Defying the cancer creed: Crusader fights to open country's first vaccine clinic in Ottawa

by Mike Shahin, The Ottawa Citizen

Bill O'Neill is just getting started in his battle to revolutionize the way people with cancer are treated in this country.

It began six years ago when he found out his 12-year-old son Liam had a brain tumour. Liam's battle spurred Mr. O'Neill and his wife Kathryn to create an Ottawa-based advocacy and research business for cancer victims that is challenging mainstream medicine and has helped more than 5,000 people so far.

Now Mr. O'Neill is working to set up Canada's first cancer vaccine centre -- in Ottawa. He hopes the centre, offering a controversial, experimental method of cancer therapy, will be a prototype for similar clinics across the country.

He now arranges for his clients to get the vaccines from the U.S., mainly from clinics in Georgia and California.

But the trips can be costly, and the burden of travelling can be heavy on some patients. Former Ottawa resident Paul Mahar, for example, said he spent about $80,000 obtaining vaccine therapy in the U.S. over the past four years in his fight against skin cancer.

The centre could be open as early as next spring, Mr. O'Neill said
but there are still obstacles to overcome. He estimated it will take between $500,000 and $1 million to set up the clinic. And government health regulators will likely want to scrutinize any plan to sell vaccines to cancer patients.

Vaccine therapy is making waves in the cancer community. Some say it is the next great hope in curative therapy, others dismiss it as the latest form of snake oil. It has shown some promising scientific results, but it is still under experimentation.

Most versions of immunotherapy, as it is called, attempt to recruit the immune system in the fight against cancerous cells (chemotherapy, by contrast, suppresses the immune system while eradicating cancerous cells). Mr. O'Neill plans to focus on personal vaccines, which are tailor-made for patients using materials from each individual's tumour cells. Drugs such as interleukin-2 are then used to stimulate their immune system.

"We're activating and educating the immune system to seek out and find cancer cells and kill them," explained Jim McCoy, a cancer immunologist who runs Immunocomp Laboratory, south of Atlanta, Georgia.

Immunocomp's therapy has produced a response rate 23 per cent better than that achieved by conventional medicine, said Mr. McCoy, who worked for the U.S. National Cancer Institute for six years. But the data is not yet conclusive, he said, because the vaccine has only been available for a few years and only about 520 people have used it. "We've still got more work to do."

A personal vaccine can't be mass-produced by pharmaceutical companies, and it can't be sold off the shelf. And, unlike chemotherapy and radiation, it is not toxic. Mr. O'Neill said he strongly believes that cancer therapy must work by boosting the immune system, rather than by suppressing it.

Mr. O'Neill's Canadian Cancer Research Group, which has its office on Bank St. in the Glebe, has arranged for two Ottawa doctors, a pathologist and a psychiatrist, to study the vaccine process at Emery State University Hospital in Georgia, which is helping Immunocomp conduct clinical trials, before returning to staff the Ottawa clinic, he said.

The research group is also setting up a foundation, called Hope, that will use cash donations to influence local cancer therapy. For example, Mr. O'Neill said, the foundation might offer Ottawa's Regional Cancer Centre money on condition that it set up vaccine therapy for its patients. Former Ottawa Senators player Jamie Baker, who invested in the research group, will likely run the foundation, Mr. O'Neill said.

Mr. O'Neill also hopes to step up the group's advocacy role with government and industry. "We will go in, solution-oriented, to manufacturers and processors of food and personal care products, and say, 'We can work with you to re-engineer your processes..."
and products so that its not carcinogenic or immunosuppressant; so that it's safe."

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Doctor Hope

Why thousands of desperate cancer patients have turned to Ottawa's Bill O'Neill for help

Just as despair can come to one only from other human beings, hope, too, can be given to one only by other human beings.

-- Elie Wiesel, U.S. writer

Liam O'Neill was a 12-year-old boy with the ability to outrun any of his classmates when his parents, William and Kathryn, received the diagnosis.

The O'Neills knew something was wrong. Liam wasn't running as fast as usual lately. Headaches and nausea were slowing him down. But the symptoms suggested nothing worse than the flu. A pediatric neurologist took one look into Liam's eyes and delivered the news to the O'Neills: The boy has brain cancer.

Tests and other doctors said there was no choice but to remove the orange-sized tumour immediately.

Liam wasn't allowed even a quick visit home to say goodbye to his dog, Brindle, or to pack his treasured stuffed animals for the stay at the Children's Hospital of Eastern Ontario. "It felt like I was in a dream," Liam said.

It was more like a nightmare, one that few children could imagine: Six hours of brain surgery, tubes entering and exiting Liam's body, doctors deciding the tumour was malignant ("Is malignant better than benign?" Liam wonders in innocence), weeks in intensive care, more tests, doctors telling the O'Neills that their son's cancer has spread -- there is a tumour in his spine and he will likely die within two years -- radiation, chemotherapy.

Shock.

Liam, meanwhile, could do little but draw pictures of himself escaping from the hospital, his IV stand rolling alongside. "It's just the most devastating news," Ms. O'Neill said. "Every parent would want it to be them, not their child."

