Cancer in kids is being beaten, but at a price

BY ROBERTA STALEY

Vikram Bubber doesn't feel anger over the side effects of chemotherapy and radiation in childhood. Alistair Eagle photo.

It's one of those universal ironies. Those who have the greatest reason to be angry are often the most uncomplaining, as if their tribulations have given them a unique ability to prevent regret from interfering with the joy of being alive.

Vikram Bubber, 29, of Surrey is like that: indefatigably cheerful and matter-of-fact about the effects that a cancerous tumour in childhood wrought in his life. An embryonic rhabdomyosarcoma, located in the middle ear on the right side of Bubber's head, was diagnosed in 1984 while he was living in Regina. Thus began two years of radiation and chemotherapy treatment to prevent the tumour from spreading to his brain and other organs. The chemotherapy was administered intravenously, the radiation via a machine that beamed high-energy waves at Bubber's head. Medical staff at Regina's Allan Blair Cancer Centre made Bubber a plastic mask covering half his face that helped stabilize his head for the 30-minute treatments as he lay on a cold steel table while invisible particles streaked into his five-year-old skull. It looked, he recalls, like the one worn by the Phantom of the Opera.

Bubber is alive today, proof of the effectiveness of the treatment. Nonetheless, the side effects of chemotherapy and radiation have been insidious and long-lasting, starting with a loss of hair that grew back, he says, "like baby hair". The treatment also appeared to have aged him: he was mistaken for a 40-year-old when he was 17 and he has profound hearing loss in the right ear and partial loss in the left.

Then, two years ago, Bubber noticed a bump on his right cheek—small but solid. He immediately suspected cancer, and his suspicions were confirmed by an oncologist. An osteosarcoma, or bone tumour, caused by the radiation he received as a child, had developed. He underwent surgery to remove the cancerous growth from his cheekbone and a chunk of his leg bone was grafted into the gaping space. A screw tightened the graft into the jaw. Now Bubber can open his mouth less than one centimetre; simple pleasures like chomping into a hamburger are but a memory. Despite an injection of fat, taken from the belly area, to make his facial contours more natural, there is still an indentation. The nerves on the right side of Bubber's face are also damaged, and, he says, it looks "as if I had a stroke".

Bubber has big, kind brown eyes and an engaging, loquacious personality. Young women like him and consider him a confidant. But they don't date him, he admits, and he wonders about his fate as a husband and partner, especially as the treatment he received also made him infertile. "I have never felt anger or asked, 'Why me?' I thought that there must be a reason," Bubber says.

Childhood cancer is being beaten, if you look strictly at the figures. *Canadian Cancer Statistics 2008*, released earlier this year by the Canadian Cancer Society, British Columbia and Yukon, shows that about 82 percent of children diagnosed with cancer today will survive the disease. However, the study reveals, two-thirds will have at least one "chronic or late-occurring health effect from their cancer treatment".

Although only about 130 children a year in British Columbia are diagnosed with cancer, improved survival rates mean that there are from 2,000 to 3,000 people alive today in the province who have prevailed over the grim disease, according to Sheila Pritchard, an oncologist at B.C. Children's Hospital who heads its long-term follow-up clinic. Of these, 25 percent have "severe long-term effects", Pritchard says.

These include severe cognitive impairment, congestive heart failure from anthracycline drug treatment, infertility, and stunted growth. Secondary cancers like leukemia or tumours, as in Bubber's case, can also result. Children with leukemia who were treated in the 1960s to 1980s are at risk for nonmalignant brain tumours, Pritchard says. And teenage girls with Hodgkin's lymphoma who have their chests irradiated have a 25-percent chance of developing breast cancer within 20 years of the treatment, she adds.

Improved survival rates are something for society to celebrate. But medicine's triumph is a sword of Damocles. The ancient parable speaks of Dionysius, a Greek ruler of enormous wealth and power who dined underneath a sharpened sword that hung from the ceiling by a single horsehair. For those families whose youngsters are in remission, the sense of impending doom never really goes away; the child's future health will always hang by a thread.

Port Coquitlam's Livian Smith was a 20-year-old single parent when her blond, blue-eyed three-year-old son Brett began stumbling into walls. Within four months, Brett went from rambunctious, cheery, and talkative to whiny, grinding his teeth, and refusing to eat anything but cereal. Doctors diagnosed a rapidly growing medulloblastoma on the brain stem, which was causing pressure on Brett's optic nerve. The next day, December 1, 1993, Brett underwent a five-and-a-half-hour surgery to remove the tumour. "My little boy came out of the surgery a totally different child," Smith says.

