



# KIDS AND CANCER



*A joint venture with the Pediatric Oncology Group of Ontario (POGO)*

*A four-part series sponsored by Rogers, Canadian Cancer Society, Caldwell Investment Management Ltd. and POGO partners*



The Perkins family: Nathan, left, Tony, Mathew, Jenny and Travis. The family praises POGO for its compassionate care.

## Family focus improves care

Each year, 400 children, some only months old, will be diagnosed with cancer in Ontario. About 3,000 will receive active treatment and follow-up care. Thanks to dramatic gains in treatment, 80% will now survive and go on to lead long and fruitful lives, compared with less than half that number just 30 years ago.

But there is more to childhood cancer than just statistics and survival rates. A focus on them cloaks the real story. Pediatric cancer is unique, explains Dr. Mark Greenberg, Medical Director of the Pediatric Oncology Group of Ontario (POGO), the province's advisor on childhood cancer care and the organization responsible for driving continual improvements to the system.

At the heart of POGO's philosophy is a simple principle: Do not just treat the patient, treat the family.

"That is where our team approach has proven so successful," says Dr. Greenberg. "Success in treatment is not a matter of survival rates for us; it is also a matter of quality of life. Not just for the patient today but for the rest of his or her days, and not just for our small patients but for their entire families as well."

Research and experience have both proven that this holistic approach greatly improves success rates, preserves the integrity of families and helps both family and patient cope with what may be the most stressful situation they will ever face.

The need for POGO's all-embracing philosophy stems from the nature of the disease.

"Not only are the types of cancer that affect children quite different from those diagnosed in adults, but the impact is as well," Dr. Greenberg says.

Childhood cancer impacts entire families, often bringing with it not just devastating emotional costs but financial ones as well. And as success rates continue to climb, so will the long-term impact on survivors.

"Then there are the long-term effects of the anxiety and psychological impact the experience may have had," Dr. Greenberg adds.

"While we know a great deal more than we did when POGO was created 24 years ago, we are still learning, and as we learn we are able to apply those lessons to current therapies."

Another complicating factor is that decisions on treatment are made by third parties — the parents — rather than the children themselves. While decisions on treatment are always based on the best medical evidence, making those decisions can impose a considerable emotional and psychological burden on parents, Dr. Greenberg points out.

The ability to track childhood cancer patients, to learn from the data gained and to adapt and develop new treatments is at the heart of what POGO does, says Dr. Ronald Barr, the group's President and Professor of Medicine at McMaster University in Hamilton.

POGO defies conventional descriptions, he says. It is as unique as the disease it addresses, covering everything from research to education, treatment, the creation of standards, assembling teams, evaluating their performance, and tracking patients from the moment they are diagnosed until their deaths decades in the future.

"While the numbers are small, the impact is enormous," he says. "There is not just the cost of providing treatment today but the potential cost to the system as patients grow and age and develop often-unforeseen side effects from early childhood treatment."

"What POGO is dedicated to is not just providing world-class, leading-edge treatment to Ontario's children but to understanding the causes and the effects of cancer so well that we may eventually be able to prevent its occurrence or prevent the long-term, adverse effects."

What makes pediatric cancers so difficult to understand, and their long-term effects so hard to foresee, are the very nature of the disease. Unlike most adult cancers, such as lung, bowel, breast and prostate, which result from a combination of genetic and environmental causes and are slow-growing, the most common forms of childhood cancers are leukemia, which accounts for about a third of new cases, and brain tumors. Both are fast-growing, often seeming to take hold and progress with near-lightning speed. The causes are not well understood, because the answers seem to lie in the new field of genetic medicine.

The nature of the disease and the impact on families today, and in the future, demand a unique approach and a unique structure. In Ontario, POGO provides both, according to Executive Director Dr. Corin Greenberg, a psychologist by training.

POGO, with its staff of 24, has, since its founding in 1983, served as central co-ordinating body, research unit, developer of practice guidelines for treatment, performance evaluator, educator and, in fact, almost any other role necessary to advance pediatric cancer care and control in the province, she explains.

It is the glue that binds together a strong working partnership of five partner hospitals and six community treatment clinics. The five hospitals, called tertiary sites, are: Toronto's Hospital for Sick Children, Hamilton's McMaster Children's Hospital, London's Children's Hospital of Western Ontario, Kingston's General Hospital and Ottawa's Children's Hospital of Eastern Ontario.

Each is fully equipped to provide leading-edge treatment, follow-up therapy and patient and family support through teams of dedicated professionals that include oncologists, nurses, dietitians, pharmacists, social workers, therapists, diagnostic imaging specialists and surgeons.

"To reduce the burden on families of having to make very long commutes for treatment and follow-up procedures, we now have six — soon to be seven — community centres," Dr. Greenberg explains. The current satellite sites are in Orillia, Soldier's Memorial Hospital, Kitchener's Grand River Hospital, Sudbury Regional Hospital, Credit Valley Hospital in Mississauga and Rouge Valley Hospital in Toronto.

