

**kids
candidly**

YOUR GIFTS AT WORK, TRANSFORMING THE LIVES
OF CHILDREN WITH CANCER.

**kids
cancer care**

**[in this
Issue**

jordan

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FALL/WINTER 2012 ISSUE

CEO message

dear friends,



**you can be a part
of something big**

**"We have already achieved so much for these kids, but somehow we must find the strength and the commitment to do more."
- Christine**

This past summer marked the dream of a lifetime for Kids Cancer Care. After an intense year of fundraising and renovations, we officially opened a brand new Camp Kindle. We are so unbelievably grateful to you for making this possible.

It's easy to lose sight of the reality of childhood cancer when celebrating such victories. I realize we must celebrate our successes, but we must never lose sight of the work to be done.

Childhood cancer is still the number one disease killing children today. Every year in Alberta we lose over 20 children to this disease. That's more than the number of children taken by cystic fibrosis, muscular dystrophy, asthma and AIDS combined.

Sixty per cent of those who do survive face long-term side effects that seriously impair their quality of life: neurocognitive deficits, mobility issues, heart problems, kidney failure, fertility issues, and secondary cancers.

I am encouraged by today's overall survival rate of 80 per cent. We have already achieved so much for these kids, but somehow we must find the strength and the commitment to do more because for some children—with brain cancers or sarcomas—survival rates have barely moved in 30 years. We need to change this.

Today's overall survival rate did not happen overnight. It happened over many years with the perseverance and dedication of many. You are among the many people who have changed the course of children's cancer in our lifetime and I thank you for your generosity and tenacity of spirit. Without you, none of our dreams would be possible.

Sincerely,

Christine McIver, M.S.M., CFRE,
Founder & Chief Executive Officer

it's easy being green

Being green just got a whole lot easier for Kids Cancer Care thanks to a \$20,000 grant from the Alberta Beverage Container Recycling Corporation (ABCRC).

The generous donation comes to Kids Cancer Care through ABCRC's Community Champions Program, which provides funding to charities and not-for-profit organizations to purchase and set-up infrastructure to run a beverage container recycling program.

"This has been an amazing program," says Dacia Lashmore, catering and housekeeping manager at Camp Kindle. "ABCRC made it so easy for us. They customized the bins with our logos and then delivered them. They're also bear-proof, which is hugely important for a children's camp."

With the grant, Kids Cancer Care purchased 15 inside bins and four large highway-style bins for outdoors. The grant also provided funds for a four-bin range trailer, which makes collecting and transporting beverage containers a simple one-step process.

"As a children's cancer charity, we're concerned about the health of the planet and sharing these values with the kids," says Dacia. "It's important for kids to see that they can help through simple, everyday actions, because one day, they'll be the stewards of our environment."

True to the principles of sustainability, the new recycling program is also financially sustainable. "We're increasing environmental awareness in the next generation, while generating revenue from the recyclables," says Dacia. "It's a win-win situation for everyone."

news & media

facebook

You can see all the great photos, video and audio clips from our camp and fundraising events all year-long. Become a fan at Kids Cancer Care Foundation of Alberta.

all a-twitter

You can follow us on Twitter @kidscancercare for the latest news and events.

youtube

Check out our videos on our YouTube channel KidsCancerCare.

website

Stay up to date with the latest news and events and find out how you can get involved at kidscancercare.ab.ca.



tumour banking

Calgary has a new tumour bank thanks to researchers in Dr. Jennifer Chan's lab. The tumour bank collects patient-derived blood, tissue and urine samples, which scientists may use in their research. Currently housing a frozen tissue collection, the tumour bank will soon hold a live cell collection. In addition to enabling researchers to create profiles of various cancers, a live cell collection will enable them to observe how these cancers respond to different drug therapies.

The tumour bank was established with funding from Kids Cancer Care, the Clark H. Smith Brain Tumour Institute and the Terry Fox Foundation.

camp re-kindled

Renovations at Camp Kindle are nearing completion and the re-kindled camp is now fully operational. Currently at 94 per cent of our \$8 million fundraising goal, staff and volunteers continue to raise funds to complete the re-kindling project. **Read more on page 10.**

award-winning staff

Tracey Stahn received a prestigious Paul Harris Fellow award from the Rotary Club of Calgary West. Named in honour of the founder of Rotary International, the award recognizes service above self and acknowledges character and work that exemplify the best of humanity. The honour recognizes Tracey's commitment and contribution to teens affected by cancer through Kids Cancer Care's Teen Leadership Program.