For the O'Neills, the choice was clear: they could either despair, or they could hope. Rather than allow the disease or the doctors to set the terms, as so many people do when weak and vulnerable, Liam's parents took control of his illness. Like the Odone family in the film Lorenzo's Oil, a true story about a boy with the rare brain disease ALD, the O'Neills researched every aspect of Liam's medulloblastoma.

From the family home in Westboro, Mr. O'Neill phoned and e-
mailed experts around the world. The couple fought for the right to be part of the medical team making decisions about Liam's care. They refused to submit to doctors who would have them play ignorant victims. They battled the system when they believed it was doing more harm than good for their middle child. (Their fight continues in a lawsuit against CHEO and three of its doctors.)

This is what other parents with children in the cancer ward saw at the time: Liam was getting better, their children were not. What were the O'Neills doing right? It was not long before these parents began to approach the O'Neills, asking if they could help their children.

Word spread quickly in the underground network of cancer support: a friend tells a relative who meets someone on a plane whose sister has cancer, and, hey, did you hear there's a guy named Bill O'Neill in Ottawa who is curing the damned disease? People with cancer, frustrated by the limits of conventional medicine, called from as far away as Tuktoyaktuk and Qatar and sought the help of the O'Neills' newly founded Canadian Cancer Research Group.

Now, six years after the diagnosis, with their son healthy again, the O'Neills’ decision to fight for Liam continues to radically affect the lives of thousands of people with the disease. Not only did they choose hope for their son, but now they sell it -- to the very people who need it most.

Family sues CHEO for malpractice

The O'Neill family is suing the Children's Hospital of Eastern Ontario and three of its doctors for negligence in their diagnosis and treatment of Liam O'Neill six years ago.

The family -- including Liam's parents, siblings, aunts and uncles -- is seeking more than $4.5 million in damages, lost wages and legal costs in the malpractice suit.

Liam had successful surgery to remove a large brain tumour when he first entered CHEO. But doctors later said the cancer had spread to Liam's spine. The prognosis was not good: the O'Neills say they were told their son would die within one or two years. Liam was treated with radiation and chemotherapy.

The family contends that the doctors erred in their diagnosis, and that further tests showed the mass in Liam's spine to be a benign cyst -- not a malignant tumour. Liam's parents are worried about the psychological effects of the diagnosis and treatment on Liam, said their lawyer, Robert Houston.

"Who knows exactly what the future will bring to a lad who was told at 12, You're going to die in a year or two," Mr. Houston said.
If Bill O'Neill is a guardian angel, as several of his patients will attest, he is definitely not of the white-winged, halo-over-the-head variety.

His vision of cancer care looks more like this: midnight trips to patients' houses to cook chicken dinner, phone calls day and night to defuse panic, visits from famous folk singers and hockey players to brighten spirits, trips to California and Georgia to obtain controversial cancer vaccines, Internet chain letters asking 20,000 strangers to pray for a sick child.

Mr. O'Neill has renegotiated mortgages and bought groceries for his patients. "If I see something that I know is freaking them out, if I can make the change, I'll do it," he said. "How can you cook a

The doctors and CHEO deny all charges of negligence in their statements of defence.

Mr. Hackland said it is his opinion that Liam's father, Bill O'Neill, is pursuing the lawsuit contrary to his son's desire. "I have some concern that Mr. O'Neill's claim is due in part to his business," Mr. Hackland said, referring to the Ottawa-based Canadian Cancer Research Group, Mr. O'Neill's cancer advocacy and research centre.

Bill Carter, lawyer for CHEO, said he could not discuss the lawsuit because it would breach the hospital's patient-confidentiality rules.

"If the father wants to make a cause celebre out of it, that's between him and his son and his conscience," Mr. Carter said from Toronto.

"But I certainly can't get drawn into that."

The doctors named in the lawsuit are: Dr. Elizabeth Hsu, a pediatric oncologist, currently on sabbatical in the U.S., Dr. Brian Luke, head of pediatric oncology at CHEO, and Dr. Mary-Anne Matzinger, a radiologist at CHEO.

If there is a trial, it is likely to begin sometime next year. But both sides say a settlement is possible.

"I don't care if it's settled or if we go to trial," Mr. O'Neill said. "I just want an admission of error. They erred in their
meal when your husband is dying of cancer?"

Mr. O'Neill also can curse a mean streak, possesses a Grade 5 sense of humour that favours farts, burps, Beavis and Butthead -- and has been known to photocopy his butt and fax it to friends and relatives for a little levity.

It is all very much part of the man and the therapy he offers.

Mr. O'Neill has a John Bradshaw (the TV psychologist of inner-child fame) quality about him. Sandy, wind-blown hair, close-cropped beard, the slight twang and delivery of a preacher, a sparkle of sympathy and laughter warming his eyes when he shares with you. Although he says he's definitely not a salesman, he carries in him some of his late father, who spent decades in construction sales and marketing. Mr. O'Neill is, perhaps unknowingly, constantly selling the message that he so believes.

It is impossible to describe what Mr. O'Neill does in a word, because that word does not exist. He refuses to be pigeonholed. He is researcher, advocate, therapist, peddler of potential cures, shit disturber and friend. He is, emphatically, not a doctor. He is driven by the belief that our old, narrow definitions of health-care must be overhauled. And his constant challenging of the old paradigm has succeeded in rattling the cages of some of the top conventional cancer specialists in the region. There are those who clearly do not like what Bill O'Neill is doing.

