

**kids
candidly**

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

**kids
cancer care**

**in this
Issue**

joel

page 4



Unique Perspectives Photography

SPRING/SUMMER 2012 ISSUE

CEO message

you can be part of something big

September is Childhood Cancer Awareness Month. Find out how you can get involved to raise funds and awareness for children with cancer. Call Lauren for details, 403 984 1223.

dear friends,

I love this time of year. As spring slowly reveals its colours, kids eagerly await camp. Our new and improved Camp Kindle opens in July and kids from across the province are in for a real treat.

Camp Kindle still has its same charm, but with new buildings, roadways and, most importantly, a pool.

We have many to thank for making these renovations possible. Donors to our capital campaign see the value of this project and how it will impact our families. If you have made a gift to Camp Kindle, I thank you from the bottom of my heart.

It is so thrilling to see your gifts come to life as construction crews put the finishing touches on the camp. If you wish to be part of this project, please call us. We

still have money to raise to meet our \$8 million fundraising goal.

As kids prepare for camp, we are heading into our busiest fundraising season. I love this time of year because it's our chance to get out and meet you. If you cycle, run, walk, golf, ride a motorbike or just need a good haircut, we have an event for you!

Thank you for your support. Here's to a great summer!

Sincerely,

Christine McIver

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



cancer & birth defects

Childhood cancer survivors are not at a higher risk of having children with birth defects according to a new study published online in the Journal of Clinical Oncology.

The study looked at 4,699 children of 1,128 men and 1,627 women, who were five-year childhood cancer survivors, and found these children did not have higher incidents of birth defects—even if the parent had been exposed to radiation to the testes or ovaries or to chemotherapy involving DNA damage.

The prevalence of birth defects in children whose mothers were exposed to radiation or chemotherapy was 3.5 per cent—0.5 per cent higher than children whose mothers did not have cancer. For children whose fathers had child-

hood cancer, the prevalence was 1.9 per cent versus 1.7 per cent. These differences are not seen as clinically significant by the authors of the study.

"Childhood cancer survivors face real reproductive concerns, including unknowns related to the effects of therapy," said lead author Dr. Lisa Signorello, associate professor of medicine at Vanderbilt University in Nashville, TN. "Hopefully this study will provide some reassurance that their children are unlikely to be at

continued on page 6

photo: (left) Jason is one of many survivors who's paid a price to beat cancer. He faces a 95-per-cent chance of being sterile due to radiation treatments.

Mark Derry Photography



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 2012 video 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.



Shave music video wins big

Our new shave music video, which launched last winter, won big at the Media Communications Association International (MCAI) Silver Awards this spring, taking home two awards for editing and for external communications. Produced by Freshwater Creative, the shave video was filmed at Nellie McClung School and Andrew Sibbald School. Music and lyrics were composed by Dewi Wood of Infinite Loop. View the award-winning video online and don't forget to share it.



photo: (above) Bald is beautiful at Elboya School.

New family camp programs

As a new landlord, Kids Cancer Care is already flexing its new-found freedom in camp programming and scheduling. In 2012, the Foundation is offering two new camp programs for Alberta families:

1. **SunMaker family camp July 9 - 13**, for families affected by childhood cancer;
2. **SunHaven family camp, November 16 -18**, for families affected by a parent's cancer.

To register or to find out more about our family camps, contact Mary at phillipo@kidscancercare.ab.ca or 403 984 1227 or visit us online.

Teen leaders build homes & hope

On March 8, 2012, 18 teens from Alberta embarked on a journey to Mexico that changed lives forever. The teens and 45 mentors from the Rotary Club of West Calgary built four homes in two days for low income families in Ensenada.

Part of Kids Cancer Care's Teen Leadership Program, the experience is designed to build more than homes. Each teen must raise a minimum of \$1,000 for the trip, so they develop fundraising and leadership skills, while expanding their sense of social responsibility and self-esteem. The experience also builds bridges across cultures and hope for families in need.

photo: (below) Jodey pitches in at the 2012 Mexico Home Build.

