



## Private company offers hope to cancer patients — for a price

Barbara Sibbald

**B**ill O'Neill claims his treatment methods deliver a 30% better chance of beating cancer than conventional medicine. No, O'Neill isn't a doctor. Or a scientist. He's a former computer consultant who founded the Canadian Cancer Research Group (CCRG), an Ottawa company that provides information and treatment options to medicine-weary, information-hungry patients — for a price.

Some physicians worry that CCRG is providing more than information, and is actually advising clients which therapies will work best. Not so, says CCRG — it's all up to the patient.

And there's no shortage of them. Since it incorporated in 1993, says the company, more than 40 000 people from British Columbia to Qatar have sought its services; another 5000 are expected this year, 80% of them Canadian. In the month of April alone, the company fielded 3400 phone calls.

One of its newest clients is Tyrell Dueck, the 13-year-old Saskatchewan youth who fought his provincial government for the right to reject conventional treatment. Dueck recently returned from a Tijuana, Mexico, clinic, and CCRG is now running a complete diagnostic work-up to determine whether its vaccines or other treatments might help shrink the tumour in his right knee.

Cost doesn't seem to be a deterrent for this latest example of private enterprise health care, which is unique in Canada. CCRG charges \$750 for a full "research report," plus \$150 for each additional hour of consultation. "We're often accused of exploiting patients, but that's crap," says O'Neill, who says he drew a salary of about \$48 000 in 1998 from reported revenues of \$400 000. "It's the industry people who are driving the Lexus."

He adds that CCRG's fees are based on means. "Sometimes we barter."

CCRG is making enough money to expand. In November 1998, it hired a physician and opened its first Cancer Vaccination Centres of Canada office in a cramped room at its Ottawa headquarters. By the fall it hopes to open a larger centre that offers not only vaccines but also other services such as MRI scans, which would be provided using leased equipment. By 2000, the company plans to begin setting up similar centres in major Canadian cities.

The group has 9 employees. They include O'Neill, whose title is director of international clinical services, naturopath Gerhard Schmidt and 2 physicians — Dr. Gerasimos Kambites, a psychiatrist specializing in oncology



Tyrell Dueck, 13, with his parents, is one of CCRG's newest clients

treatment, and Dr. Mark Patry, who specializes in complementary medicine. As clinical consultant, Patry oversees treatment and administers "cancer vaccines," which he says are just one potential aspect of treatment; CCRG says it insists on a multidimensional treatment strategy based on the client's psychological and physiological needs. Two more physicians are slated to be hired this summer.

CCRG researchers also gather new and in-progress research from their cancer database, which O'Neill says is the world's largest. He also consults routinely with several hundred experts. "Our research goes beyond peer review to transcripts, all sorts of things," he says. Patry concurs. "We're not going for the quack crap in or outside the system. We're very cautious."

They use this information to arrive at a strategy that employs the "most contemporary, hopeful, least toxic treatment that may or may not be outside the conventional paradigm."

O'Neill insists that the company does not mislead patients into thinking they can offer a cure-all. "We're very honest with patients; we don't inflate them or discourage them. I provide realistic options."

### Hope for sale

Toronto medical oncologist Robert Buckman understands why some patients gravitate to groups like CCRG: he says they provide options that give patients a sense of control, which they crave. Buckman, a well-known author, says patients threatened by illness have 3 major needs: sup-



port, control (of either treatment or information) and hope. In his 1995 book *What You Really Need to Know about Cancer: A Comprehensive Guide for Patients and their Families* (Key Porter Books), he said complementary practitioners are usually better than conventional doctors at meeting these needs.

“Clinicians don’t have time to do this for every patient,” adds Dr. Mike McBurney, a research scientist and director of research at the Ottawa Regional Cancer Centre. “We do attempt to look after the social and psychological needs, but it’s not well funded.”

CCRG is especially big on offering hope. “We want them to believe they will be the 1 in 100 who will survive,” O’Neill said during an interview at his small but elegant office in Ottawa’s trendy Glebe neighbourhood. “Belief is part of the cure.”

“Feeling better is something every physician should encourage,” says Buckman, who practises at the Sunnybrook Regional Cancer Centre. And he agrees that complementary therapies often make patients feel better — an end in itself. “I have no argument against that at all.”

### Feeling better vs. getting better

The problem, says Buckman, is that these feelings of well-being should not be confused with a true remission of the disease because “feeling better and getting better are completely separate.”

