

WEST

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Miracles for children

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kids a chance PAGE 20

Giving kids a

Children's Miracle Network saves lives and offers hope

By Mark Cardwell



Parker Murchison

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ARKER Murchison is one tough kid. In 2010, just after turning 8, he was diagnosed with acute lymphoblastic leukemia, a fast-growing cancer that undermines the creation of the white blood cells our bodies need to fight infection. Over the next six months, the Dartmouth, Nova Scotia, youngster made 70-plus trips to the IWK Health Centre in nearby Halifax, where he received dozens of sometimes agonizing treatments that included spinal taps, bone marrow tests, blood transfusions and chemotherapy injections.

Fortunately for Parker, those treatments forced his cancer into remission. Since then, he has been on a maintenance program that requires monthly injections of liquid chemo and daily oral doses of a cancer-killing drug. Now a grade 6 student who loves skiing, curling, football and lacrosse—sports he insisted on continuing to play throughout his three years of treatment over the objections of his mom and medical staff—Parker is looking forward to the day in December of this year when he is scheduled to take the last of the 14,000 pills he will have swallowed since his diagnosis.

“I won’t be sad about that,” he says, laughing. “But I will miss seeing the nurses and doctors at the hospital. They are really nice [and] they helped me get better.”

Gratitude, together with a keen desire to speak out on behalf of other sick kids—especially those who won’t have happy outcomes like his—is the reason Parker plans to continue doing work on behalf of the Children’s Miracle Network (CMN), which raises funds for the benefit of 14 children’s hospitals across Canada, including IWK.

“I was lucky because my type of cancer can be treated,” says Parker, who has given several speeches on behalf of the children’s charity. “But money is needed for research to find cures and to buy new and better hospital equipment. I think it’s awesome that CMN raises money to do that.”

Parker is not alone. All across Canada, pediatric health-care professionals, administrators of children’s hospital foundations and loved ones of the 1.2 million kids under the age of 18 who are admitted to a CMN-funded facility each year (nearly 5,000 every day) for specialized treatment of common childhood afflictions such as asthma or broken bones—or for more complex care challenges like birth defects and cancer—understand and appreciate the importance of the money raised, often a dollar at a time, by the Children’s Miracle Network.

Local funds for local kids

Founded in 1983 by singer Marie Osmond and TV actor John Schneider (*The Dukes of Hazzard*), who staged an inaugural telethon in a small studio in the United States, the organization has become North America’s leading charity for children’s hospitals, having raised roughly \$4.5 billion over the past 30 years.

Much of that money continues to come from annual telethons and radiothons, which are always



ILLUSTRATION: LORY WILLIAMS/PARKER PHOTO: SUE SIRI PHOTOGRAPHY

chance



held the second weekend in June, which the charity refers to as Miracle Weekend.

However, most of the organization's revenues are now generated during the month of May through sales of its most recognizable symbol—the red-and-yellow “Miracle Balloon” icons—at retail outlets of corporate sponsor/partners such as Costco, CMN's biggest icon seller (see “Costco, CMN and you,” page 22). In Canada, where annual telethons are held in five provinces—British Columbia, Ontario, Quebec, Nova Scotia and Newfoundland/Labrador—and radiothons in eight, CMN has raised several hundreds of millions of dollars over the past three decades, including nearly \$50 million in 2012 alone.

Notably, a guiding principle of the charity has always been that funds remain in the communities where they are raised. Donations are flagged according to postal code and directed to the foundations of the nearest network-affiliated children's hospital.

Another signature feature of CMN is that donated funds are non-designated, meaning hospital administrators decide where and how the money will be used, provided it is in one or all of three core areas: research, care and education.

“We don't dictate what they have to do with the money,” says John Hartman, chief operating officer for the charity's Canadian operations. “They are the health-care experts, so we leave it up to their discretion. We focus on our strength, which is to work on their behalf to raise money in their communities.”

Paying for world-class care

Simply put, CMN funds help treat sick kids. Teri Nicholas, president and chief executive officer of the BC Children's Hospital Foundation, which supports the work of its Vancouver namesake hospital, explains that the annual donations the facility receives from CMN (\$14.4 million in 2012 alone, including \$1.6 million raised in local Costco warehouses) play a crucial role in its ability to continue providing world-class treatment to its young patients.

“Pediatrics care is so specialized,” notes Nicholas. “Many abnormalities appear early in life and require very specific procedures and equipment to treat and repair them. But when a piece of equipment hits the end of its life span, or if new and better technologies become available, we want to acquire them and put them to use for the benefit of our patients as quickly

as possible. Having reliable funds that are not earmarked for specific uses like an endowment fund helps children's hospitals do exactly that.”

