

# Blepharospasm Australia

## NEWSLETTER

Spring-Summer 2016



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## **Blepharospasm Australia.Inc.**

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### **B**lepharospasm Australia Inc now a Registered Charity

Effective April 26 2016 Blepharospasm Australia Inc has been registered as a charity with the Australian Charities and Not-for-profits Commission and is endorsed as a Deductible Gift Recipient (DGR).

This will enable us to undertake fundraising and donations over \$2 will now be tax-deductible.

The website will soon have a DONATION page with details on how donations can be made.

## **M**ember Success Story

### **“Bibbulman Track Princess” by Ingrid Jacobson.**

Echo News article 9 August 2014 - Reproduced with kind permission of Echo News

She’s lived in Africa, been to Antarctica twice, ridden a horse to the top of the Andes and this week fulfilled a lifelong dream of completing The Bibbulmun Track.

When Melanie Kilpatrick of Gooseberry Hill stopped in at a karaoke bar in Northcliffe last winter, she should have been singing the sixties song, *I’ve Been Everywhere*.

For the bubbly 66-year-old has virtually travelled the world, despite suffering from two debilitating neurological conditions from birth, a fact she is quick to play down.

This is the part of Melanie’s story she didn’t think needed to be told, but it’s the part which turns her already amazing tale into an inspiration.

After Melanie emerged from the bush, exhausted yet triumphant with the track’s Kalamunda finish line in her sights, her proud daughter Jessie and son Bay all headed to the nearby pub. “I truly can’t believe I’ve done it”, Melanie said this week, the day after her walk came to an end.

“It’s my dream come true but you don’t need to mention my health - it’s not a big deal”.

Maybe not to her, but the combination of Tourette’s Syndrome and Benign Essential Blepharospasm (BEB) hampered more than helped this dynamic woman on her journey.

Tourette’s Syndrome is characterised by involuntary body movements, while BEB involves muscle spasms and forcible closure of the eyelids.



During the trek, Melanie had to return home twice to get injections to control the spasms. But as she admits, she was in no hurry, having already made the choice to walk the track end-to-end over two winters - the southern stretch in 2013 and the northern stretch this year.

She chose to complete the track in sections, taking time in between to recover and get supplies. Most of the time she reached the huts built for walkers on the track. Sometimes she stayed in small towns dotted along the track and was warmly welcomed by locals.

*Melanie Kilpatrick*

"I've certainly taken a lot longer than the average walker but my aim was to enjoy the journey," Melanie said. "If I got tired I just pitched a tent, rather than push on to one of the huts on the track."

Melanie's choice to walk in winter came about because of self-admitted phobias about mosquitoes, flies, heat and snakes. Her snake phobia led to her track name, Princess Ophidiophobia - Ophidiophobia being a fear of snakes

and princess because she laughingly admits to acting like one.

"There was a lot of joy during my walk but there were definitely moments when I just wanted to bawl my eyes out," she recalls. Sharing the good times and bad with her were four female companions, with one being alongside her for every leg of the track.

Lifelong friend Helen Patterson and a friend-of-a-friend, Patsy Roche, signed up from the beginning, with Melanie meeting 19-year-old Jessica Currey on the Bibbulmun Track Foundation online noticeboard. "It was a hoot with Jessica who left me for dead - she could have done 10km to my 5km but then her mother Sue Currey came down and she became my new walking companion."

Still on a natural high from her epic walk, Melanie is already planning her next adventure.

"I've signed up with National Geographic to go to the Arctic Circle next June to find the polar bears which are threatened," she said. "We're going in sea kayaks - it will probably be my swan song."

## **T**ravelling with BEB

Travelling with BEB is no longer the nightmare it used to be. Our website now list some doctors in all states of Australia who treat BEB so it is possible to arrange for treatment if you are going to be away for an extended period. You can consider having treatment from a local doctor whilst away from home thereby eliminating the cost of flying back. For example we had a lady from South Africa arrive in Perth needing treatment. Her daughter contacted us resulting in her mother getting successful treatment here in Perth.

Our good friend Dr Jeremy Raiter has kindly produced a pro forma authority letter which you can give to a new authorised treater to obtain your treatment records. Your regular treater should produce something similar which should satisfy the confidentiality protocols between doctors. A link to this letter can be found on our website:

<http://blepharospasmaustralia.org.au/medical-treatment>

## **W**eb site

Our website has recently undergone a major update with significant new features being added. We would welcome feedback - a form can be found on our website or just email us.

<http://blepharospasmaustralia.org.au/website-feedback>

<http://blepharospasmaustralia.org.au/contact-us>

If you joined our BEB Western Australian Support Group (now renamed Blepharospasm Australia to encompass all Australian states and territories) a few years ago and you did not have access to the Internet at that time, we will not have your email address. Please register again. Similarly if you were at one time a website member of the previous website, it would be appreciated if you would re-register for the new website. <http://blepharospasmaustralia.org.au/register>

## **Y**our Blepharospasm Journey

You may have read the Case Histories section of the website. If so perhaps you would like to contribute your own story. These articles are extremely useful to sufferers who may not yet be diagnosed as they may be able to relate to your own experiences. Contributors are not identified in any way. Please send your stories to the Secretary.