"Patients come to me," he says, "because they know, they've seen, they've witnessed cures where there has been no cure, hope where there has been despair."

These are fighting words and, in a way, they are Mr. O'Neill's battle cry to those who cannot see that the business of cancer therapy as we know it is very sick indeed.

"I work with families of children where, right off the mark, the parents have been told, 'Start grieving your child's death now, start grieving it now. Your flesh and blood's death.' And I come into the picture and say NO. The child is getting sicker, indeed the whole family is getting sicker, and the grief is making it all worse, he says.

"We will re-engineer that into hope. The child gets better, maybe for the rest of his or her life, maybe for a short period of time. But the child is happy, and the parents are happy."

If someone has a 99-per-cent chance of dying of a certain cancer, according to conventional medicine, Mr. O'Neill wants that person to believe he or she can be the one in 100 who survives.

This belief, in itself, is a key part of the cure.

More than 5,000 people have come to the O'Neills' Canadian Cancer Research Group since its inception in 1992. People with
cancer from across Canada, the United States and as far away as Australia and Russia continue to ask the CCRG, now based in a discreet, brick-walled office in the Glebe, for help.

Aside from a basic computer web site, though, the O'Neills have never advertised, never told their compelling personal and professional story in a public forum. With the publication of this article, Mr. O'Neill expects, and hopes, that people will storm the CCRG. If he is right, it will not be a comment on the power of the media, but proof that people with cancer are desperate for a sign that they can beat their insidious disease.

It will not be the first time either. Say the words cancer and cure in the same breath, and the world stops and listens -- because it wants to believe.

It barely matters who speaks the words. It could be a stooped, little-understood Italian physiologist named Luigi Di Bella serving a decades-old drug cocktail. It could be an eminent medical scientist waving drug research on mice newly rid of cancerous tumours. It could be a naturopath touting shark's cartilage and essiac tea.

But what does Bill O'Neill offer that no one else has? Why are people with cancer convinced he is their guardian angel and saint? Why have thousands trusted him, literally, with their lives?

The answer begins with the service that he and Kathryn provide. Amid severe cuts to public medicine and increasing frustration with the limits of conventional treatment, the O'Neills are building what one person calls a signpost in the sea, a new model for health care.

If you have cancer and you hire the CCRG, the O'Neills will run computer searches on their extensive cancer database, which they say is the largest in the world, and dig up every piece of new and background research they can find on cases that relate to your illness.

They will provide you with treatment options that they believe suit you: from the cutting edge, including immunotherapy and cancer vaccines, to the mainstream, ranging from chemotherapy to surgery, all the way to the downright alternative, such as coffee enemas and therapeutic touch.

They will connect you with doctors, therapists and naturopaths -- anyone who can add to your overall treatment.

They will be your advocate -- at a time when you likely most need one. They will press your oncologist to consider certain treatments other than the conventional, if that's what you want.

They will visit your doctor with you, to ask questions your doctor won't answer or to help you understand the piles of information being thrown at you.
If you were a professional athlete, the O'Neills would be your manager, agent, teammate -- and your biggest fan.

Many of his patients are convinced that Mr. O'Neill, a former computer consultant with a voracious appetite for information and the ability to synthesize it for his patients, knows more about cancer than most of the doctors they've seen.

While doctors are busy practising what they already know, Mr. O'Neill is busy reading the latest research and talking to experts who go beyond the limitations of the standard surgery/chemotherapy/radiation sequence of therapy. Indeed, many people come to the CCRG because they are fed up with a medical system that limits itself to these invasive, often toxic therapies.

Mr. O'Neill likes to say that conventional doctors' biggest weakness is that they treat the disease, rather than the person. "If chemotherapy doesn't work," he says, "doctors say the patient failed the treatment. The patient didn't fail anything. The treatment failed them." Cancer is part of the whole person, and must be seen that way, he says.

This explains, among other things, the visits from folk singer Garnet Rogers, who became a friend to the family and an inspiration to Liam during his illness. Out of the blue, Mr. O'Neill called Garnet when his son was sick and asked if he'd help to cheer up the boy. Bill and Kathryn were huge fans, having seen every concert given in Ottawa by Garnet and his late brother, Stan Rogers.

Garnet wrote Liam a letter, called on his birthday, visited and sent him souvenirs from the road. Garnet wasn't sure how talking to a humble folk singer could help someone facing the extraordinary challenges of cancer, but Mr. O'Neill was convinced it was worth a try.

"Bill was a novice (at cancer therapy) at the time," Garnet recalls. "He was trying every avenue. If someone came up to him and said 'If you stripped naked and painted yourself blue and stood on top of the Peace Tower, it would help your son,' he would do it.'"

He would likely do it for any of his patients, in fact, and each of them knows it.

Garnet explains that the O'Neills experience with Liam drives them in their work today. They were scared and lonely during Liam's treatment, Garnet said. "But there was also an enormous sense of anger that they were just blown off by the medical establishment."

Mr. O'Neill, more than anyone in his family, has nurtured that outrage, and uses it in his crusade for justice. Some say he is obsessed with what he does. And others seem to be attracted by
his crusade. Former Ottawa Senators player Jamie Baker invested $15,000 in the CCRG after being moved by Liam's struggle and becoming a family friend. Now,Mr. Baker, who has a degree in economics, will likely head up the foundation Mr. O'Neill's group is setting up. "People who've been helped by Bill want to donate money," Mr. Baker said.

