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Painting The Pain: Sherwood Artist Shines Spotlight On Rare Disease Erythromelalgia

by Elisabeth Antoine - The Oregon Herald Monday December 3, 2012 2:12 AM







Sherwood, Oregon, resident Laura Fisher's artwork sparks attention in the 2012 TEA "Paint Your Pain" Art Contest. Sponsored by The Erythromelalgia Association (TEA), the contest was created at the suggestion of researchers at Yale University's Neuroscience and Regeneration Research Center to bring awareness to and communicate the pain of the rare disorder called erythromelalgia (EM).

Titled "I'll Cry Tomorrow," Fisher's sketch is, in her words, a "very rough, incomplete drawing" inspired by the "inner struggles associated with the physical pains." The figure

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is manipulated by puppet strings, symbolizing the helplessness faced by a patient following doctors' orders. Vaguely reminiscent of the "Hell" portion of Hieronymus Bosch's famous triptych, tiny, mocking creatures inflict various tortures on the patient's body. The clown-like face sports a fake smile and a flower to mask the excruciating pain felt in her eye. A mirror reflects the "sadness, aloneness, and prayerfulness" that exists behind the façade. Fisher's EM—which has now spread throughout her entire body—is believed to have been caused by her father's exposure to Agent Orange during the Vietnam War. Both her father and son experience EM symptoms as well.

The hallmark of EM is red, burning feet, although many experience symptoms in the hands and/or face as well. Flare-ups are triggered by heat—warm ambient temperatures as well as localized heat caused by such normally benign things as showers or wearing socks—and relieved by cooling the affected area. In a small percentage of sufferers the condition is inherited, caused by a genetic mutation that was identified by Yale's team of researchers in 2004. While most cases are thought to be idiopathic, some are secondary to causes such as blood disorders, peripheral neuropathy, autoimmune diseases, and sports injuries. Many cases are severe, with constant, unrelenting pain; even the mild cases can be severely debilitating. Remissions are infrequent, and because there is no single etiology, there seems to be no single effective treatment. Pharmaceutical companies are currently focusing on the sodium channel Nav1.7 that has been implicated in the SCN9A gene mutations, and several clinical trials are currently in the works.

TEA is an international, all volunteer, nonprofit organization that provides educational and networking services online and offline; raises public awareness of erythromelalgia; and helps fund research into this rare disorder. Founded in 1999, TEA is funded entirely by donations and is a member of the National Organization of Rare Disorders.

For more information, visit www.burningfeet.org.