Camp Kindle ready

Construction at Camp Kindle is nearing completion and the new camp will open its gates July 9, 2012. After installing new infrastructure—water, sewage, electrical and mechanical—last winter, construction crews laid foundations and footings for the new buildings. The crews are now busy putting the final touches on the facilities, which include a new medical centre, dining hall, volunteer lodge, camper dorms, swimming pool and a state-of-the-art ropes and climbing course. Camp Kindle will also have new roadways and improved wheelchair accessibility.





research

JOURNEY OF A PRINCE

Geoff Simpson Photography

**you can
help kids
beat this**

Thank you for giving children with cancer a fighting chance at our annual **Parents' Quest for the Cure** gala. You raised \$110,000 for research.

journey of a prince

“Three days after his 10th birthday, our son Joel was diagnosed with medulloblastoma. It was the darkest day of our lives and the first time Joel ever saw his father cry.”—Ed Zukowski

They called him the Polish Prince at the hospital and, with a name like Zukowski, it's not hard to imagine why. But Joel's nickname originated from something much deeper than a surname. The nurses and doctors called him the Polish Prince because, for a 10-year-old boy, Joel exhibited uncommon valor in the face of cancer.

“Joel faced every treatment with such quiet courage,” says Joel's father Ed. “He was so brave in his acceptance of it. He made it so much easier on the medical staff because he didn't fight it.”

After months of bizarre symptoms that stumped both his parents and doctors, Joel was diagnosed with medulloblastoma. He had a tumour, about the size of a kiwi, at the base of his head. Finally they understood, the source of the migraines, dizzy spells, nausea and vomiting that had plagued Joel over the last year.

It was a solid mass, which hadn't spread, so it was operable. The treatment plan called for surgery, followed by radiation and four rounds of high-dose chemotherapy, each followed by a stem cell transplant. It demanded vast reserves of inner strength and self-mastery from Joel.

When Joel woke up after surgery, he was unable to speak or move. He would lie, staring at the ceiling for hours on end. It was weeks before Joel could move again.



Before giving him chemo, they harvested 350 million stem cells from his body, which they later froze and re-injected after each round of chemo. The hardest part for Joel wasn't the vomiting or the hair loss. It was lying perfectly still for two days straight, while they harvested the cells.

and it tells us that current therapies are not good enough for 20 per cent of kids,” says Dr. Doug Strother.*

Although Joel is cancer-free today, he and his family are learning that they'll be on this journey longer than they ever imagined. Joel will experience delayed side effects as he gets older.



Radiation demanded even more restraint and self-control. With each round of radiation, Joel's face was fit into a plastic mask secured to the gurney on which he laid. Again, Joel had to lie perfectly still, so the radiation would hit only specified areas and avoid healthy brain tissue. The procedure made him nauseous and he had to summon all his powers of concentration to avoid throwing up.

Three years ago, Joel's treatment was considered radical by most Canadian oncologists. Today, it is considered the most effective and safest treatment for medulloblastoma, curing 80 per cent of children diagnosed with it. Joel and his family were pioneers and their story is a testament to the power of research.

“But a survival rate tells us nothing of the quality of the survivors' lives

continued on page 6

photo: (above) Joel with his father Ed (right), nurse Michelle (left) and nurse practitioner Kelly after surgery. Joel had a temporary external ventricular drain inserted to redirect cerebral spinal fluid that was blocked due to the tumour and causing pressure in his brain.

photo: (left) Joel's war wound. After surgically removing the tumour at the base of his head doctors stitched Joel up with 35 staples.

* Dr. Strother is director of the Hematology, Oncology and Transplant Program at Alberta Children's Hospital and chief of the Pediatric Oncology and Blood and Bone Marrow Transplant Division for the University of Calgary, Faculty of Medicine. He is also a member of Kids Cancer Care's board of directors.

journey of a prince *continued from page 5*

The 13-year-old prince already has decreased lung capacity and muscle strength and his bones are becoming more brittle. He's also at higher risk for developing other types of cancer. Joel recently began growth hormone therapy, which he may need the rest of his life. After not growing for two years, Joel was thrilled when he grew three millimeters in a month.