As for Garnet, Mr. O'Neill continues to ask him the favour of the occasional call or note to brighten a sick patient's day. It is not only the patient who ends up inspired. While in Baltimore for a concert, Garnet called a woman in Calgary who was in hospital preparing to have her head cut open in brain surgery the next day. "I couldn't believe it," Garnet said. "She was concerned about me and whether I was eating properly and lonely while on the road."

His experience with the O'Neills and other cancer patients has indirectly informed his music, Garnet says, although he hasn't written explicitly about cancer.

Take my hand and we will walk together, Garnet wrote in his latest album. Take my hand and you will not walk alone

Take my hand, this night won't last forever
We'll harvest seeds of hope we've sown.

Czech president and playwright Vaclav Havel wrote that "hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out."

In the debate over what Bill O'Neill does, there will be much talk about alternative versus conventional medicine and questions about whether a computer nerd should be directing patients' treatment -- but the discussion will, inevitably, come back to the issue of hope.

Frankly, it would be alarming if someone did not suggest that he is a charlatan or a snake-oil salesman. He does, after all, say that his methods of treatment deliver a 30 per cent better chance than conventional medicine that his patients will beat their cancer. Such numbers, despite their admitted caveats and shortcomings, have the potential to inspire Di Bella-like stampedes among desperate cancer patients. And he is charging people money for his services.

(The posted rate for the research and a full report is $750, plus $150 for each additional hour of consultation or counselling. But Mr. O'Neill often works for free or a discount. Cash-strapped patients say he rarely has the meter running, even through marathon midnight phone sessions, and often charges far less than they believe his services to be worth. "No one needs to be beholden to me for anything," he said. "My view of the world is that it all comes out even in the end.")
Still, Mr. O'Neill appears to welcome the scrutiny of skeptics.

"Some clinicians, the ones who don't support me, say I inspire false hope," Mr. O'Neill said. "Well, what is false hope? How can you characterize or qualify hope? Hope is simply something better for the next minute, the next hour, tomorrow. What right do we have to impede or influence another person's hope?"

Mr. O'Neill is right. Physicians do suggest he is selling false hope, but they are careful not to use those words. In interviews, some were tactful in their criticism, others verged on the paranoid. One doctor called me back after being interviewed to ask that I be careful in my use of his comments because, he understood, Mr. O'Neill was suing other critics for libel (which is not the case). Another doctor cursed at a colleague when told that her name was given to me and that I might call to interview her about Mr. O'Neill. And one doctor called back to suggest I take on a mentor, someone with a background in cancer therapies who "understands" the issues, to help me write this story.

It should be no surprise that doctors are defensive, or at least sensitive. Mr. O'Neill may not be challenging them personally (in fact, he goes out of his way to say he believes most cancer doctors are honorable in their treatment of patients, and thinks many give wonderful care) but he does undercut the entire system in which they work by arguing that they are ultimately not offering the best treatment possible for people with cancer.

Doctors at the Regional Cancer Centre, Ottawa's temple for conventional cancer care, all know who Bill O'Neill is. Patients come in with stacks of research, and questions about promising experimental therapies, courtesy of the CCRG. Some patients tell their doctors they are dabbling in alternative therapies even while being treated at the cancer centre (many more do so without telling their doctors).

Dr. Shail Verma, an oncologist at the RCC's General site since 1985, says he is made "very uncomfortable" by the lack of evidence behind cancer vaccines, one of Bill O'Neill's favoured methods of therapy.

"I have looked at this data," Dr. Verma said. "I remain very, very dismayed by the wholesale promotion of these treatments because I think they're based on very dangerous premises, (and) they're based on very ill-designed trials."

Dr. Verma said he respects the fact that Mr. O'Neill is offering patients choices and empowerment, and doesn't think he has ever "misled people with misinformation." But the doctor goes on to say that what Mr. O'Neill provides can "take patients away from conventional therapies that have proven benefits."

"Does Bill give patients hope?" Dr. Verma asks. "I think he does, he offers them the chance to empower and he tries to open some doors for them. Does he give them valid hope -- that is,
hope they can count on and rely on? I don't know.

"Does he create conflict for patients? Yes, I think he does, because he creates conflict with some of their primary caregivers. And to have a patient caught in that conflict is a terrible thing."

Dr. Dave Stewart is chief of medical oncology at the Regional Cancer Centre's Civic site and, he says, he has been closely following the field of tumour immunology since he was a medical student more than 25 years ago. He does not believe in cancer vaccines as a cure.

"Immunotherapy has been about to cure cancer for the past 30 years," Dr. Stewart said. "It's frozen in a state of perpetual potential. I cannot find anything that supports his (O'Neill's) claims."

Dr. Stewart said Mr. O'Neill has "no background whatsoever in medical matters," and that this lack of training likely makes it difficult for Mr. O'Neill to accurately judge the merits of experimental treatments.

"The more conventional academic (medical) community is better equipped to spot the false hope, the false positive, and to weed it out so that people are not hurt by that," Dr. Stewart said.

