

## Local Woman Helps Bring Trigeminal Neuralgia Awareness to Kodiak, World

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Brianna Gibbs/KMXT

Today is International Trigeminal Neuralgia Awareness Day, but many folks in Kodiak may not know what it is. That's because only one in 25,000 people are diagnosed with it, statistically meaning less than half a person in Kodiak would have it. However, there is one.

"It's an extremely painful, chronic pain condition that affects the trigeminal nerve."

That's Katie Anderson, who was diagnosed with trigeminal neuralgia in 2009.

"I went undiagnosed for a long time. I went from doctor to doctor. In fact I even saw a neurologist, I had specialists look at my MRI and nothing showed up and it wasn't until I was referred to a neurosurgeon at University of Washington, where he found the mass of blood vessels in my brain."

Anderson said the condition affects the trigeminal nerve, which starts at your temple and branches into the forehead and eye area, along the cheek and sinus and toward your teeth and lower jaw.

"If you have trigeminal neuralgia even a mild stimulation of your face, like brushing your teeth, putting on make up, may trigger a jolt of extremely, extremely excruciating pain."

The pain is so bad trigeminal neuralgia is often referred to as the suicide disease.

"In fact 25 percent of people still end up committing suicide from the pain."

For years Anderson said it has gone undiagnosed for patients, and doctors have only recently begun to recognize it as a medical condition. Because of this, there are still a lot of unknowns, for instance, how it is caused. Anderson said it can happen out of nowhere, but there are theories that it can sometimes follow serious infections. There's no cure, and many of the treatments available are more experimental than guaranteed fixes.

Anderson's personal battle with trigeminal neuralgia started four years ago and led to multiple brain surgeries and nerve radiation. She's developed numbness in various parts of her face and still experiences phantom pain, despite the damage done to her nerves. But more than that, she's also developed post traumatic stress disorder from the years of medical trauma.

These days, she is off medication and focusing more on dealing with her PTSD. She said she still has daily pain, but has tried to turn her experiences into learning and awareness opportunities for people around the world.

"There's the children as young as 3 being diagnosed. There's the people from third world countries with no access to medical, there are the people with preexisting conditions. I mean we went into debt with the medical bills. And now there are all these wonderful support pages and groups. We call it like a TN family, all of us together."

Today is actually the FIRST ever International Trigeminal Neuralgia Day, and Anderson hopes it's the first of many more to come. Even though she may be the only one in Kodiak with the condition, she estimates there are about 20 people around Alaska that have it. The awareness color for it is teal, and Anderson said she hopes the Kodiak community will sport the color today and support those who suffer from the rare condition. She said you can find more information online, or by visiting the Facebook page End Trigeminal Neuralgia.