After the surgery, Brett received 30 doses of radiation, 17 of them focused strictly on the area of the tumour and another 13 along the spine and head. That was followed by chemotherapy—one year of treatment, in total. The immediate aftereffects, hair loss and vomiting to the point of skeletal malnourishment, are considered a normal reaction to such invasive treatment. But as Brett grew, further side effects emerged, including problems at school and physical deformities.

Now 17, Brett stands just under 5-1, although the males in his family are six feet tall or more. The radiation stunted the growth of his spine, curving his shoulders and making his legs and arms look out of proportion. The growth of the top of his skull was also stunted, making his jaw look unusually large. The pituitary gland was damaged by the radiation and Brett will be on human growth hormone for the rest of his life. His thyroid gland, which regulates body metabolism, was damaged and he is on Synthroid therapy permanently. At 105 pounds, Brett is almost waiflike, due in large part to a lack of appetite: Smith says the radiation damaged his taste buds and he complains that food tastes metallic.

Initially, Brett lost the hearing in both ears due to the chemotherapy drug cisplatin. He has regained some hearing in his right ear, thanks to a hearing aid. He has also had several operations to try to reduce the scar tissue in his ears caused by the radiation. He is blind in his left eye. His IQ is less than 70 and he has short-term-memory loss and reduced fine motor skills. Brett has required educational support all through school. He graduated this past June from Pinetree secondary school in Coquitlam and is enrolled in the transition program at Douglas College, which will help him make a choice between entering the work force and continuing in the adult-special-education program. Brett has already completed two five-week work-experience placements in a kindergarten class as a teacher's helper and is "really enjoying it", Smith says.

"At the time," she muses, "I never questioned the doctors, but I questioned it years later when I began doing research on the Internet. Now they don't even radiate children until they are four years old because it is so damaging."

Smith is optimistic that one day Brett will be able to live on his own with some support. She feels blessed that Brett is still alive—that he is a happy young college student with friends. Yet she cannot help grieving for what could have been. "I think about the lost potential—I think about it nearly every day," says Smith, a mortgage broker with a dynamic, healthy, two-year-old daughter named Brooke. "There has to be something else out there to cure this."

IT WAS THE ANCIENT Egyptians who first left records on papyrus in 1600 BC detailing attempts to cure breast cancer with a cauterization tool called the "fire drill". The treatment, the Egyptians wrote, was unsuccessful. In the West, cancer treatment grew out of a wartime discovery that nitrogen mustard, used in chemical warfare, suppressed some tumours. But the first effective chemotherapy drugs, called antifolates, that actually induced remission in children with leukemia, or blood cancer, were discovered in 1948.

During the following decades, however, new drugs did little to stem the high death rates among children with cancer. When children began to survive five years and beyond during the 1970s and 1980s, parents were grateful and thankful. Side effects, Pritchard says, were considered the "price to pay for a cure".

Now, she says, the oncology fraternity regards optimum long-term quality of life as being as important as saving a child's life. "It is not a case where the public has to rise up and demand better treatment—that is happening already; that's what everybody's focus is."

There are some health-care practitioners, however, who repudiate radiation and chemotherapy for cancer treatment. Simply put, chemotherapy and radiation are poisons that kill off cancer cells, which are normal body cells that, for reasons unknown, multiply out of control. However, healthy cells become collateral damage in the chemotherapy and radiation blitzkrieg.

For someone like traditional Chinese medicine physician Henry Lu, killing healthy cells along with the rogue cells is a counterintuitive way to treat cancer. Lu, who is CEO of the International College of Traditional Chinese Medicine of Vancouver, considers the use of chemotherapy and radiation on children a form of "brutality. We describe it as using a hammer to kill a fly."

Western oncology treatments work by attacking the cells in the body; traditional Chinese medicine (TCM) claims to administer herbs that will strengthen the patient and transform the cancer cells back into normal cells, according to case studies provided by Lu. This more benign type of treatment is especially important for the elderly and children, whom Lu considers constitutionally "weak".

TCM is a 3,000-year-old system of health care with about 6,000 medicinal substances developed to "cure diseases and promote happiness". It is based on the idea that a healthy body is a balance of yin and yang, representing, respectively, cold and hot energies within the body. Illness is regarded as an imbalance of yin and yang, caused by many things, including emotions.