And there’s the rub. CCRG may be making its clients feel better, but is it offering treatments that give clients a better rate of remission? O’Neill claims it is, citing a “30% improved” chance of beating cancer based on CCRG’s unpublished data, and more. Much more. With conventional treatment, a Canadian woman with stage III or IV breast cancer has an 11% to 14% survival rate. “Our 5-year survival rate for stage III and IV is 82%,” he says.

“These are amazing statements,” says an astounded Buckman. “I say either prove it or stop saying it.”

But O’Neill is adamant that CCRG uses only data that are supported by good research. “We don’t have blinders on. We believe there are charlatans inside and outside the conventional system.”

An example within the system? He says surgery, chemotherapy and radiation have no effect on stage III or IV cancers. O’Neill backs this up with an extensive data search. “There are no reports in any databases, libraries or journals demonstrating that surgery, radiotherapy or chemotherapy have any benefits in stage III or IV cancers. Those reporting do so in limited terms describing ‘duration of response.’”

McBurney says many patients with stage III cancer have

been cured, but “a widely disseminated disease is not good news and a lot of conventional medicine is certainly palliative for these stages. But people [are surviving] longer and have a better quality of life.”

McBurney also objects to O’Neill’s research group on a purely semantic level: he says the company name implies that it is doing original research, and this simply isn’t the case. “I find it confusing.”

O’Neill also tells his clients there are no double-blind studies to prove the efficacy of chemotherapy, surgery or radiotherapy. “Baloney,” says Dr. Robert Phillips of the National Cancer Institute of Canada (NCIC). “There are lots of studies — and many double-blind studies — showing the effectiveness of chemotherapy and radiotherapy.”

O’Neill is not surprised that physicians and scientists doubt his claims. “I’m sympathetic to doctors because they know that most of what they are doing is not effective,” says

O’Neill. (A \$4.5-million lawsuit the O’Neills launched against an Ottawa hospital and 3 of its doctors is still outstanding. O’Neill and his wife, Kathryn, claim there was negligence in the diagnosis and treatment involving their son, who had cancer.)

O’Neill also says that his work is undermining a huge “multibillion-dollar cancer business.” He argues that physicians are part of a system that is propelled by pharmaceutical companies and other business interests and has a vested interest not in curing cancer but in treating it for a long time. “It can cost \$40 000 to cure or \$80 000 to put a patient in the grave,” he says. “It’s a business.”

Asked for evidence, he says that despite the billions spent on research, cancer mortality rates are not improving. He cites an article in the *New England Journal of Medicine* (1997, 36: 1569-74) stating that age-adjusted cancer mortality in the US increased by 6% from 1970 to 1994.

“Canada is 20 years behind other countries in cancer treatment,” claims O’Neill. “We haven’t changed our service delivery for cancer since the mid-50s.”

“That’s a wonderfully inflammatory statement,” says Buckman.

McBurney was left incredulous. “Per capita we [are] the most active country in [terms of] clinical trials. Canada is renowned in the world for conducting good clinical trials. Sure some of the treatments are 20 years old, but that’s because they work.”

The NCIC’s Phillips is a little more conciliatory. He admits that Canadian cancer therapy “may be a bit behind” but adds that there has been “progress in treatment in almost every area.” He will not comment on CCRG’s information services — “our position is that patients have the right to know



Barbara Sibbald photo

**Bill O’Neill founded CCRG after his 12-year-old son developed medulloblastoma and was given 18 months to live. He is now 19.**



what we know” — but adds that there are ways to get good information without paying \$750 or more for it; he pointed to the Canadian Cancer Society’s Cancer Information Services. The NCIC doesn’t endorse alternative therapies, but it does provide information about them so that patients have access to “the best data and can pursue it if they like.

“Our worry is that people will forgo proven therapies for something that is unproven,” adds Phillips. “Is this company just giving patients a broad spectrum of information for the patient to use and to make up [his] own mind? Or is it recommending specific treatments that might encourage the patient to [refuse] proven therapies and follow experimental therapies? I’m apprehensive that it . . . is making specific treatment recommendations without having an oncologist on staff.”

Whether or not CCRG makes recommendations depends upon which person is asked. “I don’t tell *patients* [italics added] to do one thing or another — I present rational options,” says O’Neill. “To say ‘don’t do this, do that,’ — [because of] the morality and ethics of it, I just couldn’t live with myself.”