Emma MacIsaac, manager of sponsorship and events, was recently awarded the inaugural Outstanding New Fundraising Professional award from the Association of Fundraising Professionals. The award recognizes fundraising professionals with less than five years' experience in the field who are making outstanding contributions to the profession and who embody the values of philanthropy.

EI benefits for parents of sick kids

A proposed change to the Employment Insurance Act could help Canadian parents who are forced to take time off work to care for a child with a life-threatening illness or injury. The new benefit will allow eligible parents to collect up to 35 weeks of Employment Insurance benefits. Its purpose is to help ease the financial hardship of these families, so parents don't have to choose between the family's financial wellbeing and the child's wellbeing. In addition to facing tough financial decisions around work, parents with critically ill children also face significant unexpected expenses. Families with a child on cancer treatment, for instance, lose up to a third of their after-tax income to out-of-pocket expenses. The new benefit is expected to affect approximately 6,000 Canadian families each year.





camp

"My heart sank. The one thing you want to do as a parent is protect your child," - Michelle.

SUCH A LONG JOURNEY

such a long journey

“Imagine having to wear rubber gloves for three days to change your son’s diaper because the chemo going through his little system is so toxic,”—Michelle Heglin.

Michelle Heglin remembers well the day her four-month-old son was diagnosed with retinoblastoma, an aggressive eye cancer that robbed Jordan of his right eye and continues to threaten his left eye.

“It was the scariest day of my life,” recalls Michelle. “The ophthalmologist said Jordan would probably lose an eye and that the cancer is fatal if not treated. My heart sank. The one thing you want to do as a parent is protect your child. I sat in shocked silence as the doctor looked into his other eye. ‘Yes, it is bilateral,’ he said, ‘and you need to get to Toronto as soon as possible.’”

Stunned, Michelle went home and booked their flights. She and Jordan were in Toronto the next day. Grandma Lucy joined her daughter and grandson in Toronto for the first two weeks.

Jordan’s condition demanded specialized ophthalmological equipment and technology, which wasn’t available in Calgary, so in the beginning, they travelled to and from Toronto every two weeks. A single mother, Michelle was forced to take far too much time off work.

“Our fridge was an ice bucket in the hallway,” Michelle says, recalling the hotel-living conditions of those first weeks in Toronto.

Jordan underwent surgery for a port insertion, so he could receive regular doses of chemotherapy and painkillers. He endured a gruelling kidney function test, followed by three months of chemotherapy. Not long into his treatments, however; the doctors ordered a stop to the chemo because they feared it was causing hearing loss.

“There were a lot of tears shed by my son, my mom and myself,” Michelle recalls. “I remember sitting in a rocking chair, rocking and singing to Jordan. Still to this day, Mom gets choked up when she hears that song, ‘The Ants Go Marching One by One.’ But, at the time, it was the only thing that seemed to soothe him”

Jordan lost his right eye a year ago and he now wears a prosthetic, which brings with it a host of unforeseen problems.

Finding a community for Jordan is paramount, something Michelle and Jordan found this past summer at Camp Kindle. “To find a community where prosthetics are okay, where it’s okay to be bald, where it’s okay to be leery of sick people and not to be the odd one out, it’s pretty important,” she says.

“I want a place my son can be part of. Where he feels safe and can explore and learn new things with others who have won or are winning the same battle.”

Sadly, the battle is not over yet for two-year-old Jordan. Jordan and his mom still travel to and from Toronto every eight to 12 weeks for laser treatments and close monitoring. And, there are no signs the travel will let up in the near future. Jordan is at risk for developing other cancers later in life and, until his good eye fully matures, he will require constant monitoring.

photo: (left) Jordan lost his right eye to cancer at age one but the busy two-year-old doesn’t let that stop him.

photo: (right) Michelle Heglin has found a community for her son Jordan who is battling an aggressive eye cancer.



you can help build community

Thank you for building a community for kids like Jordan.

