



# KIDS AND CANCER



Second in a four-part series sponsored by Rogers, Canadian Cancer Society, Caldwell Investment Management Ltd. and POGO partners

## Whole family affected by child's cancer

For Leanne La Rocca, the next 12 months will be the longest year in her life, she says.

That is how long it will be before doctors at Hamilton's McMaster Children's Hospital can say whether her four-year-old son Mitchell Frydrych is free and clear of the leukemia that suddenly gripped him last November.

"He is in remission now and gets treatment about once a week, but it will take another year before we know anything for sure," says the 36-year-old hairstylist.

One thing she does know for certain, however, is that the experience of having your toddler stricken by leukemia, as terrible as it was, could have been worse.

"I am so grateful to all the staff at McMaster and to groups like POGO (the

ment and then there is support, support for the child and family during that treatment stage and support after treatment is concluded."

Support, she adds, can range from providing per diem subsidies for meals and accommodation for a parent while the child is in hospital, to advice from dietitians, pharmacists and social workers and arranging for local groups such as Super Sibs to help relieve the emotional burdens on brothers and sisters.

"The whole family is impacted when a child develops cancer," says Jane Cassano, a social worker at McMaster Children's Hospital. "We try to address every issue we can identify and ease the burden."

In Ms. La Rocca's case, support from Ontario's childhood cancer system included subsidies from POGO's financial assistance program. When Mitchell was treated on an outpatient basis, the daily meal subsidy was \$5. The Canadian Cancer Society is a significant contributor to this financial assistance program.

"Like many young couples we have a big mortgage. We had to cash in RRSPs and savings as well," Ms. La Rocca says. "At one point, Mitchell was in hospital 32 days straight. The cost could have resulted in us losing our home without those subsidies."

The team at McMaster also arranged for Joey to receive letters of support and regular encouragement.

"It has been hard on him because all the attention has been focused on Mitch," Ms. La Rocca says.

"Getting little gifts and encouragement has made a difference, we think."

Ms. La Rocca and Mr. Frydrych know that Mitchell's support and relationship with POGO will not abruptly end once he is pronounced cured. The effects of chemotherapy on a developing body and the psychological impact of such intensive treatment may result in long-term problems with cognitive learning, fertility, heart and other organ diseases.

Through the POGO network of survivor clinics, young Mitchell's progress will be tracked for the rest of his life, learning from his own experience, adjusting or developing new therapies based on them and simply being there as a resource to help resolve any problems that do appear.

"Knowing that a group like POGO will always be there for him is a real comfort," Ms. La Rocca says. "I just don't know what families did before it came along."

**'KNOWING THAT A GROUP LIKE POGO WILL ALWAYS BE THERE FOR HIM IS A REAL COMFORT'**

Pediatric Oncology Group of Ontario," she says. "They have provided not just wonderful care to Mitchell but have been there to give us all financial and emotional support when we most needed it."

Ms. La Rocca, her husband William Frydrych, their seven-year-old son Joey and Mitchell may be typical of families that are going through the agonizing process of dealing with childhood cancer, says Dr. Lillian Sung, pediatric oncologist at Toronto's Hospital for Sick Children.

"There are two distinct parts to what we do," she says. "First there is treat-

## NEXT WEEK

### AFTER THE CANCER TREATMENT

- The realities of life after cancer, for survivors and families
- POGO's partners — the people and groups who provide medical, community and financial support
- Expanding the boundaries for effective treatment

## We fight childhood cancers.

This gold daffodil represents the fight against childhood cancers.

