Funding for Research into Cancers with Low Survival Rates Submission 21

Lisa Wolker

To whom it may concern,

I am a brain tumour survivor and concerned about the lack of funding towards brain cancer. It amazes and disappoints me that there is so little funding when so many people die from it.

I was first diagnosed back in 2002. I spent a year going back and forth to Doctors trying to find what was wrong with me but I was always fobbed of.

I was having seizures at night, (but I didn't know what I was doing, as I leaped out of bed dry retching) it felt like I was falling over when I walked, starting to get pounding headaches and when I drove I thought the car was lopsided.

Unfortunately If our Doctors had more information on brain tumours one of them might have thought to give me a scan.

It took me 8 months later and the tumour growing, having a grand mal seizure one night, my husband having to do CPR on me and two trips by ambulance to RPH for them to finally do an MRI scan and find my brain tumour.

It is on the right hand side of my temple. Apparently this is where you dream from so every time I fell asleep the tumour pushing on it would cause a seizure.

They were awful and i don't want anyone else to have to experience this from lack of understanding and not enough research.

My only information I could find on brain tumours was a few statistics on the internet saying I had 5% chance of surviving. There was books, documents, lots of advice and help if I had breast cancer. This made my diagnosis scarier that nobody knew much!

After a biopsy I was diagnosed with a grade 2 & 3 anaplastic oglioglioma. Luckily it was a slow growing tumour.

I was one of the first people to trial the chemotherapy drug temozolomide and radiation. The Doctors were all very negative telling me if treatment worked I would be lucky to live 5 years.

Lucky for me 10 months of chemo, 6 weeks of 5 day a week radiation my tumour shrunk from egg size to 2mm and remained stable for 13 years. A few years ago I started having seizures. Any time of the day and night and scare the bejesus out of me.

My Neurologists insisted it was old scarring causing them and for 3 years I was doped out on anti seizure medication which wasn't working and had 3-6 partial seizures a day. I couldn't drive, became scared to go out and became depressed.

I was devastated but relieved when my following yearly MRI scan showed the tumour had changed that something would finally be done.

I finished another 12 months of temozolomide last March 2016. The seizures stopped as soon as I started chemo. Luckily for me the chemo worked well and once again you can hardly see anything abnormal on my 3 month scans

It has now been stable for a year and no seizures for 2 years. Touchwood!

I wrote a book called "A New Beginning" so anyone diagnosed could read it and know what to expect and give them some positive thinking and insight.

Unfortunately I had to self publish it through an American site called Blurb booksmart so the delivery is expensive. I sent my new manuscript to Fremantle Press in the hope they would publish it so

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copies could be left at hospitals etc. They weren't interested. If you think it can help or like to read it google me. I have sold and given away many copies for people with cancer who say it helped.

Can you PLEASE provide more funding, especially to Dr Charlie Teo because I for one do not want to die from this awful disease.

If we can raise more awareness to start with it could save lives with people being aware of the symptoms.

If my tumour grows back again the only option I have is more chemotherapy. Which is not fun! With funding hopefully we can find a cure.

Regards,

Lisa Wolker