Lu acknowledges that western medical advances like surgery, which is not practised in TCM, and the discovery of prophylactics like vaccines have profoundly improved human health. Although TCM and conventional western medicine are fundamentally different in philosophy, Lu does not consider them to be antithetical. Rather, Lu says, these two systems of knowledge should be regarded as complementary: partners in the quest to achieve optimum health in patients. For example, people who are very ill with cancer could have their strength boosted with TCM herbal remedies or acupuncture to help them better tolerate surgery. Lu says, though, that "cooperation between TCM and western medicine is zero. We have a long way to go yet."

The problem with TCM is the problem that western scientists have with many alternative forms of medicine: they have not been subjected to the rigorous testing developed during the 500-year evolution of the scientific method, which rests upon the pillars of rationalism, observation, and hypothesis.

But Pritchard agrees that non-western protocols have a role to play in medicine. She gives a nod to Chinese medical researchers who, several years ago, discovered that arsenic is a "very effective treatment against a particular type of leukemia. It is now part of our treatment for that particular type of rare leukemia."

However, TCM's herbs, medicines, and methods must be held to the same standards of laboratory testing as new drugs in the West are. "It's important that TCM isn't taken at face value," Pritchard says. "Many of these alternative medicines can cause as many long-term side effects as chemotherapy."

WHEN CHILDREN WITH cancer survive against extraordinary odds, as 10-year-old Brendan Whieldon has, the question becomes: what allowed them to beat the bookie? Six years ago this past September, just as he was about to enter kindergarten, Brendan, a lean little athlete who loved skiing and swimming, was diagnosed with an N-myc amplified stage IV neuroblastoma. Only five percent of those diagnosed with this extremely aggressive form of cancer survive beyond eight months, says Brendan's mom, Shannon Whieldon, a nurse at Langley Memorial Hospital.

The neuroblastoma sets down roots in the bone marrow, which produces the body's red and white blood cells and blood platelets. The bone marrow also produces stem cells, which grow into any of the body's 200 cell types and are key to regenerating tissue.

By June 2003, after intensive chemotherapy and radiation therapy as well as a bone-marrow transplant, the doctors' prognosis was grim: Brendan would die by year's end. Whieldon refused to accept the news. "I asked Brendan, 'What can you do to get this out of your bone marrow?' And Brendan said, 'Mom, I can fling it out of my bone marrow through karate.'"

One of Whieldon's friends practised karate, and she asked him to ask his *sensei* (teacher) for permission to bring Brendan to the dojo (martial-arts school). After Brendan's next radiation treatment, Whieldon scooped him up in her arms, snuggled him into the car, and drove to the Valley Shidokan Karate Club in Chilliwack. "I carried Brendan into the sensei's dojo; I think he was terrified to meet us. Brendan couldn't walk. The sensei looked at him and picked him up and carried him away. And I just stood there wondering and looking around. And he brought Brendan back in a karate outfit and then explained to him that karate is about what is on the inside, and you have to have a good strong character. And he taught him the punches and said to Brendan that he wanted him to come back that afternoon for another class. And Brendan walked out of the dojo."

Karate became an emotional, psychological, and physiological buttress for Brendan, giving him the mental toughness to endure the cancer and the treatments. "The philosophy is," Whieldon says, "you have to heal yourself from the inside and show no pain. You train when you are weakest, because that is when the enemy will attack you."

When Brendan's hemoglobin was low, indicating depleted red blood cells, Whieldon would still send him,

see page 7

Cancer in kids

from page 5

"white as a ghost", to karate class. "He sleeps on the way home, and when he wakes up, his face is pink. The exercise forced his body to make blood." By doing this, Brendan has avoided hundreds of blood transfusions, Whieldon says.

Brendan has had eight serious relapses—"the disease is smart and evolves itself genetically, which is why medication can't do its job"—and there have been days when Whieldon didn't know if her son with the large grey-blue eyes "would live or die".

The chemotherapy, radiation, and bone-marrow transplants have kept the disease in check, but they have also pushed his body to the brink, causing a litany of side effects, from high-frequency-hearing loss to frail bones that fracture easily. As a nurse, Whieldon has been better able than some parents to access information about natural alternatives to help alleviate the treatment's insidious side effects. Rather than have Brendan on antinausea drugs, she has a collection of quality perfumes for him to inhale to make him feel better. Neuroblastoma cells replicate best in heat, so when Brendan is relapsing, Whieldon cools his body using cold plasters and peppermint lotion. She uses therapeutic touch, visualization, multivitamins, calcium, magnesium, vitamin D supplements, the pain killer belladonna, lots of rest, and high-caloric and highly nutritious food. The strength of many of these things, she admits, lies in their placebo effect. And, she adds, although nurturing, they cannot replace the disease-fighting power of chemotherapy and radiation.