It all comes back to that overriding philosophy, she says: Treat the family as well as the small patient.

For more information, visit [www.pogo.ca](http://www.pogo.ca).

## 'A DAY I CAN NEVER FORGET'

Late last March, Tony Perkins, 35, and his wife Jenny, 32, watched as their eight-year-old son Mathew slammed into the boards at the local arena during the finals of his hockey league. He came off the ice limping. At the time they thought little of it; just another bruise or pulled muscle.

The next day, Mathew's school in Cardinal, Ont., north of Brockville, called Tony at work. Come get Mathew, the principal said; he can't walk.

"We let him sit on the couch all day Saturday but it didn't get any better, so late Sunday I thought we should take him in for an X-ray," says Jenny, an aide at a nursing home. "There was no radiologist to read the X-ray, so we went home."

That night, the hospital called. The X-rays showed a chunk eaten out of Mathew's leg bone. Rush him to the Children's Hospital of Eastern Ontario in Ottawa, the hospital said. The diagnosis came April 3. "That's a day I can never forget," says Jenny. Mathew had Ewing's sarcoma, cancer of the bone.

Pediatric cancer's effects, both immediate and long-term, are devastating, says Dr. Ronald Barr, Chief of Pediatric Hematology/Oncology at McMaster

Children's Hospital in Hamilton and President of the Pediatric Oncology Group of Ontario (POGO).

"This is a disease that does not only affect the child," he says. "The entire family can be devastated emotionally and financially. Research shows that during the first year of treatment, disposable income

## 'YOU WONDER WHAT WOULD HAVE HAPPENED IF POGO HAD NOT BEEN AROUND'

can drop by one-third as parents take time off work to deal with treatment and care and as they spend money commuting to hospitals.

"What is more, with a survival rate of 80%, that means that childhood cancer patients will live long lives, lives that are often affected by the experience. Radiation to the head can create subtle brain damage which may lead to cognitive

difficulties later in life; the incidence of heart disease seems to be greater in these children as adults."

Childhood cancer is unique among diseases. Success cannot be measured only in terms of survival rates; the lives and welfare of an entire family and the long-term future of the patient is at stake.

For the Perkins, POGO's help, support and all-encompassing approach to Mathew's disease proved vital, says Jenny. "We had just built a new house with a big mortgage. We also have two other boys — Travis, 11, and Nathan, seven. The whole community came to our aid."

"POGO provided financial support for the commute between Cardinal and Ottawa. It made available dietitians and social workers. The nurses and doctors were just wonderful. Without [POGO's financial support], I think we would have lost the house."

Mathew underwent chemotherapy and surgery. Last month, surgeons transplanted 18 inches of bone from a 24-year-old Halifax donor. He is home in a wheelchair. In February, they will know if treatment has been a success.

"We worry every moment of every day," she says. "What will the doctors say this winter? How do we get through the next five months? I thank God each day for the care and treatment Mathew received. You can't help wondering what would have happened if a group like POGO had not been around."

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

- Interlink Sites**
  - Children's Hospital of Western Ontario, London
  - MCMaster Children's Hospital, Hamilton
  - The Hospital for Sick Children, Toronto
  - Children's Hospital of Eastern Ontario, Ottawa
  - Sudbury Regional Hospital, Sudbury
- After-Care Clinics**
  - Children's Hospital of Western Ontario, London
  - MCMaster Children's Hospital, Hamilton Health Sciences, Hamilton
  - Princess Margaret Hospital, Toronto
  - The Hospital for Sick Children, Toronto
  - Cancer Centre of Southeastern Ontario, Kingston
  - Kingston General Hospital, Kingston
  - Children's Hospital of Eastern Ontario, Ottawa
  - The Ottawa Hospital Regional Cancer Centre, Ottawa
- Satellite Programs**
  - Windsor Regional Hospital, Windsor
  - Grand River Hospital, Kitchener-Waterloo
  - Credit Valley Hospital, Mississauga
  - Rouge Valley Community, Scarborough
  - Soldier's Memorial Hospital, Orillia
  - Sudbury Regional Hospital, Sudbury
- Tertiary Centres**
  - Children's Hospital of Western Ontario, London
  - MCMaster Children's Hospital, Hamilton Health Sciences, Hamilton
  - The Hospital for Sick Children, Toronto
  - Kingston General Hospital, Kingston
  - Children's Hospital of Eastern Ontario, Ottawa

\*Pediatric Oncology Group of Ontario

## NEXT WEEK

### WHEN YOUR CHILD HAS CANCER

- Treatments and life decisions that must be made
- Nurses, social workers and additional professional supports and programs for families
- Waiting to hear what the future holds, and absorbing the impact



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