

A New Day Dawns for Kidney Cancer Patients

*at least for those with the
very best private drug insurance*

DEBORAH MASKENS

Bill and Kim Dompierre have both enjoyed successful careers as teachers in Nova Scotia. After years of being active within their local community, they had a small army of loyal friends and supporters who rallied behind Bill when he was first diagnosed with renal cell carcinoma in 2001 and later in 2003 when he required surgery to his right lung.

In 2007 when Bill's kidney cancer returned to his lungs, the Dompierres were shocked to learn that the one and only drug his oncologist could recommend was not covered by the province of Nova Scotia. As long-time teachers who have paid into a private health insurance plan for over 30 years, they anticipated full coverage for Bill's oral cancer drug, Sutent. After Medavie/Blue Cross denied coverage for Sutent, Bill and Kim were left with no other option but to pay \$7,800 every six weeks out of pocket.

"As a high school teacher for 31 years, I have paid literally thousands of dollars into Blue Cross," says Kim.

"I trusted the Nova Scotia Teachers' Union to secure the best health coverage for me and my family." The Nova Scotia Teachers' Union joined the Dompierres in appealing the denial of coverage. All the while, Kim watched television ads for private health insurance in the Maritimes – commercials that advertise how, for \$2 per day, a family could be saved from catastrophic drug costs – but clearly not if you have the misfortune to be diagnosed with kidney cancer.

Nova Scotians without private insurance have appealed to local MLAs and to the Health Minister. Few letters have been answered, but one letter from the Health Minister advised people like the Dompierres to access the financial needs office. As teachers and home owners who were looking forward to retirement in 2010, people like the Dompierres simply don't qualify.

Instead, their small army of supporters planned a series of fundraising events to help pay for Bill's cancer tablets. Kim pursued financial aid available from her employer and committed to do "whatever it takes" to make sure Bill has access to a life-saving drug. Finally, after three presentations to the Board of Medavie/Blue Cross and threatened legal action, the Dompierres received word in January 2008 that Bill's cancer treatment would be covered.

Kim despairs at the choices other patients in the Maritimes must now face – whether to sell their home and pay for the drug, or accept an average one-year survival with metastatic renal cell carcinoma with traditional (and largely ineffective) treatments. "How can Canadians justify a patient being funded to receive Sutent in Quebec, but not in New Brunswick? Can we accept that patients' home addresses may determine their eligibility to receive effective cancer therapy?"

International studies presented at ASCO 2006 and ASCO 2007 presented by Dr. Robert Motzer reference Sutent as the new reference standard for first-line treatment of metastatic renal cell carcinoma. These results have since been published in *The New England Journal of Medicine* and have been referenced in international



Bill and Kim Dompierre

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guidelines. A recently published article in *The Journal of Urology* demonstrates a median survival for patients receiving Sutent of 23.9 months. Other agents currently in clinical trials are expected to extend survival time even further. For the first time in decades, patients with kidney cancer can expect to make choices about preferred first, second, third, and fourth-line treatments. The case for Sutent is clearly not unique. As new targeted treatments are approved, Canadian patients cannot be left to die while governments decide who does and doesn't qualify for extended survival.

Patients like Bob Eaton in Ontario hardly knew what all the fuss was about. "I pick up my prescription at my local pharmacy" says the retired Ontario MPP. "The slip says \$8,676.13 but I've never paid a penny." Bob's private plan covers 90 per cent of the cost for Sutent and the manufacturer (Pfizer) picks up the ten per cent co-pay amount. "I was shocked when my doctor informed me that other Ontarians and other Canadians have to pay for this drug out of pocket" says Bob. "As a former MPP for 13 years, I have to ask – what on earth has happened to our provincial plans for catastrophic drug coverage? My plan is the same as current MPPs. If they are covered for this, then everyone should be covered."

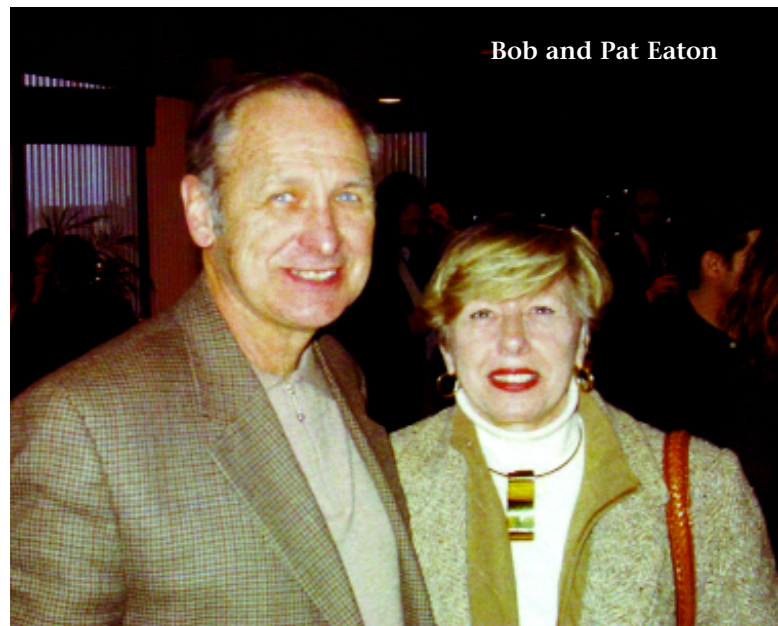
Diagnosed with metastatic renal cell carcinoma in October 2006, Bob was initially given a bleak prognosis. Dr. Peter Ferguson, the orthopedic oncologist treating the cancer in his hip and pelvis, put it plainly: "looks like you've got six months." A year later, that same doctor calls Bob his miracle man.