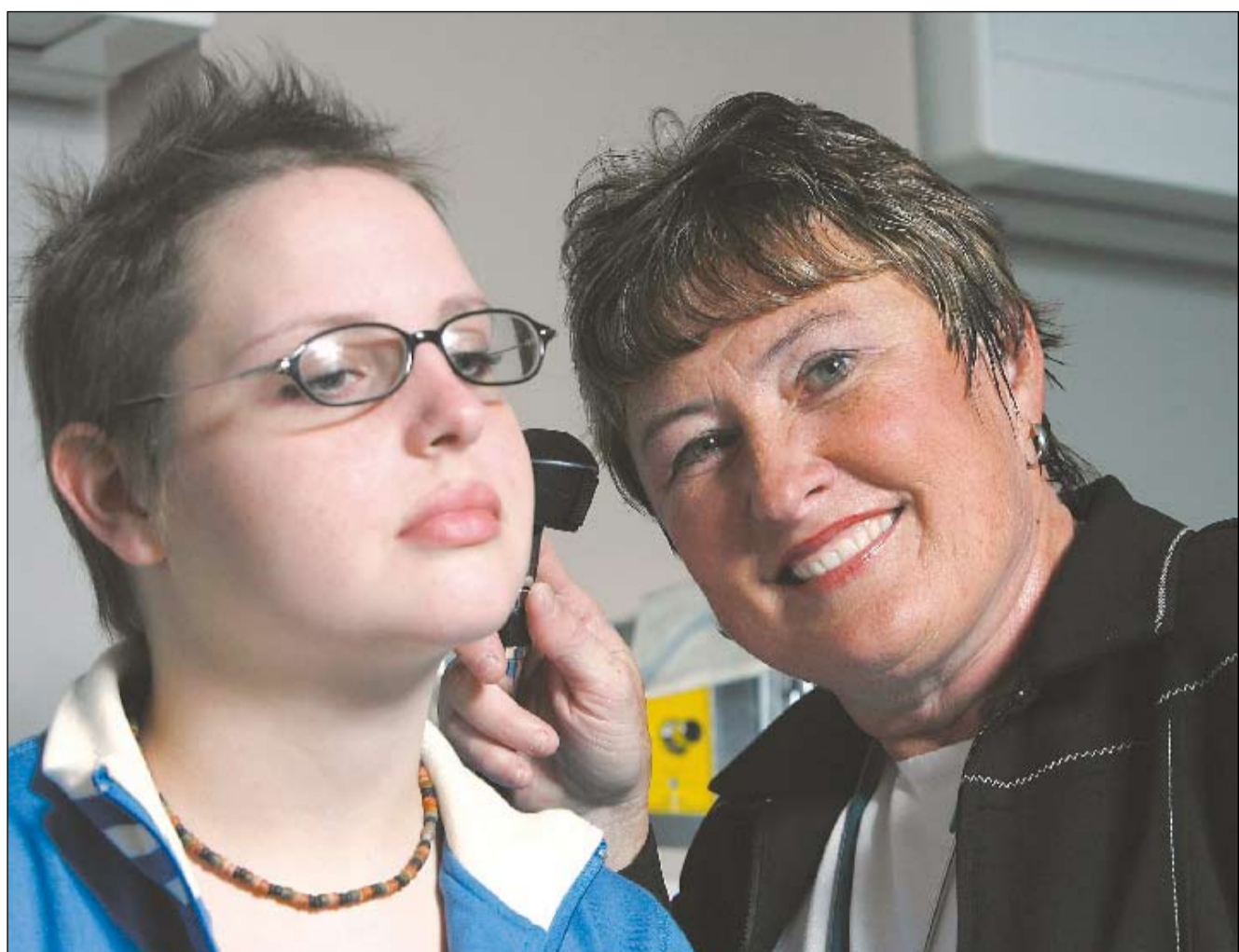
In the past decade, the Canadian Cancer Society has funded \$20 million for childhood cancer research nationally.

For almost two decades, your donations have contributed more than \$5 million to Ontario's Camp Trillium for children with cancer.

And since 2003, donations to the Pediatric Oncology Group of Ontario have exceeded \$1 million to help ease the burden of cancer for children and their families.

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Nurse specialist Anne Chambers examines Kait Bida, 16, at Children's Hospital of Western Ontario in London.

## EXPERTS FIND RELIEF IN HELPING THE YOUNG

At Toronto's Hospital for Sick Children, Dr. Sheila Weitzman, Associate Director of the division that treats children with cancer, goes to work each day knowing the huge difference that dedicated teams such as hers have made in the lives of her small patients and their families.

