

Dear Sir / Madam,

Our daughter suffers from Relapsing-Remitting Multiple Sclerosis (MS) which she developed about 5 years ago whilst living in the UK. She has recently returned to live in Australia and is unable to obtain one of her prescribed pharmaceutical drugs - Sativex Oromucosal spray (27 mg delta-9-tetrahydrocannabinol / 25 mg/ml cannabidiol from Cannabis sativa L. - manufactured by GW Pharma Ltd) – a **proven** treatment deemed safe to use, by the National Health Service. She takes a number of other drugs including Gabapentin 3 times a day, daily Copaxone injections, Citalopram, Dosulepin, however **Sativex** has undoubtedly been her saviour **over the past several years** and she and my husband and I are devastated that it she is not going to be able to access it here in Australia. In short, we are not sure how she is going to cope without it. It helps her deal with the constant pain and side-effects of MS including severe seizures and spasticity, as well as motor control, speech, cognitive abilities and incontinence, a terrible thing for anyone especially a young woman.

Sativex is not just important, it is imperative to her health and wellbeing and assists her to deal with the severity of her seizures, manage her constant pain and assist with her daily functioning and she has required much less use of self-catherisation since using it. She has had **no side effects** from using it and in fact finds it much more tolerable than her other medications. Her neurologist and Pain Management doctor have recommended that she continues using it so that in time she may be able to reduce her dose of Gabapentin, (a drug used to control pain in MS sufferers) which is good news as this drug has significant side effects which affect her quality of life. Since coming home to live with my husband and I we have witnessed first-hand the debilitating symptoms of these seizures and spasticity attacks – frightening to say the least. We have also witnessed the efficacy of Sativex and how it assists her to cope with pain and alleviates the severity of the attacks.

Sativex has markedly *improved* her quality of life and whilst taking it in the UK she was able to continue to work, which is incredibly important for her mental wellbeing and self-worth. As parents of a child with an incurable disease we would welcome Sativex being made available in Australia to enable her to continue to work in her chosen career as a teacher of children with special needs.

I attach an article dated 11 April 2011 saying the pharmaceutical company GW has signed an exclusive licence to commercialise Sativex in Australia:

<http://www.gwpharm.com/GW%20Signs%20Exclusive%20Licence%20Agreement%20to%20Commercialise%20Sativex%20in%20Australia%20Asia%20Middle%20East%20and%20Africa.aspx> . I also attach an information sheet about Sativex issued by GW Pharmaceuticals.

As background information, the hallmark pathology of MS is demyelination, leading to nerve damage which causes symptoms that adversely affect quality of life. Spasticity is one of the most common, chronic and disabling of these symptoms, affecting up to 80% of MS patients. Sativex is a life-changing MS treatment which **is proven** to help people who suffer mobility issues, spasticity, pain, and urinary incontinence. MS Australia welcomed the listing of this treatment as an option for doctors to prescribe to people with MS, to help them to manage their disease.

There is no cure for MS spasticity and it is widely recognized that currently available oral treatments afford only partial relief and have unpleasant side effects. **Sativex offers the prospect of treating patients who have failed existing oral therapies and who might otherwise require invasive and costly alternative treatment options such as intrathecal baclofen or surgery.**

Sativex is approved and marketed in the **UK, Europe, Canada and New Zealand** for the relief of spasticity in MS, as a treatment for symptom improvement in patients with moderate to severe MS

spasticity who have not responded adequately to other anti-spasticity medication and who demonstrate clinically significant improvement in spasticity related symptoms during an initial trial of therapy.

There are no side effects from using Sativex and is much more tolerable than other medications. MS UK published a survey of nearly 4,000 people living with MS and found that 82% of those taking Sativex considered it essential and a high priority. For these people, Sativex is invaluable and makes life worth living again.

Sativex has been shown to provide effective relief of spasticity symptoms, including reduced spasms, improved sleep and improved function in patients for whom existing anti-spasticity treatments have failed.

Although Sativex is listed for use by the Therapeutic Goods Administration (TGA) it is not available on the PBS, which makes the cost of purchasing Sativex extremely prohibitive. In 2013, the Australian National Council on Drugs' reported that Sativex cost about \$500 per month. This puts the drug out of the reach of most MS sufferers who struggle with daily living and are often restricted in being able to work.

I am cheered and encouraged by the number of responses that have been sent in regard to support this inquiry and in particular the submission by MS Research Australia. I can only reiterate and fully support MS Australia's comments regarding muscle spasticity – it is a very big problem for MS sufferers and I can verify this completely - I see this every day with my daughter and how spasticity and seizures negatively impact on her mobility and indeed personal independence. Without Sativex her independence will be severely curtailed – she will be unable to travel on public transport or travel any distance without support. Her ability to complete everyday tasks, let alone hold down a full-time job will be compromised, her self-esteem will suffer as a result and in fact she will become a burden on the public health service and no doubt she will become totally reliant on medical and disability resources to help her cope.

I know that Sativex is not a cure for MS, however, it is a proven drug to help her deal with the everyday symptoms of living with MS.

Many thanks for taking into consideration my heartfelt plea for assistance, not just for myself and my daughter, but for all sufferers of this terrible, incurable (to date!) disease.

Sincerely,

Althea and Edward Giuliani