

Your kid has cancer. You're broke. Now what?

Along with everything else, families of kids with cancer face financial hardship. Now a fund to help them is in danger too

BY LISA PRIEST

Linda Bernier remortgaged her home, put everything on credit cards and at one point, lost her job after her daughter was diagnosed with a form of childhood cancer.

"There was always the risk that we could lose her at any time," Ms. Bernier says of her daughter; Kim Oswick, who was diagnosed with a form of leukemia at the age of 8. "And to have the financial burden on top of that is really incredible."

What Ms. Bernier didn't realize until shortly after: her daughter was diagnosed were the hidden costs of childhood-cancer treatment: They included accommodation and meals for out-of-town treatment, not to mention hospital parking and costly medications that weren't covered. For others, it also can include babysitting costs for siblings.

Ms. Bernier drew on the Pediatric Oncology Financial Assistance Program, which is run by the Pediatric Oncology Group of Ontario, a group founded by childhood-cancer doctors.

She drew \$2,000 to \$3,000 from the program fund to offset food and accommodation costs.

The fund provides money to 1,200 patients annually whose children are being treated for cancer in Ontario hospitals, half of the fund is used for those whose kids are treated at Toronto's Hospital for Sick Children.

But its funding agreement with the Canadian Cancer Society, which funds \$180,000 of it annually, ends in March, 2006.

The Ontario Ministry allowed the Pediatric Oncology Group of Ontario to spend \$320,000 it had in unused funds each year for the past two years for the program, but this money is also coming to an end.

If one thing is certain, it is this: Despite a universal health-care system, the hidden costs of childhood cancer are estimated to consume at least one-third of the average family's after-tax income. The Berniers estimate it cost \$65,000 in lost income, parking and medications.

In Ontario alone, the hidden costs linked with childhood cancer are pegged at \$10-million annually, according to Dr Ronald Barr, who did a study on the subject.

"There is a big burden on the families of newly diagnosed children with cancer, despite our much-vaunted health-care system," says Dr. Barr, who also is president of the Pediatric Oncology Group of Ontario's board. "These families face big challenges in employment, added travel costs and the costs of caring for kids with additional needs."

Faced with treatments that can last as long as 2½ years, many mothers take leaves from their jobs to care for the sick child. Others aren't as fortunate; Ms. Bernier lost her job as an office manager at an Ottawa company.

She eventually landed another job in another company that allowed her to take time off when her daughter received lengthy treatment for acute lymphoblastic leukemia, a cancer of the white blood cells, which normally fight infections. That treatment lasted 2½ years or until April 2003, then Kim relapsed in November of the same year, precipitating another round of chemotherapy.

Last summer, Kim underwent a bone-marrow transplant that necessitated a nine week admission to the Hospital for Sick Children. Almost one year later, Kim is 13 and healthy having recovered from the disease.

For Ms. Bernier's family of four, which includes another daughter, Shauna, and husband, Rick Oswick, it meant squeezing every penny. Their friends and family chipping in as well as the program fund all helped to offset some costs.

While the fund doesn't come anywhere close to reimbursing parents for their real costs, it does ease some of their financial pain: It funds up to 160 hours of babysitting, \$10 a day for parents meals when the child is in the hospital, and \$5 a day if the child is an outpatient.

As well, it pays the \$20 a day for Ronald McDonald House, which heavily subsidizes accommodation for parents who travel with their children for out-of-town cancer treatment.

Bill Frid, the Pediatric Oncology Family Assistance Program's administrator, says he has been given no indication the program will receive any money from the cancer society after March, 2006, which means that the \$500,000 a year has to be raised through the community. And so there has been a sailing regatta, a gala and a barbecue to raise funds.

"The easiest fix we can give to parents is money," Mr. Frid says. "We're not making anybody rich."

Dave Doig, Canadian Cancer Society's senior manager for community services, says the society is not ending the program but is working to ensure that it is continued in some way after March, 2006 adding that "we need to discuss if we're going to continue a partnership and evaluate whether this was the best to administer the money."

The society, he stresses, is still committed to assisting families whose children have cancer.

Whatever the case, Mark Greenberg, Medical director for the Pediatric Oncology Group of Ontario, says fund raising efforts are going well, though he says they are only "scratching the surface" to help offset some of the costs these families face.

"We'd sure like to do better than we're doing," Dr. Greenberg says, "The amount we're able to give each family is a token."

Claire O'Halloran, a Hamilton-based community cancer nurse with Interlink, says the disease often strikes young children whose young parents are just starting out in life. Many have mortgage and car payments to make.

"They don't even have a bit of a nest egg," Ms. O'Halloran; says "Some parents have to leave work because the demand of treatment. Who can afford a cut in pay like that?"

Jill Daugherty, 34, was in graduate school and working as a geological engineer in Kingston when the youngest of her two children developed a brain tumor at the age of 2½. Her husband, Brian, works as a chef for the military.

"He got sick very, very quickly over the course of a day," Ms. Daugherty says of her son, Eric, who had emergency surgery in Kingston, followed by a year of chemotherapy.

"It's unbelievable how all the costs add up, You don't think of the meals you eat out, toothbrushes you have to buy:

She estimates that she spent thousands on babysitting costs alone.

And she may be shelling out again when her son finds a match for a bone-marrow transplant, which will necessitate a lengthy treatment in Toronto's Sick Kids.

Ms. Bernier and her family says the fund allowed her to keep her home.

"Our house is falling apart. but at least we still have one. We are one of the fortunate ones: