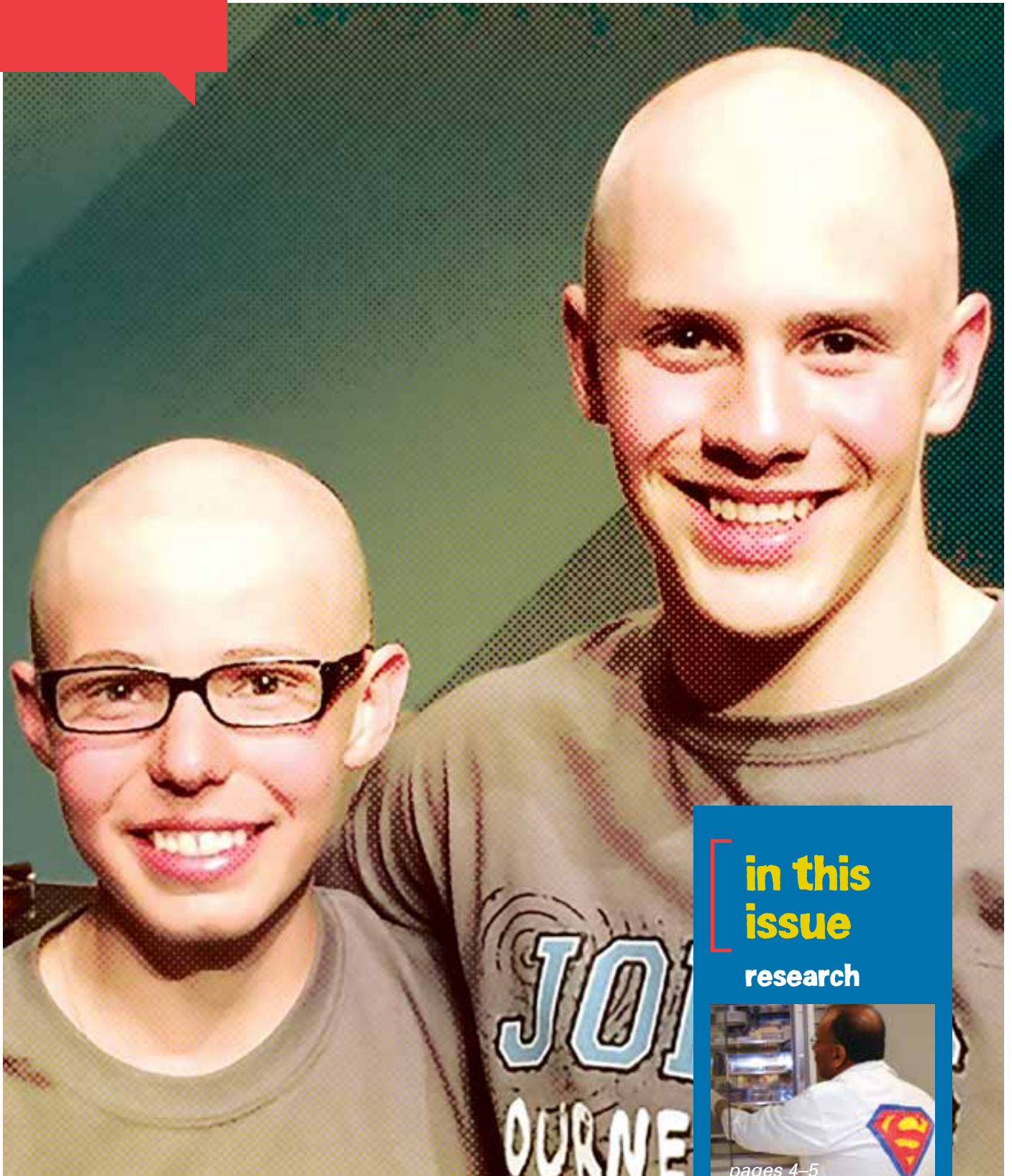


**kids  
candidly**

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

**kids  
cancer care**



**in this  
issue**

**research**



pages 4-5

## CEO message

## dear friends,

**“Once you choose hope, anything’s possible.”**

– Christopher Reeve

Writing today I am reminded of news headlines warning of falling oil prices, layoffs and further economic decline. From all accounts, it appears a difficult year lies ahead.

Here at Kids Cancer Care, we are feeling the sting of this new economic reality.

But I remain hopeful.

It wasn’t long ago, during another economic downturn, that we set out on our boldest adventure ever—to purchase and renovate Camp Kindle. It was 2009 and we were reeling from the worst economic recession to hit the world since World War II.

In retrospect it seems incredible. At times, it seemed impossible. And yet, under the leadership of Michael and Linda Shaw, Albertans stepped up and gave over \$12.5 million to make our dream a reality. Camp Kindle is now a vibrant healing space for hundreds of happy campers each year.

They say *“hard times will always reveal true friends;”* you have proven this true. Your generosity sustains us and inspires hope for a better future for children with cancer. You are an integral part of the healing and recovery of countless children with cancer. Thank you.

I hope this issue of Kids Candidly shows you how important you are to the children and families at the heart of Kids Cancer Care.

Sincerely,



**Christine McIver**, M.S.M., CFRE,  
Founder and Chief Executive Officer



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**Please give generously to our spring fundraising appeal.**



Photo courtesy of the Carrington family

## the financial burden of childhood cancer

**Canadian families spend thousands upon thousands of dollars on medical care and treatments for their children. They also incur miscellaneous costs for extras such as transportation to and from the hospital and high parking fees.**

The Canadian Cancer Action Network (CCAN) sponsored a one-year initiative called Mobilizing Opportunities to Systematically Address Issues Impacting Caregivers of Children (MOSAIIICC). Their mandate is to make recommendations to government, family and patient support groups to address the financial hardships and highest-priority needs of families who have a child with a life-threatening or life-limiting disease.

Last year, the MOSAIIICC advisory committee held a series of web-based focus groups with parents from across Canada, inviting feedback on their draft

recommendations, which included the following practical action items:

1. Financial planning checklist;
2. Advocacy to expand tax deductibility criteria for caregiving expenses; and
3. An interactive information portal for families.

MOSAIIICC is currently raising funds to build the online information portal. This interactive portal will be a virtual home for parents, where they can access information, tools, resources and tips to ease the financial stressors related to having a child with a life-threatening or life-limiting illness.

To learn more about the MOSAIIICC initiative, visit [ccanceraction.ca](http://ccanceraction.ca).





## We Are One: online now

More than 900,000 children worldwide raise their voices for children with cancer.

On February 15, 2016, in honour of International Childhood Cancer Day, Canadian composer Christophe Beck released a new song, We Are One, composed especially for children with cancer. The song features some of the world's most popular child YouTube singers and the voices of more than 900,000 children from around the world, singing the chorus. Children from the Kids Cancer Care community are among the many voices and faces to appear in the song and video.

You can download a copy of We Are One via iTunes or Spotify. To learn more about the song and the global awareness campaign behind it, visit [child4child.com](http://child4child.com).



Photos courtesy of child4child.com



Photos courtesy of KCC archives

## Meet Maddie

Full of sparkle and mischief, Maddie Tutt is our 2016 spokeskid. Maddie was 15 years old when life threw her a serious curve ball—cancer. When chemotherapy failed to shrink the 15-pound tumour in her abdomen, she underwent a near impossible surgery to remove the massive tumour wrapped around her aorta. They managed to get the entire tumour and Maddie proudly donated it to science.



During her cancer journey, Maddie found healing and comfort at our camp and outreach programs. She savours every second and opportunity life offers and she's looking forward to representing Kids Cancer Care at fundraising events around the province this year. ■

## Kids Candidly digitally

Look for your first digital issue of Kids Candidly in your email inbox. If you're not sure we have your email and you'd like to receive news and updates from Kids Cancer Care electronically, please send us your email address at [staff@kidscancercare.ab.ca](mailto:staff@kidscancercare.ab.ca).

# your support helped bring a new children's cancer drug to clinical trial

**The drug is called Carfilzomib and clinical health researchers at 10 major pediatric hospitals across North America are now evaluating it in a phase I clinical trial for difficult-to-treat children's cancers.**



Open to all eligible children with relapsed leukemia and solid tumours, the study will closely monitor and analyze the side effects of Carfilzomib to determine the maximum dose children can safely tolerate. The trial will cost approximately \$3.5 million (U.S.) to administer.

Previously tested and approved for use in adult patients, Carfilzomib has shown promise for treating adults with multiple myeloma—a high-risk leukemia. Studies in a University of Calgary lab revealed that the drug also acts on pediatric cancer cells. These findings from Dr. Aru Narendran's lab were presented last year at a meeting of the American Academy of Cancer Research.

Carfilzomib is a proteasome inhibitor. Because cancer cells divide and multiply so quickly and recklessly, they make a lot of mistakes, leading to abnormally formed proteins within the cancer cells. These poorly formed molecules put stress on the cancer and threaten its survival. To get around this, the cancer cells increase their use of the proteasome mechanism to repair their mistakes. By inhibiting proteasomes, Carfilzomib prevents the cancer cell from repairing itself and ultimately helps it to die of its own imperfections.

"The beauty of this drug is it goes after a mechanism used by all cancer cells, so it can be used against different cancers," says Dr. Narendran, a pediatric cancer researcher with the Experimental and Applied Therapeutics (ExpAT) program at the Alberta Children's Hospital and University of Calgary. "Normal cells don't make so many mistakes, so this drug will be less toxic to normal cells, which may mean fewer side effects for children."

Another promising attribute of Carfilzomib is that it works synergistically with other chemotherapies to boost *their* ability to kill cancer cells. This is especially important for chemo-resistant cancers.

"It's kind of a safety net," says Dr. Narendran. "Because the chemo agents and their toxicity are already known to us, we can use these chemotherapies with Carfilzomib to boost their potency for better outcomes."

Although the drug looks promising, Dr. Narendran stresses that "what we know so far comes only from adult patients or from laboratory studies against pediatric cancer cells. We do not know if it will actually offer any benefit to pediatric cancer patients yet."

*If it lives up to its potential, Carfilzomib may one day offer hope for children with incurable cancers.*

*“The beauty of this drug is it goes after a mechanism used by all cancer cells, so it can be used against different cancers.”*  
—Dr. Aru Narendran

#### **A brief history of Carfilzomib**

Carfilzomib was originally synthesized from a natural substance made by a soil bacterium to protect itself. Scientists in Dr. Craig Crews’ lab at Yale University serendipitously discovered in 1998 that Carfilzomib also has strong anti-cancer properties. Their discovery led to clinical drug trials and FDA approval in 2012 for use in adults with multiple myeloma—a high-risk leukemia. The drug is marketed under the trade name Kyprolis by Onyx Pharmaceuticals Inc. and is now being studied in a phase I clinical trial for children with difficult-to-treat cancers.



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As a phase I clinical trial, the study is not intended to cure children, but to understand its toxicities and determine suitable doses for treating children in the future.

Still, it is the first important step in a long quest to find safe and effective treatments for children with incurable cancers.

If it lives up to its potential, Carfilzomib may one day offer hope for children with incurable cancers. ■

*ExpAT researcher Dr. Aru Narendran (above) of the Alberta Children’s Hospital and University of Calgary and Dr. Jessica Boklan of Phoenix Children’s Hospital are the principal investigators in a new phase I clinical trial, studying the side effects of a drug called Carfilzomib on children with high-risk cancers. Dr. Tony Truong, co-principal investigator at the Alberta Children’s Hospital, along with U of C clinical research staff, Karen Mazil and Pina Giuliano, are helping to monitor side effects and analyze findings from the study.*

**Thanks to you, Kids Cancer Care renewed its commitment in 2015 to the Experimental and Applied Therapeutics research program with a \$1.25-million gift over five years. ExpAT researchers like Dr. Narendran are focused on screening and developing new drugs to move them more quickly from the research lab to the bedside of children at the hospital.**





power  
of you

# fire on ice:

## teenage hockey heroes score big for kids

**"I saw what Kids Cancer Care did for Joel and how much he touched so many lives. I'll do anything to ensure his legacy lives on."** —Tyler Oakenfold

Tyler Oakenfold meant it when he said he'd do anything to honour his best friend's memory.

When he and his teammates from the Northwest Calgary Athletic Association Midget AAA Flames committed to raising \$30,000 for Kids Cancer Care, they lit a fire in the community that wouldn't stop.

"We didn't want the boys to just put their hands out for donations," says Kathy Traptow, a parent who helped organize the team's fundraising efforts. "We wanted this initiative to build character and compassion. The boys really connected with it. They were out shoveling sidewalks, collecting bottles, canvassing online and door-to-door throughout the Christmas season."

But the Midget AAA Flames didn't stop at fundraising.

Half of the team shaved their heads on CTV Morning Live, extending a brave show of support for the children who lose their

hair to chemotherapy—a gutsy gesture for teenage hockey stars in high school.

The Midget AAA Flames also wanted to meet the kids they were helping, so in December, they opened up their practice time to five young hockey players from the Kids Cancer Care community. Afterwards they played a friendly game of shinny together—with a surprising number of goals from the little guys making it into the net.

