Epilepsy Australia Submission

Dear Sir/Madam,

I have been living with epilepsy for 32 years. As a person who has had epilepsy throughout childhood and adulthood I can tell you that the emotional and social costs can weigh heavy on the minds of those living with this disease. It is a very lonely disease because it is so misunderstood by so many. I feel epilepsy is even misunderstood by most medical professionals themselves. It is a disease with so many variables. If I could describe it in a philosophical manner I would describe epilepsy as being like a tree and coming off that tree are branches of things like anxiety, mental illness, ADHD (research has shown that 75% of people with epilepsy suffer from ADD or ADHD) and common ailments due to side effects of anti-convulsant medications. In one of my experiences I started a new medication and as soon as I was on that medication I developed bowl issues. I told my neurologist and I told my GP and none of them believed me when I said I thought it was due to my new medication. I had to take matters into my own hands and went down the path of researching all I could about natural gut health to counteract the side effects of this new medication, which has since worked. But, the point I am trying to make here, is that both neurologists and GP’s are not looking outside the box. All they want is a bandaid fix. You can’t put a bandaid on a disease like epilepsy. Medication alone is not enough to control epilepsy. The doctors have to know the patient's triggers and each patient's triggers can be different. In my case it is stress and hormone fluctuations. Which leads me into my next suggestion.

There needs to be more research and awareness into the role that hormones play into the effects epilepsy has on people. I was practically laughed at by a young know it all neurologist who said that “it was not hormones changing, you’ve just become immune to your medication” and so instead of taking me seriously and looking into what I was saying, more medication. However, I now have a neurologist that listens and has actually explained to me the role that hormones play into the effects of epilepsy. Young girls coming into their menstrual cycles for the first time, need to be made aware that not only are their bodies changing but that they are then at a higher risk of becoming more prone to seizures so they can talk to their neurologist about how to best manage their epilepsy going forward. The same goes for women starting their journey into menopause, again the risk of seizures is higher. Had I known sooner I firmly believe that my epilepsy could have been better managed and seizures avoided.

More research into alternative therapies would also be something that I would suggest. Both natural medicinal therapies and therapies that work hand in hand with medication. For example, music therapy, meditation, art therapy and animal therapy.

Also funding to train seizure detection dogs.

Diet as well. The only diet that is available is the ketogenic diet and the modified atkins diet. Both are limiting and the ketogenic diet is more suited to children. Research into certain foods that would be helpful in managing epilepsy needs to be done. I am not recommending a new diet. I am just recommending that the foods should be looked at.

I have generalized epilepsy. This means that they do not know what part of the brain the epilepsy is coming from. For this reason, surgery is not an option for me. Research into generalized epilepsy would be beneficial. Surgery is only available to those that have localized, meaning they know what part of the brain the epilepsy is coming from. I also have a heart condition and I would like research done into the correlation between the heart and if heart complications can affect the brain. There was a professor in America that had written a book on this particular subject but here in Australia something like that is again not something that is taken seriously.

I strongly feel like epilepsy is a disease that is not taken seriously and misunderstood because not enough knowledge is available to medical practitioners. How can they treat something that they know little about? And I do not just mean GP's I also mean Psychologists and Psychiatric professionals. Being that anxiety and mental health issues come hand in hand with epilepsy I think it would be prudent to educate those particular health care professionals as well.

At the end of the day. More can be done. More than purple day once a year.

Thank you for taking this submission into consideration.