



*Sarah 1964 - 2020*



On Sunday, I'll be taking part in Ironman 70.3 Geelong and wearing orange race gear to pay tribute to my sister Sarah, who recently passed away. In November, Sarah was diagnosed with a rare degenerative brain disease called Sporadic CJD (Creutzfeldt-Jakob disease) which took her life in just a few short months.

Sporadic CJD is a rapidly-progressive brain disease that occurs at random, and affects one in a million people – that's just 20-30 people in Australia per year. The disease develops when normal brain proteins called prions spontaneously fold, creating abnormal prions. These abnormal prions then rapidly spread and accumulate in the brain, destroying otherwise healthy brain cells.

Symptoms of this cruel disease start out looking much like severe anxiety (memory loss, impaired decision making, and social withdrawal) but quickly move on to involuntary movements, unusual sensations, spasms and mental degradation. And in the final stages (often just a month or two later), a loss of speech, motor skills, sight, and cognitive function sets in, before deteriorating to an inability to drink or swallow, and finally coma leading to death.

There is no treatment, no known cause, and no cure. It is always fatal, and most people die within 3-6 months. Sarah had just 9 weeks from initial diagnosis.

I'll be wearing orange (the charity's colour) to raise awareness for the disease and hopefully raise a few dollars for the CJD Support Group Network. They provided us with invaluable support, information and assistance, and continue to do so for many medical professionals and researchers, as well as impacted family members and friends of patients suffering with suspected CJD and other prion diseases.

Please join me in supporting this cause by wearing an orange arm band, and if possible donating a few dollars to this worthy charity.

<https://www.facebook.com/donate/1237527249971518/>