

Dear Members,

Senator John Kissel has informed me that he has proposed a bill to name October 7th as Trigeminal Neuralgia Awareness Day. I am asking for your support in this. Trigeminal Neuralgia is considered an “orphan disease” due to its rarity. The current statistic is 4.3 per 100,000 individuals a year.

I suffer from Trigeminal Neuralgia II, and am in pain every waking moment. The pain can be from 2/10 to 8/10, and is one or a combination of intense burning, aching, pressure, stabbing, eyeball exploding, and hot poker pain on the left side of my face. All the time. Type I sends electric shocks, lightning bolts, drills, pokers, and knives into one, sometimes both, sides of the face. There is no cure. Medications used to alleviate the pain, which are generally very ineffective, cause side effects of liver toxicity, extreme fatigue, mental confusion, memory loss, and malaise. Surgery, for those “lucky” ones who have this option, is a brain surgery with all the risks that entails, plus weeks of terrible pain as they recover. Surgery may or may not stop the pain, it may even bring on a new pain. Many who suffer from the “Suicide Disease” are unable to work or even participate in family life, often losing family and friends in the process. Many have had to apply for Social Security disability payments.

The worst part of this disease and other related neuralgias – Occipital, Genticulate, Glossopharyngeal, PIFP – is that too many doctors and dentists don’t recognize the symptoms, and the sufferer is left untreated or mistreated for years. I know many people who have asked to have all their teeth removed in an effort to end intense shooting pain in their teeth, and their ill-informed dentists actually do this. All to no avail because the pain isn’t coming from the tooth. Or they’re told it’s all in their heads – of course it is! – and sent for therapy. How horrible it must be to be in such excruciating pain with no help or end in sight. This has to stop! We can’t keep losing people to suicide because they lose hope.

These neuralgias affect anyone from infants to seniors. A teenager in New Haven has just had her 5th brain surgery this month. Abbie is someone who should speak to the Assembly regarding this. Her bravery astounds me.

Please read the information provided by the TNA Facial Pain Association, then support and pass this bill. Help us help those undiagnosed and unsupported.

<http://fpa-support.org/trigeminal-neuralgia/>

I would also like assistance in having at least one state building lit up in teal or blue on October 7th, or assistance in reaching the company in charge of lighting the Travelers Tower. Buildings are lighted blue all around the world as a means to bring awareness about these diseases; none are in Connecticut. As the 7th oldest state in the Union, I believe we have an obligation to stand up for those with TN.

Respectfully submitted,

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