Amid all the fundraising fervor, the Midget AAA Flames did what they do best. They played hockey. They took the championship title in the 2015-16 Mac's AAA Hockey Tournament, defeating six teams in six days

"These boys didn't take the easy way out," says Lauren Ellis, team lead for community fundraising events at Kids Cancer Care.

"They worked hard for every cent they raised. They're busy kids, with school and hockey and other commitments, so we really appreciate the sacrifice they made to raise so much money."



Photo courtesy of Tyler Oakenfold

*"We didn't want the boys to just put their hands out for donations. We wanted this initiative to build character and compassion."—Kathy Traptow*

*"I remember those backyard games with Joel—we sang Oh Canada! before every single game."—Tyler Oakenfold*



Photos by Kristine Kennedy



## For Joel

Just weeks before the fundraising frenzy began in November 2015, Tyler Oakenfold lost his best friend Joel Zukowski to cancer.

Joel passed away on October 3 at the age of 16, after a courageous seven-year battle with brain cancer. He was a quiet, gentle soul who touched countless lives through his kindness and wisdom.



Joel and Tyler first met in pre-school at the age of four. They went to elementary, junior and senior high school together.

Both quiet and unassuming, the two boys shared a love of hockey, playing shinny on the homemade rink in Tyler's backyard.

"We were the crazy neighbours with the sprinkler going all night long in the winter," says Tyler, now a draft-pick for the Western Hockey League's Swift Current Broncos. "I remember those backyard games with Joel—we sang Oh Canada! before every single game."

Stirred by the memory of Joel and inspired by the promise of five hockey-hopefuls from Kids Cancer Care, the Midget AAA Flames brought fire to ice. Undefeatable both on and off the rink, they dominated at the 2015-16 Mac's AAA Hockey Tournament and later flexed their fundraising muscle, bringing in \$44,000 for Kids Cancer Care—\$13,000 over their original goal and enough to send 29 kids to Camp Kindle this summer! ■

outreach

# soul food

**There's magic in cooking.** As you combine ingredients, experiment with new flavours and share secrets, you bring a meal to life. Cooking is a form of love and friendship. An art, a skill and a gift we share with the people who matter most.

**"There are things you do because they feel right and they may make no sense and they may make no money and it may be the real reason we are here: to love each other and to eat each other's cooking and say it was good."—Anonymous**



Food has the power to heal, and comfort and nourish, but for a family going through the agony of childhood cancer, a home-cooked meal is a godsend. Between hospital visits, appointments, work and school, finding time to cook quickly falls to the bottom of a long list of to-dos.

"Our daughter Keera was diagnosed in February with a brain tumour," says Jessi St. Laurent. "It had metastasized throughout her brain and down her spine. Keera was just two years old at the time and it was devastating. Our social worker told us about Kids Cancer Care and the Cooking and Caring program and I got in touch right away."

Our Cooking and Caring volunteers got straight to work for the St. Laurent family, whipping up some especially delicious snacks and meals along with some family favourites.

"When we received the meals, we were speechless," Jessie says. "We almost needed to buy a second freezer to store all the food."

Along with the homemade meals, the St. Laurent family received freshly baked goods from COBS Bread on 130<sup>th</sup> Avenue and gift certificates to Famoso Neapolitan Pizzeria in Country Hills.

"The treats from COBS and the Famoso Pizzeria gift certificates were an added bonus and such a kind gesture from both companies," says Jessi.

Being a recipient of the Cooking and Caring program has meant more time for Jessi to spend with her family and to focus on Keera's recovery.

"It's one thing I can check-off my list," she says. "I don't have to worry about cooking and if I'm at an appointment with Keera, I know my husband and son will have something healthy to eat. Keera has completed her cancer protocol and her prognosis is good. Now we can just enjoy some family time."

As Jessi and her family work their way through the freezer full of food, they remain incredibly grateful for the meals.

"We are so grateful for the Cooking and Caring program and to the volunteers who gave their time, energy and own money to cook for us. They are genuine angels." ■



Photos courtesy of the St. Laurent family





# self-care for caregivers

The Cancer Knowledge Network reports that Canadian caregivers contribute more than \$5 billion of unpaid labour annually to the health care system, caring for aging parents, children, partners or friends. Although it can be a rich and deeply rewarding experience, caregiving can also be overwhelming, exhausting and isolating. As a caregiver it's important to look after yourself too. Learning to pace yourself, look after yourself and accept help from others is vital and will help you in the long run.

*"There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers and those who will need caregivers."—Rosalynn Carter, former First Lady*

## 5 tips for self-care

### 1. Identify your support system

You may find it helpful to join a support group in your community or online. Talking to other caregivers will show you that you're not alone. Talk to your friends and family too.