At the Children's Hospital of Western Ontario, Advanced Practice Nurse Anne Chambers shares that same sense of satisfaction and accomplishment. She has spent the last 22 years of her life delivering top-notch care to very sick children.

"We have made amazing advances," says Dr. Weitzman. "In 1963, the survival rate for children with ALL, one of the most common forms of childhood leukemia, was just 3%. Today, it is nudging above 79%, with the prospect of even further improvements."

In the 1970s, research found the use of multiple drugs in the chemotherapy process greatly enhanced results, and survival rates climbed dramatically. Ongoing clinical trials involving Ontario's five pediatric cancer centres continue to make a difference, she says. The results may yield a small improvement or a large one. The point is the campaign continues, with determination and great hope for success.

Pediatric cancers are unique, medical science knows. The most common is leukemia, which affects about 33% of the 400 new patients diagnosed in Ontario each year. Second is brain tumors, which account for about 25% of new cases.

Treatment is immediate and aggressive because cancers in children move quickly. For leukemia, chemotherapy — administered intravenously or in pill form — is the most common and successful. The chemicals attack the cancers in the bloodstream. They also produce devastating side effects, such as hair loss, nausea, vomiting and sometimes infections.

Brain tumors are most often surgically removed and the surrounding tissues treated with radiation to kill remaining microscopic cancer cells. Chemotherapy is often used as well. The goal is to

remove the tumor and forestall its recurrence.

In all forms of therapy there is another level of care. The goal of pediatric cancer teams is to treat the patient and support the family, Ms. Chambers says. The Pediatric Oncology Group of Ontario (POGO) has advocated for resources to put multidisciplinary teams in place in each childhood cancer hospital.

"In every case, we bring these teams into action," she says. "There is the case nurse, who acts as main point of contact with the family. He or she can call on social workers, community support workers, professionals who work with the child's school, psychologists, art and play therapists and groups, such as POGO, which co-ordinate care and treatment for children with cancer in Ontario, including tracking patients for life and providing financial assistance to families."

"Within the hospital, there are the oncologists and nurses like me who carry part of the treatment load doing physical assessments, educating families, providing answers to their questions and prescribing chemotherapy. There are also dietitians, pharmacists, imaging specialists and surgeons. We work on a holistic approach, not just for the patient but for mothers, fathers, sisters and brothers as well. Cancer affects entire families and not just for a brief period of time but for decades afterward."

Diagnosis usually starts with the collection of biopsies, samples of tissue, body fluids and blood. Diagnostic techniques have become so well refined that treatment centres today can zero in on myriad sub groups of cancers, classifying patients within each to determine the precise treatment and dosages of medication and chemotherapy that will deliver the best outcomes, says Dr. Weitzman.

Some treatments demand anesthesia to eliminate or greatly reduce stress on the small patient. At Toronto's SickKids, that anesthesia is delivered in the Cujo room, a suite decked out like a hockey locker room and named after former

Toronto Maple Leafs goaltender Curtis Joseph.

"With the parents' consent we try to take samples of sufficient size to allow ongoing research," she explains. "We are now doing research on the cellular level and, bit by bit, understanding much better the mechanisms involved."

Also with the parents' informed consent, patients are often included in clinical trials. The goal of these studies, conducted by the North American Children's Oncology Group, is to test new therapies, new medications and new dosages of existing ones to find the best when it comes to treatment or the reduction of side effects.

Research does not end with treatment. "Thanks to POGO and its POGONIS data bank, we are now starting to track childhood cancer patients through their lives," Dr. Weitzman says. "That will give us a remarkable ability to see the effects of treatment and adjust therapies to prevent potential future side effects, such as fertility problems, learning disabilities and the physical long-term effects on major body organs such as the heart."