In a voice message left for me after our interview, Dr. Stewart had this to add: "Just to perhaps get a better understanding of some of the problems that I might have had with buying into what Bill O'Neill is doing, I suggest you call him and find out how difficult it is for you to get (a straight answer)."

Dr. Stewart's worry was that patients were possibly being misled about Mr. O'Neill's qualifications. Even the name of Mr. O'Neill's group, Canadian Cancer Research, group is "symptomatic, perhaps, of the credibility problem," he said. "There's a huge number of cancer researchers in Canada that would not strongly endorse what he's doing."

But in our first of several discussions, even before Dr. Stewart's suggestion, Mr. O'Neill was quite forthcoming about his training, or lack of it.

He has a BA from Carleton University, took some MBA courses from the University of Western Ontario but never graduated, and taught himself how to be a computer whiz. He also taught mathematics at Algonquin College for awhile. And he was a computer systems consultant working for the City of Ottawa until Liam got sick.

Does this sound like the resume of a cancer therapist? Not even close. But Mr. O'Neill says this is exactly where his strengths lie - by not being limited by conventional rules of what therapy should be and by being free to use his tenacity and his analytical skills to seek solutions to problems.
Mr. O'Neill was also quite willing to answer questions about money, one of the first concerns raised by critics. He will draw a $48,000 salary from the CCRG's $400,000 in revenues this year, he drives a leased Jeep Cherokee, owns a $3,000 sailboat and a small cottage in the Gatineaus, and has sunk thousands of his family's dollars into setting up the business. Mr. O'Neill was making much more money as a computer consultant, he said. He won't apologize for earning a living and supporting his family, and reminds people that he makes far less than oncologists earn.

Dr. Leslie Eidus, a pathologist at the Ottawa Hospital's General site, is impressed with the fact that Mr. O'Neill "gave up everything" to help his son, and has sympathy for what he does for other cancer patients. He believes that information equals choice and power, and he thinks Mr. O'Neill is giving that to people who need it.

But Dr. Eidus said he cannot support the immunotherapy Mr. O'Neill advocates because he has not seen any statistics proving that it works. Despite asking for it, Dr. Eidus said, "I have never gotten the data from Bill."

It is true that Mr. O'Neill can be hard to pin down on numbers. But his position is that conventional medicine's methods of measuring success are misleading and useless. This is a position shared by most people who believe in alternative therapies, and it is probably the cause of the huge gap that separates them from mainstream proponents. Doctors say 'Prove it.' Alternists say 'your definition of proof is all wrong.'

Mr. O'Neill's answer is that instead of waving around data-based scientific studies, we need to look at evidence -- patient by patient. If a patient gets better after using a certain therapy, Mr. O'Neill argues, that is proof enough that something works. The challenge, then, is to find out what it is and offer it to others.

If cancer is unique to each person afflicted, then the treatment must follow the same logic, he says. Ask him for proof, and rather than offer a pile of data, Mr. O'Neill will give you one case in which the patient's cancer improved, then another case, and another.

That, he says, is the only way to understand, and ultimately defeat, cancer.

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'Bill saved us, he saved our sanity'

Here are several cases of people with cancer who, in their search for hope, have come to Bill O'Neill. Each of their stories is
remarkable and inspiring. Each of their personal struggles is -- or was -- epic.

There are clues in these stories that will help us understand what these people receive from Mr. O'Neill, and what they, and so many others with cancer, can't find anywhere else.

**Patrick Kennedy, 7, Ottawa**

It is four months since Joan and Robert Kennedy's youngest son died of medulloblastoma, a word far too big for a seven-year-old to have to suffer from.

Patrick was diagnosed in May of last year with the same type of cancer that Liam O'Neill had defeated. Doctors operated on Patrick's brain tumour, attacked the cancer with six weeks of radiation, and injected him with chemotherapeutic drugs. An MRI test showed a tumour in his spine. It had spread.

The doctors gave Patrick Kennedy, six years old at the time, 18 months to live.

When Joan met Bill O'Neill, she believed he had been sent to the family to save Patrick.

It's not that Mr. O'Neill ever promised to cure the boy. But the fact that Liam beat his cancer gave the Kennedys hope that Mr. O'Neill could help Patrick do the same.

Mr. O'Neill's message was that no doctor can decide when anyone will die. "That's between you and God," Joan said.

"I didn't want to give up before we tried to help (Patrick)," she said, still raw and emotional from her loss. "We felt that we had to try as hard as we could. We had to do that for Patrick. I didn't want to let him go -- let him die -- and then feel like I didn't do enough."

The Kennedys travelled to Georgia to get a cancer vaccine therapy for Patrick, and flew in a doctor from San Diego to perform laser resonance, an alternative therapy. Patrick seemed to be doing well, didn't appear to suffer much, but in the end nothing stopped the cancer's progress. Aside from the government-paid costs of conventional treatment, the family spent more than $10,000 (including travel costs) for the vaccine, the laser therapy and Mr. O'Neill's services.

This is what Mr. O'Neill did for the Kennedys: He provided them with information, he interpreted test results for them, he suggested they seek second opinions, and he offered constant guidance. He gave them choices, Joan said, but always left the decisions up to the family.
Joan apologizes for crying, as she tells of an astonishing transformation in her ill son. As the youngest of three boys, Patrick was always "quite intense," very aware of the division of justice with his brothers. It could have been toys, or it could have been attention from his parents, but Patrick "always felt shortchanged."

It would be natural to expect that Patrick would have been furious that he, and not his brothers, was struck by cancer.

But he was calm and at peace in the face of the disease, Joan says. "He was so accepting." Patrick's strength came from Liam's inspiration, and from the fact that his parents truly believed he could live, Joan says. "I think (Patrick) was hopeful."

Along the way, Joan came to realize that it was unfair to expect Mr. O'Neill, or any one person, to cure her son. No one, ultimately, had that power.

But Mr. O'Neill gave the Kennedys, including Patrick, the ability to hope -- and for that Joan will be "forever indebted" to him.

"Bill saved us as a family, he saved our sanity -- even though he was not able to physically save Patrick."

Matthew Moran, 23, Skaneateles, N.Y.

Matt Moran credits Bill O'Neill with saving his young life, despite never having met the man in person.

Matt, an all-around athlete who had just finished a lacrosse college scholarship, was diagnosed in January 1997 with what doctors in Syracuse and Washington said was a pseudo-tumour, a condition that mocked cancer in his brain.

Based on the symptoms, he and his parents doubted the diagnosis from the beginning. Doctors performed a lumbar shunt to ease the pressure in his brain. But complications forced them to go in again and again.

Finally, doctors saw "millions and millions of tumour fragments" throughout Matt's brain. His "pseudo-tumour" was in fact medulloblastoma, a deadly brain cancer.

Matt was immediately given heavy doses of chemotherapy to kill the malignant cells. The chemo turned his strong, athletic body to mush. He lost weight. He got depressed. No matter how positive he tried to be, he couldn't convince himself that it was helping.

In one session, a nurse accidentally splashed some of the chemotherapy liquid on her face, and left the hospital room screaming. Matt was shocked. "They're pouring that in my body, and she's screaming because it touched her skin!" he said. "I decided that if I was going to go out (and die), I didn't want to go out like this, suffering on chemo."
That's when Matt asked his parents to look into alternatives. By sheer chance, a friend of theirs had met a patient of Mr. O'Neill's in Vermont, who said that Mr. O'Neill had saved his life. She gave Mr. O'Neill's number to the Morans with this advice: "I just have this feeling; it may be a complete dead end, but just try it."

The connection was immediate. Matt had the same type of cancer and was nearly the same age as Liam. "He felt like Matt was his son," said Sue Moran, Matt's mother.

But Matt got sicker. A neuro-oncologist prescribed radiation therapy and gave him a morphine-like drug for the pain. Matt began hallucinating, fell unconscious and remained in a near coma for four days. Only a ventilator kept him alive.

Doctors gave the family a choice: leave the 23-year-old hooked up to a machine indefinitely, or unplug him and he will die. Matt responded just enough to blink an answer to his folks. Take me off the ventilator, he urged. They did, at 11 p.m. on Sept. 21, 1997. The doctors said he'd be gone within minutes, Ms. Moran said.

Five hours later, Matt opened his eyes and started asking why his relatives were in the Washington hospital when they should have been on vacation. Ms. Moran ran out to tell the doctors about this miracle. Impossible, she was told, it's just a fluke. Matt will die during the night. And, by the way, said the head of intensive care, he is paralysed from the head down.

The hospital put Matt in a palliative care ward, pumped with narcotics, to die. The family found a "do not resuscitate" order in his file.

Ms. Moran called Mr. O'Neill in Ottawa. "Brain tumour my ass," he fumed. "You're talking about a severe drug reaction in your son. Get him off the narcotics."

Ms. Moran had to battle the hospital to stop the drugs quickly. "They thought I was crazy because I was trying to do something that they said was impossible." She fought to get her son a physiotherapist, and real food rather than a feeding tube.

A week after doctors said he was paralysed and would die, Matt was out of bed and sitting in a chair.

"Bill was our confidence in everything," Ms. Moran said. "He's our guardian angel."

Matt is now back on his feet, regaining strength. He takes several naturopathic vitamins and supplements, including garlic, ginseng and licorice root Mr. O'Neill also arranged for Matt to try vaccine therapy from Georgia, but his body appeared to reject it.

Matt says he believes the cancer has left his body, and he credits
the radiation, vitamins and buildup of his immune system for half
the "cure." The other half is thanks to a positive mental attitude,
much of which came from Mr. O'Neill.

"Just talking to him gives me the confidence that I'm getting
better," Matt explains. "He doesn't talk to me as if he was better
than me. He listens.

"He makes me feel like I'll be OK."

(A footnote: Matt was back in hospital this past week; doctors say
his tumour has metastasized and spread to his abdomen. He was
given between two weeks and two months to live, Sue Moran
said. "One doctor went in and said, in these words, `It's over,
you're going to die.' It brought Matt to his knees.

"Our shining ray of hope is to tear it all up (what the doctors say)
and find out what we can do." At Matt's request, Mr. O'Neill is
back to work on his case.

"I'm not ready to say `That's it'," Matt told his mom.

"There's just been too many times that they (doctors) have been
wrong.")

Annette Pypops, 36, Cantley

Annette Pypops, proud feminist, chuckles when she catches
herself describing her breast cancer as a male monster living off
of her body. "I will not let him -- I'm sorry but it is a him -- I will
not let him invade me, take my place," she says.