### 2. New routines

Remember, caregiving is a marathon, not a sprint. As a caregiver, your daily activities will change. You will have new daily chores, appointments and responsibilities. Depending on your relationship, you may be asked to help with decision-making and information-gathering for your loved one. Try to balance your own needs and schedule with your loved one's needs.

### 3. Maintain relationships

On stressful days, you'll need to call on your close friends and family for support. As a caregiver, it's important to lead your own life and maintain your personal relationships for your own well-being. Friends and family may want to help, but they may not know how. Identify ways they can help, so you're ready when they ask.

### 4. Maintain YOUR health

Go for regular check-ups, screening and get proper sleep and nutrition. Eat a balanced diet and stay physically active.

### 5. Stress management

Relax. Rejuvenate. Recharge. Take time for yourself. As a caregiver, it's easy to become overwhelmed, depressed or burned out. When you start feeling this way, do something to revive yourself—physically, emotionally, and spiritually. Explore ways to relieve stress, such as music, art, meditation, prayer, guided imagery. ■



*Abridged and published with permission from the Cancer Knowledge Network <https://cancerkn.com>. The Cancer Knowledge Network is a comprehensive online resource for cancer patients and caregivers. For more information on self-care for caregivers, including a complete list of caregiver tips, go to <https://cancerkn.com/category/caregivers/caregiver-stories/>.*

what's up  
at kindle?

# teams that play together work better together

Employees from Canadian Oil Sands, now Suncor, spent a day at Camp Kindle teambuilding through a series of adventure-based activities such as the giant swing, low ropes course and high ropes course.

Your team can enjoy Camp Kindle too! Visit [campkindle.ca](http://campkindle.ca) for information on corporate packages and rental opportunities. Or ask about our Kindle Care Days by emailing [staff@kidscancercare.ab.ca](mailto:staff@kidscancercare.ab.ca). ■



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how  
to help

# 5 things you can do to help

## facebook



You can see all the great photos and videos 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



See our stories of hope and courage. Check out our YouTube channel KidsCancerCare.

## websites



Stay up-to-date with the latest news and events and find out how you can get involved at [kidscancercare.ab.ca](http://kidscancercare.ab.ca).

Book your next school or corporate retreat or family reunion at [campkindle.ca](http://campkindle.ca).

### 1. DONATE

Please give generously to our winter fundraising appeal, delivered this month to your home. You can make a one-time gift or join our League of Superheroes Monthly Giving Program and make a meaningful contribution to kids overtime.

### 2. JOIN

Events need people like you. Register for one of our many fundraising events this spring or summer. There really is something for everyone. Whether you love to dance, golf, run, cycle or just need a haircut, we have a fundraising event for you.

### 3. FUNDRAISE

Become one of many Albertans hosting fundraising events on our behalf and show kids with cancer you care. A community fundraising event can be as big or as small as you like. Whether it's a chili cook-off, a bake sale, a Stampede ho-down or charity golf tournament, it's all fun and helps the kids.

### 4. SHAVE

Show moral support for children who lose their hair to cancer by shaving your head and raising funds. If bald isn't your style, you can always opt for a new haircut or support someone else with a generous donation.

**5. TAKE ACTION** during Childhood Cancer Awareness Month. We have big plans in store for this September with lots of ways you can get involved—chalk, talk, Tweet, donate, fundraise or volunteer. Let the world know its Childhood Cancer Awareness Month and that you're taking a stand for children with cancer. ■



Mark Derry Photography



Mark Derry Photography



# events

## you can get involved

To find out how you can get involved in our programs and fundraising events as a participant, volunteer or sponsor, contact us at 403 216 9210 or [staff@kidscancercare.ab.ca](mailto:staff@kidscancercare.ab.ca).



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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 contact us at 403 216 9210 or email [staff@kidscancercare.ab.ca](mailto:staff@kidscancercare.ab.ca).

For a complete list of our fundraising events and our kids and family programs, please visit us online at [kidscancercare.ab.ca](http://kidscancercare.ab.ca)

# give kids a mulligan this summer

THURSDAY  
AUGUST 4

Cottonwood Golf  
& Country Club



22<sup>nd</sup>  
annual  
Don and Joanne  
and the Coach  
Golf a Kid  
to Camp 2016  
tournament

REGISTER TODAY!  
[kidscancercare.ab.ca](http://kidscancercare.ab.ca)

kids  
cancer care



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