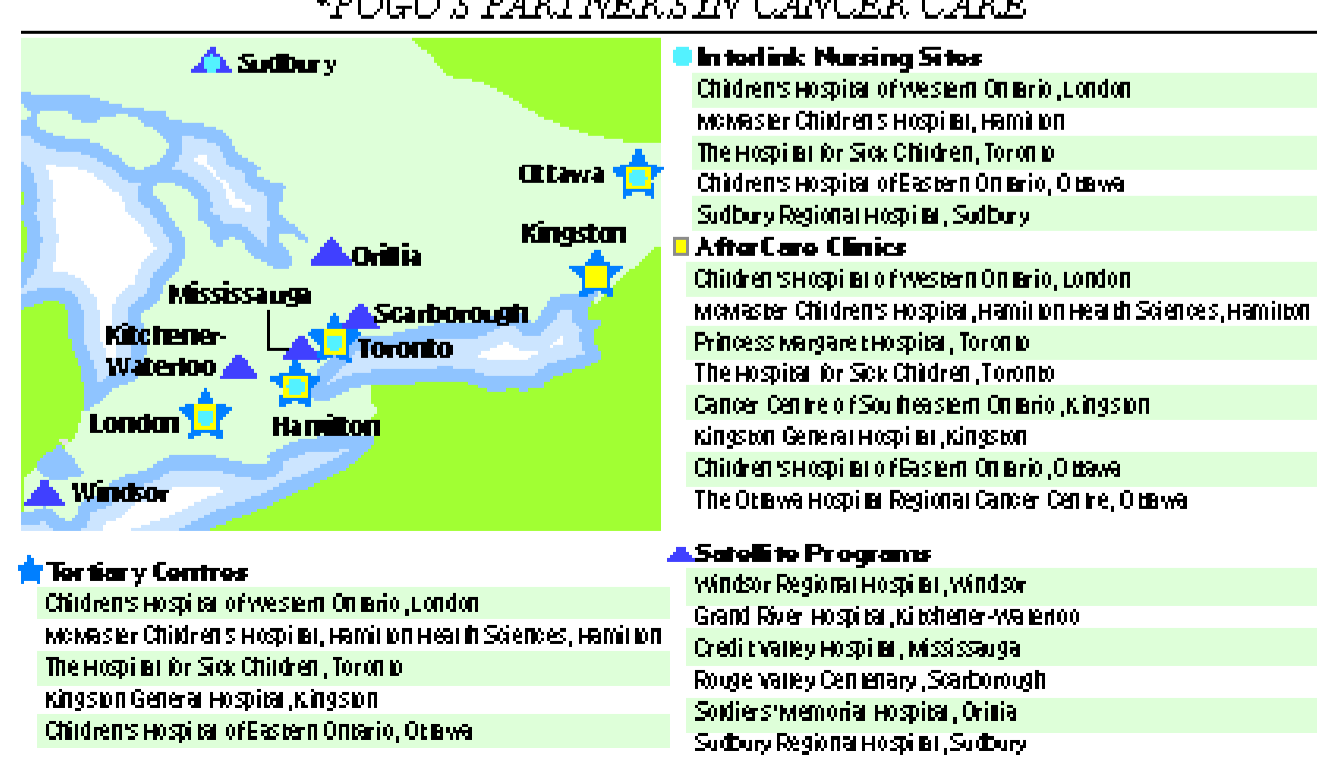
To ease the disruption on the lives of the children and their families, some care can take place at one of POGO's six regional satellite sites and in the home, Ms. Chambers says. POGO's Interlink community care nurses or social workers visit the child's school and make home visits with the parent.

"The goal is to help the child lead a normal life," she says. "We tell schools and parents alike not to reduce expectations for academic progress, not to make special arrangements but, rather, just to cut these kids a bit of slack now and then. If they were high achievers before, they will want to be high achievers afterwards. They will not want a free ride."

Sadly, for two out of 10 patients the demand will be for palliative care should the child want to go home for the remaining days. Ontario's pediatric oncology teams provide help and support with that process as well, Ms. Chambers says.

"Grief counselling for families and for entire schools is another aspect of what we do to provide that vital support," she says. "Our overriding philosophy is not to just treat the child but to bring to bear every resource needed to help ease the burden on the entire family as well."

### \*POGO'S PARTNERS IN CANCER CARE



\*Pediatric Oncology Group of Ontario