But the fact is these patients depend on CCRG for the type and quality of information they receive. And CCRG makes options, such as vaccines, readily available. “If their oncologist doesn’t agree with the treatment, we find them another oncologist,” O’Neill says later.

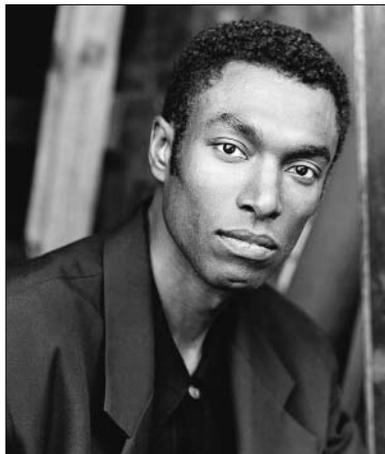
### “Start with Bill”

One of CCRG’s star clients, Toronto actor Conrad Coates, says he has followed the group’s recommendations. O’Neill “promoted [vaccines] as the way to go,” says Coates. Diagnosed with chronic myelogenous leukemia in August 1995, he recently refused a bone marrow transplant — against the advice of his oncologist — on the strength of advice and vaccine treatments provided by CCRG. “[O’Neill] said he could help me. He said he wasn’t sure if the transplant was the best way to go.” O’Neill gave him a 2-inch binder full of research studies and information. Coates was torn at first, but in August 1997 began self-administering the vaccine. He says his energy level increased right away, and when a marrow match was found he declined. “I feel I’m living a hell of a lot better life than I would be if I’d had a transplant.”

Coates commonly works 50-hour weeks. He has acted at the Stratford Festival for 2 seasons, and on TV programs such as *Street Legal* and in films such as *Critical Care*, a satirical look at the medical system. He played a doctor.

“My confidence is with Bill [O’Neill] and what he’s doing. He’s someone on the inside rather than someone dealing with numbers and statistics. When I see people in trouble I say, ‘Start with Bill.’”

Coates says O’Neill’s lack of medical background doesn’t worry him. “He has learned the language. He’s my advocate.”



Conrad Coates: “He’s my advocate”

“The real problem,” Buckman warns after hearing about Coates’ case, “is when you put all your psychological eggs into the complementary basket.”

Part counsellor, part benefactor, part researcher and part advocate — CCRG is undoubtedly providing a lot of these eggs. The company has even been known to buy patients’ groceries, renegotiate their mortgage and arrange for a new washer and dryer. It is in the process of setting up the Hope Foundation, which is headed by Jamie Baker, a former Ottawa Senators hockey player, and his wife Annie, who have invested \$15 000 in CCRG. Cash donations to the foundation will “influence local cancer therapy.”

### Cancer-fighting vaccines

CCRG’s main focus these days is cancer-fighting vaccines administered by Patry, who has been providing “alternative treatments” for about 25 years. Since 1985 he has specialized in managing hormonal problems at his Ottawa Menopause Clinic.

“It is leading edge,” Patry says of vaccines, “but like anything new . . . it manifests a certain amount of scepticism, disbelief, lack of trust, sometimes even anger.”

Vaccines are supposed to enable the immune system to recognize the tumour as a foreign body, and attack it. Buckman is profoundly sceptical. He says alternative clinics worldwide offer vaccines. In his book he commented: “Without exception, those complementary types of vaccines have proved useless.”

“The world is full of people who say they can cure cancer,” adds Buckman, who also holds a PhD and is an associate professor at the University of Toronto. He cites previous “breakthroughs” such as interleukin-2, interferon and others. And vaccines are nothing new in cancer research; they have been under investigation since the 1930s.

The vaccines used by CCRG are made by Immuno-comp Laboratories in Atlanta and range in price from “zero to \$10 000 for the total protocol,” says O’Neill. The price depends on the client’s means.

Patry says there is enough success to explore vaccines seriously. “It’s vital to me to offer alternatives to the 10% to 15% survival rate. Even if we double it, to 30%, we’ve done the patients an immense favour.” (The overall lifetime survival rate for all cancers is from *Global Health Statistics*, which was published by Harvard Press in 1998.)

And Patry’s not concerned about how his colleagues react to these treatments. “If I was looking over my shoulder all the time I wouldn’t get anything done. Besides, if you’re convinced that you have the truth, why bother with them?”

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