For 16 months, Ms. Pypops has refused to cede control of her
body to the monster. She feels like she is slowly winning the
internal struggle. But she is finding that the bigger enemy lives
outside.

When diagnosed in March 1997, Ms. Pypops was told she needed
surgery to remove her tumour and breast, otherwise she would
likely die within two years. There was no choice, the doctor told
her, and there was no time to think about it.

She reacted with fury to the thought of having her breast
amputated. "How would you like it if I cut your testicles off?" she
lashed out at the doctor.

She sought another opinion, and another, and another; some of
the top breast cancer surgeons in Ottawa, Montreal and Toronto.
They all said immediate surgery was necessary, though no one
was able to guarantee that even by removing the breast Ms.
Pypops would have better than an 80-per-cent chance of survival.

She channelled her anger by buying every book on breast cancer
that she could find. She studied her illness ("It was like doing
another Master's degree," she said), she meditated, she asked God
what she should do.

"The more I read, the more I realized that nobody really knew what to do with cancer." When she thought of conventional treatment, surgery, chemotherapy and radiation, she only saw death.

She came to realize that her cancerous tumour was very much a part of her. She couldn't believe that to help herself she had to destroy part of herself, through amputation.

So she chose to help her body heal itself.

And Bill O'Neill was one of the people who helped her make that choice.

"Bill allows me to ask questions, and helps me to find answers," Ms. Pypops says. He helped her make sense of the "jungle of information" that she needed to digest in her search.

Initially, she thought she was hiring a researcher, but over the weeks and many phone calls, he became part social worker and part therapist as well. Ms. Pypops wasn't sure if she was comfortable with this at first, but Mr. O'Neill explained that he refused to work in a paradigm that sets up limits in a patient's treatment.

"Cancer consumes your whole life," he told her, and she knew he was right.

"He treated me as an intelligent being, not simply as another cancer patient, as a victim," Ms. Pypops said. He didn't pretend to have all the answers.

There were times that the doctors' insistence on surgery made her question her sanity. Was she killing herself by refusing to take their prescribed route? Many of her friends and other women with breast cancer called her crazy for not cutting the cancer out. The doctors wanted nothing to do with her, as a patient as long as she refused surgery.

She fought depression and self-doubt, and emerged determined to give her body a chance to defeat the enemy within. This meant a regimen of natural therapy (called Gerson therapy) that some people consider pure quackery, and others see as nature's way of healing.

Shark's cartilage. Coffee enemas, four times a day. Ten glasses of organic carrot juice a day. Essiac tea. Acupuncture. A careful diet of only organic foods. Herbal supplements that her mother and grandmother used to take. Three months of cancer vaccine therapy from Georgia.

Ms. Pypops believes she is better now. Her energy level, since starting therapy, is way up. To the touch, her tumour appears to
have stopped growing. And blood and cell tests suggest good news. "If the doctors are right, I should be dead by April. But I'm not on that road, the way I feel."

But she can't know for sure how her cancer is doing unless she gets an MRI test, the least invasive and most precise diagnostic tool for cancer so far built. The problem is that her current doctor recently refused to put her on the MRI waiting list because, according to Ms. Pypops, he didn't think taxpayers should pay for the test as long as she was following unorthodox therapy and not considering surgery.

Ms. Pypops is outraged and has sent letters to the doctor and to the CEO of the Ottawa Hospital demanding an MRI. She says taxpayers should be reminded of how much money she has saved them by not having surgery, chemotherapy and radiation since being diagnosed.

"The money issue is only an excuse anyway," she says. "It all comes down to a question of power." And Ms. Pypops is convinced that as long as she and Mr. O'Neill challenge doctors' beliefs about how her cancer should be treated, the power struggle will continue.

**Calvin Johnson, 62, Plantagenet**

Perhaps deep inside there rages a fiery anger at the injustice dealt them. Perhaps in their darkest hours, alone and unseen, they cry with anguish at the pain -- physical, emotional and financial -- that they feel.

But in the face of the monster, Sandra and Calvin Johnson hold themselves with quiet strength. On the surface, they endure it all with superhuman dignity. It is, simply, the way they are.

Calvin Johnson has been told that he is dying of cancer. It all began when Sandra noticed a small dark spot on Calvin's back in June 1994. Three years, three operations and several removed nodes later, doctors were very pessimistic about his survival. It was decision time.

The Johnsons are not the kind of people who would, under normal circumstances, be open to a different, alternative way of healing. Calvin is a meat-and-potatoes man, a man of few words who drives disabled children to school. He is most in his element when working outside, clearing trees and building a septic system on his retirement property. Sandra has been a nurse for 33 years, since she was 20, and is as conventional as it gets in terms of medical values. Going against those beliefs represented a deep conflict for her.

But "desperate people do desperate things," Sandra says. "You keep looking for an answer. The mainstream medical community didn't have an answer. When the mainstream says they don't have much to offer, that's when you start looking elsewhere."
Sandra heard about Bill O'Neill from a social worker friend.

The Johnsons worried that this guy was in business to take advantage of them. But Mr. O'Neill allayed their fears. "He didn't pretend he had the cure. He left the choices up to us." While Calvin and Sandra felt as if the doctors had closed the door, Mr. O'Neill was willing to leave it open, just a crack.

