

Leading the charge against rare form of cancer

By Chris Halliday
November 8, 2010

Dufferin County first municipality in Canada to proclaim Nov. 10 Worldwide NET Cancer Awareness Day

When Orangeville resident Beverley Claxton, 33, was first diagnosed with a Neuroendocrine Tumour (NET), also known as carcinoid cancer, in August of 2003, "I called the Canadian Cancer Society and they said, 'You have what?'"

In fact, during her first medical appointment following diagnosis, doctors were googling for information about NET cancers from the same website Claxton had been visiting.

"That is scary because they had no idea," Claxton said. "They had no clue what to do with me."

Many years prior, Claxton's symptoms led doctors to believe she suffered from an irritable bowel at age 14. Several years later, thinking she had "the worst case of liver cancer you could ever have," doctors said she had six months to one year to live — "if I was lucky," Claxton added.

It wasn't until receiving advice from a support group headed by Maureen Coleman, who is now president of the Carcinoid Neuroendocrine Tumour Society (CNETS) of Canada, that Claxton found specialists that could treat her at the London Regional Cancer Centre in London, Ont.

A slow-growing cancer, NET develops from cells in the endocrine system. Commonly found in the lung and gastrointestinal system, NETs can also originate in the pancreas, ovary and testes, among other areas of the body.

With those tumours secreting hormones to the body at an amplified rate, symptoms can include severe diarrhea, stomach pains and a red flushing of the face, among other complications. Claxton's biggest hurdle is "pain control," as she can feel fine one minute and then awful in a matter of moments.

"You wake up, you feel fine, you go about your day and the next thing you know, you're completely out of the running," she said. "You can't say I'm going to go to the city shopping because you might last 20 minutes, or you might last the whole day."

In October, Dufferin County became the first municipality in Canada to proclaim Wednesday, Nov. 10 as Worldwide NET Cancer Awareness Day, which aims to raise consciousness, both in society and medical circles, of the disease.

For Linda Dean, CAO for Dufferin County, it was a no-brainer, as she was diagnosed with NET cancer following a CT scan at Headwaters Health Care Centre, earlier this year. Dean, however, who underwent



Leading the awareness: Orangeville resident Beverley Claxton and Linda Dean, CAO for Dufferin County, both have Neuroendocrine Tumour (NET) cancer. *Chris Halliday*

surgery to remove her primary tumour, isn't impacted by the symptoms brought on by carcinoid syndrome as adversely as others.

"I'm sick, but I'm not sickly," Dean said. "To be able to have my municipality be the first in Canada to proclaim that day, and through that the support that council showed to me by doing that, is really, really important."

Another goal of NET Cancer Awareness Day is to allow the medical community to become more aware of the disease, "the symptoms and where they can find resources about it," Dean added. Accounting for less than one per cent of all cancers, the "rare" disease is growing and awareness needs to as well, Dean said, especially since it is difficult for doctors to pinpoint where problems appear first.

Unfortunately, Claxton's roller coaster ride of diagnoses is a common occurrence for many. Although early diagnosis can dramatically improve outcomes for patients, CNETS estimates more than 90 per cent are incorrectly diagnosed. In addition, many are treated for the wrong disease an average of five to seven years before actual diagnosis, which is usually made once their tumours have spread or metastasized.

"They figure I've had it since I was 12 to 15," Claxton said. "I assume many, many people have been misdiagnosed with cancer. But I don't think that happens as much in the last three or four years. ... Doctors are learning more about it."

There is treatment, however, as both women receive Sandostatin LAR, which can control symptoms and in some cases, "decrease the size" of tumours, Claxton said. She receives two treatments from Community Care Access Centre nurses per month, while Dean is treated once every 28 days.

"It has a very high percentage success rate in controlling the growth rate of the tumours," Dean said. "It (can) stop it, slow it, or reduce the growth."

NET Cancer Awareness Day takes place on Wednesday (Nov. 10). For more information or commonly asked questions about the disease, symptoms, early diagnosis as well as treatments, visit www.cnetscanada.org and www.netcancerday.org.

This article is for personal use only courtesy of Orangeville.com - a division of Metroland Media Group Ltd.
