

## Sufferers of rare cancer speak out: NETs often misdiagnosed

Posted 10 hours ago

At first, Jackie Raney's doctor thought she had blood spots in her liver and that she suffered panic attacks.

Beryl Lemke's doctor thought her patient suffered from irritable bowel syndrome.

Margaret Binkley's daughter suffered through her teen years, the problem resulting in an appendectomy, and more years of uncertainty.

But when Beverley Binkley Claxton was diagnosed with carcinoid neuroendocrine tumours (NETs), her reaction was the same as Raney and Lemke.

"What is that?"

"Even most medical people have never heard of it," Binkley said Wednesday as she, Raney and Lemke manned a table at North Bay and District Hospital to raise awareness of the disease. They are members of the Carcinoid NeuroEndocrine Tumour Society of Canada.

NETs secrete hormones, some of which produce extra stomach acid, which is one of the reasons patients are often diagnosed with irritable bowel syndrome or other stomach ailments.

"It's rare," Lemke said. "Out of 100,000 people (diagnosed with cancer), one will be carcinoid."

It is extremely misdiagnosed — some estimates are that 90% of all cases are incorrectly diagnosed — and a lot of those stopping to talk to the three women Wednesday morning were doctors and nurses.

Part of the reason it is so often misdiagnosed, the three women said, is that it does not look like a traditional tumour in CT scans or MRIs.

Tumours can also appear in any organ,

Raney's initial diagnosis in 2000 was blood spots in her liver. That had been after several years of problems that never seemed to surrender their secrets.

But it wasn't until 2005 that, during a bowel scope, a tumour was discovered in her colon. When

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the tumour was examined, the doctor discovered it had metastasized into her liver.

Lemke started to experience symptoms back in about 1995, and was diagnosed with NETs in 2009.

Those hormones have also been known to attack heart valves, and patients now receive an injection monthly to protect their heart.

While not curable, the disease is treatable. Unfortunately, though, traditional cancer treatments tend to be ineffective.

Lemke is part of a drug study operating out of Princess Margaret Hospital in Toronto, but so far things don't look too promising. She said the tumours she has are still growing — they have grown 10% since April. If they continue to grow, she will have to leave the study.

After that, she isn't sure what her options will be, although European doctors have had some success with both diagnosis and treatment.

Binkley's daughter, Claxton, is now preparing to travel to England for treatment. The cost of treatment will be picked up through Canada's health system, but she will have to cover her own travel and accommodations costs.

An estimated 12,000 to 15,000 Canadians are believed to be affected by NETs, but only about 10% have been properly diagnosed.

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