A case in point is the new hybrid operating room for pediatric cardiac surgery that opened last year half a continent away at Montreal's Sainte-Justine Hospital. Backed by \$3.5 million in donations from CMN's Quebec wing—Opération Enfant Soleil—the new suite enables doctors to treat severe heart defects in young patients, including fetuses, by performing cardiac catheterization and surgery simultaneously.

“It gives us the ability to do all kinds of complex interventions that we were previously unable to,” Dr. Joaquin Miró, one of only three pediatric cardiac surgeons who use the room, tells *The Connection*. “It makes a huge difference in the quality of care we can provide.”

In addition to improving treatment and lowering patient morbidity rates, the new room will also serve to train doctors, residents and fellows from across Canada and around the world, according to Miró. “Having such ultra-specialized equipment is very rare,” he

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“A children's hospital is a scary place for parents, [and] the money CMN provides helps to take some of the scariness out of it.”

—Jo-Anne Morris,
Costco employee,
Langley,
British Columbia

Jo-Anne
Morris and
her daughter,
Cayla



Costco, CMN and you

THE COLOURFUL paper balloons that appear in May like flowers in Costco warehouses are signs of very kind actions.

A balloon goes up on the warehouse wall any time a member makes a donation to Children's Miracle Network (CMN) while shopping at Costco. This annual balloon drive is the most visible sign of Costco's support of CMN, which takes place in several creative ways.

In the warehouses, members are asked if they want to donate when they make purchases. Everybody who gives \$2 or more gets their name on a balloon that is posted on a wall, sometimes in clever murals created by artistic employees. In some warehouses, you'll see an employee in doctor's scrubs greeting members at the door to remind them of the fundraiser.

At Costco's corporate headquarters in Ottawa, the biggest event is a golf tournament and a gala for suppliers that draw a thousand participants. Employees at Costco's regional office in Burnaby, British Columbia, also hold fundraising events.

To top it all off, Costco matches all funds raised by members and employees by 20 cents per dollar, up to \$1 million.

All in all, these efforts have made a tremendous difference. Since 1988, Costco and its members have raised \$49 million for CMN in Canada. Last year's total was \$6.7 million.—*Tim Talevich*



Signs of the CMN campaign can be seen throughout Costco in May.

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says. "It has caught the attention of specialists everywhere in our field."

He adds that CMN's contribution to the new room, which was 50 per cent more than what the Quebec government invested, was the key to making it a world-class facility. "The money the government gave us helped us to buy the basic machines we needed," he points out. "But the [CMN] funding enabled us to upgrade and buy the best machines on the market [and] to buy the equipment we needed to make the best possible environment inside the operating theatre, which is a sterile room."

Hope for tomorrow's cures

Of course, CMN's non-designated dollars aren't limited to the purchase of life-saving pediatric equipment. At Toronto's Hospital for Sick Kids, for example, the charity's locally raised donations are used—and relied upon—to sustain potentially groundbreaking research on many childhood illnesses and diseases, including cancer.

"One feature of a hospital like ours is that both clinical and research priorities change over time," says Dr. David Malkin, a senior staff pediatric hematologist/oncologist and director of the world-famous institution's internationally renowned cancer genetics program. "Having non-designated funding allows us to put money into new and emerging areas of work that may not have been apparent even a year before."

Examples include money to help kick-start projects that might explore a particular aspect of a childhood cancer such as leukemia or to train graduate and post-doctoral students and support projects they are developing.

For William Chiasson, a 15-year-old Quebec City resident, CMN funds help advance medical knowledge in the hope of finding cures for illnesses like his. He has suffered his entire life from eosinophilic

gastroenteropathy, a severe food allergy that requires him to make regular trips, some of them urgent, to the CMN-affiliated children's hospital (Centre Hospitalier Université Laval, or CHUL) in Quebec's provincial capital.

"It's no fun being sick," says William, who is president of his grade 9 class and works as a poster boy for Opération Enfant Soleil. "But it's great when people give money to a charity like CMN that helps to improve the treatment sick kids get today and gives them hope that a cure will be found tomorrow."

Hope, however, is relative. Take the story of Jo-Anne Morris, who works at the Costco warehouse in Langley, British Columbia. Her daughter Cayla is an affectionate but intellectually challenged

11-year-old who was finally diagnosed last fall with a rare and untreatable chromosome syndrome that is known to affect only one other living person in the world, a 17-year-old Italian boy named Umberto. Their dream is to one day travel to Europe to meet him and his family.

"A children's hospital is a scary place for parents, [and] the money CMN provides helps to take some of the scarieness out of it," says Morris,

who is an active organizer of CMN events at her warehouse, including activities for her fellow employees, such as paying \$5 to wear jeans to work. "But if you have a kid with a long-term illness or special needs, there is also a ton of pressure on a parent to try and give your other kids normal lives. That's why I'm looking forward to the day when I can meet Umberto's mom and hug the only other woman on earth who knows exactly what I've been through." [E]

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