg@internode.on.net (Colin)
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