Between Christmas and New Year 2006, Bob considered himself at death's door. "I had accepted that I would never work again – that this was the end." Down to 150 lbs then, he had surgery to remove the tumors and then started Sutent. Today, Bob is back to 180 lbs and CT scans show no evidence of disease. He suffers from very few side effects, just a few mouth sores in the last week of his four-week cycle of tablets. Now back to

work as a real-estate broker operating four offices, Bob and his wife Pat recently joined his colleagues in Bermuda for the annual conference.

In his spare time, Bob is working with Kidney Cancer Canada, a new patient support and advocacy organization, to ensure that patients like him have access to life-saving treatments such as Sutent. "I was an elected member of the provincial legislature for 13 years and served in Cabinet and Management Board of Cabinet, and so I appreciate the difficult decisions governments must make sometimes. But to deny someone a chance to try these remarkable new drugs is unthinkable. How can an elected member face a constituent and tell them that their life isn't worth the cost of this drug?"

Bob's oncologist, Dr. Mary McKenzie in London, Ontario plans to keep Bob on Sutent. Cases of other patients like Wally Vogel in Toronto are showing unprecedented long-term potential for these drugs in the fight against kidney cancer.



Bob and Pat Eaton

We are literally making history here – at least for those who can access the drugs

At 43 years old, Wally Vogel credits Sutent with saving his life. His prognosis in 2004 was extremely poor with extensive metastasis to his liver, spleen, and throughout his abdomen. Starting Sutent at the Cleveland Clinic gave Wally a head start before the drug was approved by Health Canada. Beginning in January 2006, he continued receiving Sutent in Canada under clinical trials at



Princess Margaret Hospital in Toronto.

Sutent shrank his tumours by 85 per cent, allowing surgeons to remove the remaining metastasis. Pathology proved that many of his tumors had necrotized and were no longer active. The final remaining met in the lumbar muscle was removed using RFA (radio frequency ablation) in May, 2007.

In June 2007, Wally had CT scans that confirmed the words he never thought he would hear: he is now clinically free of any evidence of disease. He is back to work running his own software company and living a full and active life. Wally's Medical Oncologist, Dr. Jennifer Knox, comments that with drugs like Sutent now available, "we are literally making history here" – at least for those who can access the drugs.

After the failure of the Common Drug Review (CDR) to review new cancer drugs, patients and oncologists rest their hope in a new process that will, in theory, bring about some standardization across Canada. A new national process, the Joint Oncology Drug Review (JODR), with representatives from each province (except Quebec), is being piloted. This body will review the efficacy of oncology drugs at a national and provincial level to develop uniformity and consensus.

So far, the jury is out. From Health Canada approval in August 2006, Sutent was first denied by the CDR seven months later in February 2007. Quebec was first to fund the drug in June 2007, followed by British Columbia in July 2007, and then Ontario in November 2007. Time will tell whether provinces with lesser health care budgets will adopt the JODR recommendation in favour of Sutent.

In the meantime, patients like Bill Dompierre will go on thanking the private fundraisers who organized fundraising events to pay for his drugs. "We never expected to be in this position" says Kim Dompierre. "We've worked all of our lives. We've paid our taxes in Nova Scotia, and we've paid into private insurance. If I had breast cancer, all of my drugs would be covered here. Why is that kidney cancer patients are being left out in the cold?"

*Written by: **Deborah Maskens**, kidney cancer patient and Vice-Chair, Kidney Cancer Canada. Deb is clinically free of kidney cancer thanks to new targeted agents only available to rcc papillary patients through private insurance in Ontario.*

Bill Dompierre lives in Bedford, Nova Scotia. Until his medical leave, Bill taught at Nova Scotia Community College (NSCC) for 31 years.

Bob Eaton lives in Dorchester Ontario. Bob is a former MPP for Middlesex County and currently works in real estate.

Wally Vogel lives in Mississauga Ontario where he is resuming his life after two years of successful treatments for metastatic kidney cancer.

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