**the
power
of you**

childhood cancer awareness month

it started with you

Individuals and organizations across the province joined Kids Cancer Care teens, families, staff and volunteers during Childhood Cancer Awareness Month. A total of 25 fundraising and awareness events took place in September, raising more than \$70,000. These funds will directly impact the lives of Alberta children with cancer and their families through our camp, research, hospital and scholarship programs. **Here are a few highlights from September.**

september game plan? childhood cancer awareness

When the Calgary Stampeders and Edmonton Eskimos kicked off the Labour Day Classic in September, they kicked off Childhood Cancer Awareness Month in honour of Alberta children with cancer. Six-year-old Sloan had the privilege of tossing the coin before the game to determine which team would take the ball first. Later in the game, Sloan and his brothers Ryder and Cruz took centre field with Jaymee and her little brother Lukas and, together, they shared a message about childhood cancer with 10,000 football fans at McMahon Stadium. Go kids! Go Stamps! Go!



mud pies never tasted so good

Calgarians learned they could satisfy their sweet tooth, while fulfilling their charitable interests this past September with a decadent mud pie doughnut at Jelly Modern Doughnuts. Created by Calgary Chef Grayson Sherman with kids and camp in mind, the camp mud pie doughnut, topped with gummy worms and gummy spiders, raised \$177 for Kids Cancer Care.

photo: (above) Taeden samples one of the mud pie doughnuts with gusto.

photo: (left) Sloan shows off his Labour Day Classic loonie.

sun salutations shine light on childhood cancer

Candace Cooke, a bereaved Calgary mother and yoga instructor at Yoga Santosha, led children from the Kids Cancer Care community in a zoo-themed yoga session to promote a yoga fundraising event, 108 Sun Salutations. Candace held the fundraising event during Childhood Cancer Awareness Month to honour her late son's life and cancer journey and the communities that helped her family heal. Yoga participants raised \$7,000 in pledges for Jamie's Preschool and Kids Cancer Care.

photo: (below) Alainna strikes a pose during class. A swan? An elephant? An Ostrich?



hop(e)scotch

Alberta schools, teens and families from the Kids Cancer Care community took to the sidewalks September 26 through 30 with colourful messages of hope and gratitude during our chalk campaign. The four-day campaign was designed to generate awareness and spark discussion about childhood cancer, while empowering young people and families affected by cancer to take action and speak their minds about the disease.

"If at least one person sees our messages and smiles, it's worth it to me," — Jessie.



photo: (above) Jessie was one of many teens from the Kids Cancer Care community to take part in the chalk campaign. A bereaved sibling, Jessie's messages to Calgary were deeply personal.

community partners

Special thanks to YOU for raising funds and awareness during Childhood Cancer Awareness Month!

Aaron Lipsey
Albi Renova
Astral Radio Calgary
Calgary Herald
Calgary Stampeders
CTV
Carmen Knittig Memorial Golf Tournament
Carrington Family BBQ
Elevate Auctions
Great Western Containers 2nd Annual Charity Golf Tournament
Harmony Yoga
Jelly Modern Doughnuts
Joe Media
Karma Kids Yoga
Kenny Knittig
Kool 101.5
Pattison Outdoor
Red Deer Rampage 24-Hour Hockey Game
Rogers Communications
Shaw TV
Smart Betty
Stolo's Pizza
Trilogy Energy
Yoga Santosha

It takes a province to save a child. Get involved during Childhood Cancer Awareness Month 2013. For information, please contact Lauren Ellis at **403 930 6951** or **ellis@kidscancercare.ab.ca**.

finding peace in stormy places

**"He who binds to himself a Joy, does the winged life destroy.
He who kisses the Joy as it flies, lives in Eternity's sunrise"
—The Tibetan Book of Living and Dying.**

Candace and Alastair Cooke were forced to live the wisdom of these words five years ago when they lost their 18-month-old son Kaidan to infant leukemia.

Although it felt like the last thing in the world they should do, their path to acceptance and true contentment would come by following through on a long-held dream of opening a yoga studio.

Kaidan's cancer diagnosis in 2006 changed everything in the Cooke household. It was hardest on Kaidan's three-year-old brother Josh who found the isolation and his family's new hospital routine difficult. Everyone was terrified they would pick up something and pass it along to Kaidan. Even trips to the grocery store became a place of angst.

"Some days it felt like prison," recalls Candace. "Most of the time we were in isolation for one reason or another, which meant that everyone who came to visit had to gown up, wear a mask and gloves."

photo: (below) Kaidan.



"Some days it felt like prison. Most of the time we were in isolation for one reason or another, which meant that everyone who came to visit had to gown up, wear a mask and gloves," — Candace.

Kids Cancer Care offered the Cookes respite from the intense hospital regime and isolation. "They invited us to all their programs and events," Candace says. "It was nice right from the beginning to be with other people who were going through similar experiences. It made a world of difference to our family. We felt normal again!"