Nonetheless, Whieldon has insisted upon a gradual reduction of Brendan's chemotherapy. "They always want to up, up, up it." She has also taken him home following chemotherapy treatment, against medical advice. But each year "we make huge progress. Each time, the duration of the relapse is shorter and fewer drugs are used. Brendan's immune system needs to evolve; it is Brendan's own body that will cure this."

Traditional Chinese medicine physician Henry Lu believes that herbal remedies can complement western cancer treatments.

At B.C. Children's Hospital, Shahrad Rod Rassekh, a 34-year-old pediatric oncologist, loves working with families, marvelling as his young patients, tubes and needles sprouting from body parts, whiz around the ward on tricycles, gleefully oblivious to their illness.

There is, Rassekh says, nothing worse than having to break the news to parents that their child has cancer, then double alarm and distress by listing all the possible short- and long-term side effects of the treatment. Rassekh was the primary investigator on a preliminary study looking at the role that genes play in the development of side effects. Dryly titled *Pharmacogenetics of Adverse Drug Events in Pediatric Oncology*—pharmacogenetics being the study of how genes influence an individual's response to drugs—it focused on cisplatin-induced hearing loss and anthracycline-induced cardiac failure. He says that the improved cancer-survival rate for children, due to increased dosing and chemotherapy-and-radiation combinations, has come at the price of toxicity. "On many chemotherapy protocols, children die due to treatment toxicity and not the underlying disease," Rassekh writes in the study. "In children, adverse reactions to cancer drugs are expecially severe. A striking failure of modern medicine is the debilitating and lethal consequences of adverse drug reactions."

Children are especially susceptible to adverse drug reactions (not just related to cancer treatment), which rank as one of the leading causes of child death and illness in the United States, claiming 100,000 to 218,000 lives and costing US$30 billion to $130 billion each year, according to a 2001 article in the *Journal of the American Pharmacists Association*. In Canada, Rassekh continues, an estimated 2,500 to 5,400 children die each year from adverse drug reactions. These deaths are not limited to pediatric oncology, "although the drugs used in oncology are some of the most dangerous medications given to children".

Some children, however, Rassekh says, have no adverse reactions to chemotherapy drugs. He theorizes that there are genetic differences in key enzymes involved in drug metabolism. The ultimate objective is to identify genetic biomarkers predicting adverse reactions. In the future, Rassekh says, patients' DNA will be mapped to determine if their genes make them more susceptible to adverse reactions and side effects. This will allow oncologists to determine drug regimens that fit the genetic makeup of each patient. "This is a high priority for us, because the side effects are so devastating."

Such research, although holding much promise, is still at the preliminary stage. Many parents, Rassekh says, are looking to alternative therapies to try to support their children's health during and after treatment. Rassekh happily discusses complementary medicines with the parents of his young patients, and that open-minded attitude is permeating upward into the large umbrella organizations that control the cancer purse strings in this country. The Canadian Cancer Society has given $2.1 million for research into complementary and alternative medicine. With studies showing that about 50 percent of cancer patients use such treatments (with or without a doctor's blessing), it is commonsensible that the medical fraternity discover how oncology drugs interact with alternative remedies. The society also funds a 12-member team of practitioners and scientists at the University of Waterloo who are doing research in this area.

As well, groundbreaking research is being conducted in British Columbia under the direction of Mary McBride, a senior epidemiologist with the cancer-control research program at the B.C. Cancer Agency. McBride has been given a $3-million grant for a five-year study of relevant issues, including education and hospitalization risks. She is also investigating individuals' ability to fit into society following treatment. Do they find spouses? Can they find jobs? How much money do they make? As well, the long-term costs to the health-care system will be assessed, McBride says. The findings will be presented to policymakers and medical-care providers, such as family doctors, to ensure that they are all aware of the specialized care and tests required by childhood-cancer survivors throughout their lives.

Given that childhood-cancer survivors endure an extraordinarily rough start in life, it behooves us to acknowledge their continuing struggle as adults. More importantly, perhaps, childhood cancer also challenges the medical fraternity to come up with more creative ways of dealing with this disease while its victims are undergoing treatment. As the western world becomes more open to the wisdom of other protocols, the opportunity is there for conventional medicine to become more nurturing—yet still powerful—as it deals with the destructiveness of cancer.