

Governor aids woman's awareness campaign

By **Todd Moen** on

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An effort by Lisa Fontanna of Waconia to help raise awareness about NET cancers, caused from rare neuroendocrine tumors or NETS, has resulted in Minnesota Governor Mark Dayton proclaiming Saturday, Nov. 10 as NET Cancer Day in Minnesota. The proclamation coincides with worldwide NET Cancer Day on Nov. 10.

"I have carcinoid cancer, which is a form of NET cancer," said Fontanna, who is known by many in the community for her work with the Waconia United Food Shelf, the Waconia Relay For Life, and the Waconia Area Women of Today.

"I was diagnosed on Jan. 27, 2012," Fontanna continued. "The average diagnosis takes five to seven years because the cancer is so slow growing, it doesn't show up on CT scans as it's growing, so the symptoms are often misdiagnosed."

For years, this was the case for Fontanna. Although she exhibited all of the symptoms of NET cancer, her doctors thought she was battling Crohn's Disease or irritable bowel syndrome. An ulcer-related surgery at the Mayo Clinic led to her cancer diagnosis.

"This type of cancer requires lots of surgeries to help slow it down," said Fontanna, who is undergoing additional procedures and surgeries related to her NET cancer in the coming weeks. "The sooner they find the primary tumor, if they can get that out, your chances for a longer, healthier life are better. The surgeries extend the quantity of life is how I look at it."

Fontanna began her effort to get Dayton to proclaim NET Cancer Day in Minnesota at the end of September. Using resources found on NET cancer support websites, she learned that governors from seven other states had made similar proclamations. Following the proper channels, she asked Dayton if he would do the same.

"A representative from his office called me mid-October and told me they had received my



Lisa Fontanna stands with a copy of the proclamation made by Governor Mark Dayton that declared Nov. 10 to be NET Cancer Day in Minnesota. Patriot photo by Todd Moen

request and that he would do it,” Fontanna said. “I was filled with pride and shock. It’s not everyday you get a call from the governor’s office like that.”

On a similar note, one of Fontanna’s friends in Northwoods NETS, a patient support and advocacy group based in the Twin Cities, was successful in getting the I-35W bridge in Minneapolis to be lit up in a special way on the evening of Nov. 10.

With the governor’s proclamation and the special lights on the bridge, Fontanna and others hope awareness of NET cancers is raised on Nov. 10 and beyond.

“If someone sees (the efforts) and if they end up helping even only one person get diagnosed earlier, it will have been worth it,” she said.

- To learn more about NET cancers, visit www.carcinoid.org. Fontanna also said she is happy to talk to anyone with questions about NET cancer. To reach Fontanna, contact (651) 343-4377 or email lfontanna@mchsi.com.

NET Cancers

NET cancers, caused from rare neuroendocrine tumors or NETS, are the “zebras” of the cancer world. When doctors are in medical school, they learn when diagnosing illnesses that they should be looking for horses, or common disease causes, rather than zebras, or rare causes. NETS are rare, occurring in approximately 35 in 100,000-cancer diagnosis annually. That is why NETS are zebras, their unique stripes being a symbol of the disease.

Although they tend to be slow growing, neuroendocrine tumors can turn into cancers including Carcinoid, MEN-1, Medullary carcinoma, Gastrinoma, Glucagonoma and many others arising from various organs including the lungs, pancreas, thyroid, stomach and intestinal tract. NETS frequently masquerade as other more common illnesses such as IBS, Crohn’s, Asthma and even other types of cancers. In 2011, Steve Jobs of Apple died from a pancreatic neuroendocrine cancer known as an Insulinoma.

Many doctors are unaware of NET cancers or understand how to treat them. Frequently, they have never treated another patient. As a result, NET cancer patients can go years, sometimes decades, before diagnosis. While NET cancers are not curable, with proper management, they are treated as a chronic condition, like diabetes. By bringing awareness to this rare cancer, we hope that both patients and medical professionals are able to “see stripes” earlier in the diagnosis process.

Learn more NET Cancer Awareness Day at www.netcancerday.org.