Driven into survival mode, Candace and Alastair put their dream of building a yoga studio on hold. But that would eventually change.

"Near the end of his treatments, the doctors told us Kaidan was doing so well and that we should start building our lives again, so Alastair and I started building our dream—Yoga Santosha."

When Kaidan died unexpectedly of a blood infection a few weeks later, Candace and Alastair were devastated and unsure how to proceed.

"We really didn't know how we could possibly continue building a yoga studio where we were supposed to inspire others, help them find their inner peace and strength!" says Candace. "How could I teach yoga? I was a mess! Truly broken-hearted and devastated."

After careful reflection and soul-searching, the Cookes decided the best thing they could do for their family was to finish the yoga studio.



"Building this studio was the one way we could be together, really together, as a family," say Candace. They decided that building the studio would honour their son and the spiritual lessons he imparted—slowing down and being in the present moment.

Living moment to moment, the Cookes built a studio, a practice and a community. "We're so grateful for our yoga studio, for our wonderful community of teachers and practitioners," says Candace. "And we are so grateful for the community and support we have through Kids Cancer Care and Jamie's Preschool. Really, they all saved us!"

photo: (above) Candace and Alastair Cooke founded Yoga Santosha after losing their son Kaidan to cancer. They have found peace and contentment through their yoga practice and through the healing communities of Yoga Santosha, Jamie's Preschool and Kids Cancer Care.

exploring the health benefits of exercise in young cancer patients

“Our hope is that a stronger immune system will mean less risk of infection and less need for hospitalization. We believe that all of these factors will improve the child’s chances of recovery,”—Dr. Chamorro Viña

There’s no shortage of research when it comes to understanding the health benefits of exercise in adult cancer populations, but when it comes to childhood populations, there’s a resounding absence.

That’s why University of Calgary kinesiology researcher Dr. Nicole Culos-Reed is teaming up with Dr. Carolina Chamorro Viña, a U of C kinesiology researcher specializing in rehabilitating children with cancer through exercise. Together, Drs. Culos-Reed and Chamorro Viña hope to change the standard of care for children with cancer, so one day it includes exercise.

Drs. Chamorro Viña and Culos-Reed, who heads up the Culos-Reed Health and Wellness Research Group at U of C, recently launched a research study called SCORE (Stem Cell Patients Ongoing Recovery through Exercise), which will examine the effects of a moderate exercise program in children currently undergoing a hematopoietic stem cell transplant (HSCT) to fight cancer.

Although combining high-dose chemotherapy with a stem cell transplant has drastically improved outcomes for cancer patients, the treatment, previously known as a bone marrow transplant, brings with it high levels of toxicity. The high toxicity levels leave patients feeling fatigued, along with a range of severe side effects, including a drop in health-related fitness. The treatment plan also seriously lowers the patient’s immune system, which increases their risk of infection and need for hospitalization.

Based on the wealth of data demonstrating the health benefits of exercise in adult cancer survivors, Drs. Culos-Reed and Chamorro Viña hope to demonstrate that moderate exercise will also help children with cancer. They hypothesize that by improving the child’s fitness and energy levels, exercise will enhance the child’s immune system and quality of life.

“Our hope is that a stronger immune system will mean less risk of infection and relapse and less need for hospitalization,” says Dr. Chamorro Viña, who has carried out similar studies in Spain. “We believe that all of these factors will improve the child’s chances of recovery.”

Drs. Culos-Reed and Chamorro Viña believe that introducing an exercise program during treatment will help motivate these kids to adopt a healthy, active lifestyle during treatment and beyond.

yoga for pediatric cancer out-patients

Amanda Wurz (MSc student) in the Culos-Reed lab is looking for children to participate in a research study exploring the effects of yoga on children with cancer. The program is open to all pediatric cancer out-patients and begins in January 2013.

Visit them online at <http://www.kin.ucalgary.ca/healthandwellnesslab/Site/Home.html>

SCORE study

Researchers expect that moderate exercise in childhood cancer patients will

- 1. Enhance the child’s immune system recovery**
- 2. Improve the child’s physical fitness level**
- 3. Reduce the child’s fatigue**
- 4. Enhance the child’s quality of life**
- 5. Inspire the child to adopt an active lifestyle**

For more information on the SCORE program for children, please contact Amanda at 403 210 8482.