In times of crisis, Sandra called. He referred Calvin to some of the best melanoma oncologists. He suggested radiation when the tumour sprouted. "He has a way of calming you down," Sandra explains, as Calvin nods in accord. "He gave us a plan. He sets out steps for you to do, you do them, and in the process you calm down. Before, you just panicked."

Rather than do everything for his patients, Mr. O'Neill aims to help them help themselves. "He tries to harness your own energies, your own optimism, and helps you to use your own mind to project yourself forward," Sandra says.

Despite everything that Mr. O'Neill offers the Johnsons, theirs is not a story of a miraculous cure. Calvin is sick.

After the third surgery, around November 1997, he travelled to Baton Rouge and started on three trials of a personal cancer vaccine offered by Immunocomp Laboratory, now based in Georgia. The vaccine did not appear to help. In January of this year, the tumour mushroomed under his arm. It is now the size of a snowball, bulging out from under Calvin's right armpit, a lymph node stretching the skin in a teepee-like point nearby.

Perhaps to the surprise of their critics, Mr. O'Neill and Immunocomp both suggested that radiation, a very conventional treatment, may help shrink the tumour. Five days a week, for 33 days, Calvin submitted himself to electromagnetic rays that burned his skin, made him nauseous, weakened and tired him.

Doctors now tell the Johnsons that the tumour is inoperable; there is no way to get it all. But Calvin has visited a doctor at the John Wayne Cancer Institute in Santa Monica, California, and is considering having the surgery done there -- if the cancer hasn't already spread. In the meantime, he has tried changing his diet, taking vitamins and rubbing flax seed oil to soothe the burns caused by radiation.

Now, Calvin is undergoing extreme doses of chemotherapy and, along with the cancer, which appears to be growing, it is sucking every remaining bit of strength out of him.

The Johnsons aren't certain they've chosen the right path for Calvin's treatment. They are confused, because nothing seems to be working. "I really don't know what to think, to be honest," Calvin says. "I guess we've done what we thought was best, and just kept on hoping."
In the process, the couple has watched their retirement savings disappear. For the vaccine trials and the trips south, they spent more than $10,000. They are helping to put two daughters through university. Calvin and Sandra have had to dip into their RRSPs to help pay the bills, and wonder whether their retirement home will ever be built. Wonderful friends, to whom the Johnsons will always be indebted, helped out by holding a fundraising dance for them.

"You save for your whole life for retirement, and suddenly, boom, boom, boom, it's gone," Sandra says.

Calvin shakes his head and wonders why the treatments he is seeking are not covered by Canadian medicare, especially given all the money in the field of cancer care and research. And why are certain treatments available in the U.S. but not in Canada, he asks.

As for Mr. O'Neill, well, Sandra worried that the cost of his services would be astronomical.

Everything in life is negotiable, Mr. O'Neill told her.

"That's the way it is with Bill," Calvin says quietly.

"He's a beam of light," Sandra adds, "in a whole bunch of darkness."

**Paul Mahar, 58, Montreal**

"Desperation," Paul Mahar explains, echoing Sandra Johnson's words, "makes you do some strange things."

Paul's desperation was born in 1991, when he was diagnosed with melanoma, cancer of the skin. An operation to remove the growth temporarily allayed Paul's fears, though, and he was "fine" for three years. Doctors told him he was cured.

But the cancer spent that time secretly invading his tissue, setting up camp in his lymph nodes. In 1994, a doctor at the Ottawa Civic Hospital sliced 27 lymph nodes from Paul's body.

He was advised by doctors to retire from his job and to "get all my affairs in order." He understood that he had only a few months to live. This is the time, as Bill O'Neill likes to say, that patients are told to "cancel your magazine subscriptions and don't buy green bananas."

Desperation, and the strange things that accompany it, set in. But it was not easy for Paul to follow a path so foreign to him.

The 58-year-old always considered himself to be a "right-wing, conservative guy." He was a buttoned-down director of marketing for a Dallas-based high-tech company, handling mostly
government sales during his five years in Ottawa. So it was natural for him to trust the conventional medical system. He considered many alternative therapies to be "obscure."

But he felt like he had exhausted his options. Doctors at the Civic and the Montreal doctors who treated former Quebec premier Robert Bourassa "offered me nothing" after the surgery, except "ruthless" chemotherapy.

Paul liked, and trusted, Mr. O'Neill the minute he met him. "He knows more about cancer than all the doctors I've ever met."

His desperation has led him to spend about $80,000 of his own money during the past four years, seeking an experimental cancer vaccine in California. With the help of Manotick naturopath Gerhard Schmidt, Paul has also reformed his diet and created a menu of vitamins and natural substances designed to strengthen his immune system.

How does he know that the people selling him hope aren't merely charlatans? Paul says he met several people who were surviving while on the treatments. And he feels really good, even cancer-free, right now. "There's no quackery here."

He admits the surgery may have been the reason for his turnaround, but "how can you know?" He already had one recurrence after the first surgery, and it was way too much of a risk to do nothing, Paul said.

"If you have cancer," he said. "knowledge becomes your best friend, and ignorance is your enemy."

Bill O'Neill provided Paul Mahar with enough knowledge to defeat his enemy. "I think Bill sells hope and encouragement. It's a large part of the healing process."

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