SCORE is funded by the Childhood Cancer Collaborative (Kids Cancer Care, Alberta Children’s Hospital Foundation and Alberta Children’s Hospital Research Institute).

**you can help
kids beat this**

Thank you for making new research possible for children with cancer.

camp kindle

you can be part of
something big

We are nearing the end of our \$8 million fundraising campaign. Please help us raise the last \$470,000 with a donation today.

brand new spaces

Camp Kindle officially re-opened on July 13 after a year of intense construction and fundraising. Kids Cancer Care celebrated the milestone with a day-long festival, treating guests to guided tours of the new camp, a barbeque lunch and optional rides down the zip line. Kids enjoyed face painting, field games and dancing to live music by local musicians Michael Bernard Fitzgerald, Amy Thiessen and the Alberta Fiddlers.

photo: (right) Calgary folk artist Bernard Fitzgerald helped Kids Cancer Care officially re-open Camp Kindle with his song, Brand New Spaces.



re-kindled

Renovations at Camp Kindle are nearing completion. Our spring to-do list includes landscaping, wayfinding, finishing the walkways, building a wheelchair lift for the pool and improving the trail systems.



photo: Camp Kindle now boasts a state-of-the-art initiatives course.



photo: Two new camper dorms and a volunteer and staff dorm will house a lot of happy campers.



photo: Kids will enjoy delicious meals prepared in a brand new commercial-sized kitchen.

how you can help

Dear Santa,

The kids and families of Kids Cancer Care have been especially good this year. We're hoping you'll leave some of the following gifts from our Christmas wish list under the tree at Camp Kindle:

- 90 Ikea Goliat dressers
- 1 new roof for the barn
- 1 trailrider to transport kids
- 25 children or youth sized life jackets
- 25 flutter boards

If you can help please contact us at 403 216 9210 or staff@kidscan-cercare.ab.ca.



'tis the season for giving

5 ways you can help kids this holiday season



1. Rudolph's wine cellar

Ever wonder why Rudolph's nose is so red? Ask your friends or colleagues to each bring a bottle of their favourite wine. Sell tickets at the office or among friends for a chance to win the wine collection.

2. Mr & Mrs Claus date night

Looking for the perfect stocking stuffer? Surprise Mrs. Claus with a pair of tickets to the 2013 Parents' Quest for a Cure gala. Or if you'd like to recognize a team of hard working elves this year, purchase a whole table and celebrate their hard work in style.

3. Tiny Tim's party piggy

Pick up a piggy bank at Kids Cancer Care and bring him out for all your holiday gatherings. Ask friends and family to fill him up with donations and then bring him back to Kids Cancer Care in the New Year. You'd be surprised how much cash Tiny Tim's piggy belly can hold.

4. Goodies galore

Invite your colleagues to bring in their favourite baked goods and hold a holiday bake sale. Sell the goodies to co-workers with proceeds going to Kids Cancer Care.

5. Clark Griswold ugly sweater day

Dress up a lacklustre casual jean Friday with an ugly sweater. Ask colleagues to donate \$5 to be part of the ugly Christmas sweater day. Take photos and share them on Facebook and Twitter.

If you can help, please contact us at 403 216 9210 or staff@kidscan-cercare.ab.ca.



events

you can get involved

To find out how you can get involved in our fundraising events as a participant, volunteer or sponsor, contact us at 403 216 9210 or staff@kidscancercare.ab.ca.



All photos courtesy of KCC archives unless otherwise noted.

save the date

Parents' Quest for the Cure Gala A Night in Bloom

presented by MNP
Saturday, March 9, 2013
Westin Calgary

Mother's Day Brunch

Sunday, May 12, 2013
Camp Kindle

Survivor Day

Sunday, June 2, 2013
Camp Kindle

High Hopes Challenge

presented by Citytv
Saturday, June 15, 2013
Camp Kindle

Ride for a Lifetime

presented by Brookfield Homes
June 21 – 23, 2013
Canadian Rocky Mountains

Tour for Kids - Alberta

July 19 – 21, 2013
Canadian Rocky Mountains

Don & Joanne Golf a Kid to Camp tournament

presented by Trico Homes & XL103 FM
Thursday, August 8, 2013
Cottonwood Golf & Country Club



We appreciate the opportunity to communicate with you about our activities. If you wish to alter the amount or type of mail you receive, please call us at 403 216 9210 or email staff@kidscancercare.ab.ca.

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