No one knows the importance of ongoing research better than the Zukowskis: "Medical teams are not only trying to save lives," says Joel's mom Dale. "They're constantly striving to improve existing therapies to reduce toxicity and the damage it imposes on their little bodies."

But Joel and his family seem to have a greater share of courage and strength and they're taking things in stride. Joel is doing well at school. He's returned to hockey and plays with the Bow Valley Fiddlers.

"Although it has been so challenging," says Ed. "This experience has given us so much. It's forced us to open up and share our burdens with others, so we could work

through it and allow ourselves to heal. What kept Joel going the whole time was remembering all the people who love him and Kids Cancer Care, who showed us we are not alone."

photo: (left) New research and an aggressive treatment plan saved Joel's life. Now he's living life with gusto. Joel (left) with his mother Dale and his brother Eric at the 2011 High Hopes Challenge.

you can help kids beat the odds

New insights into medulloblastoma

With your generous support Kids Cancer Care awarded Dr. Jennifer Chan a \$300K research establishment award in 2010, attracting this talented young cancer scientist to establish her research lab here at the University of Calgary. Dr. Chan is part of a Calgary research team that is making new discoveries into medulloblastoma.

Calgary cancer scientists are now discovering that medulloblastoma is not really one entity. There appears to be subtypes of medulloblastoma, which behave differently from one another and, are therefore, more or less sensitive to certain treatments. The behaviour of these medulloblastoma subtypes is determined by defects in the genes of the tumour cells.

U of C scientists are now creating models of medulloblastoma and other brain tumours, so they can study these cancers and the effects of drugs on them before introducing them to children. Working with these models enables medical teams to more quickly and more safely introduce promising new drugs to kids whose frontline therapy has failed.



cancer & birth defects *continued from page 2*

increased risk for genetic defects stemming from their earlier treatment."

Radiation to a girl's reproductive organs can lead to infertility or increase the risk of miscarriage, stillbirth, low birth weight and pre-term birth. It can also cause infertility in boys if applied to their testes. Chemotherapy can also cause reproductive organs to malfunction.

For these reasons, the researchers set out to determine whether offspring of childhood cancer survivors were

also affected by cancer treatments.

"Whether humans have the capacity to repair damage to germ cell DNA or whether the various processes of reproduction filter out such insults (through early pregnancy losses or infertility) merit exploration," write the authors.

Read the original story <http://www.cbc.ca/news/health/story/2011/12/13/childhood-cancer-birth-defects.html>

**the
power
of you**



IT TAKES A TOWN

"In the excitement and craziness of it all, there were quiet moments that reduced me to tears. One day, a small envelope with Rowan's name on it was left at her school. It contained \$6 from a 6-year-old boy and \$4 from his 4-year-old sister—their allowances." - Tara Jacques

That heartfelt donation from the little boy and his sister was just one of many donations received by Rowan Jacques last winter, when she shaved her head for children with cancer. But it was a donation that stood out for her mom Tara Jacques.

"I knew their father had just finished treatment for prostate cancer, so seeing their contribution touched my heart in the deepest place," Tara says. "It was a humbling reminder that each donation has a story behind it and that everyone has been affected by this disease on some level."

Whether people were personally touched by cancer or simply moved by Rowan's courage, the news of her head shave spread like wildfire.

It started in the principal's office, where the seven-year-old Innisfail girl shared her plans and received full support. Four weeks before the shave, Rowan announced her plans at a school assembly in the gymnasium. That's when the vice principal and four more students stepped up to join Rowan's shave fundraising movement.

The local newspaper ran a story about the shave, creating even more buzz. Enthusiasm swept through the hallways of Ecole John Wilson Elementary School and into the streets of Innisfail, where community-minded individuals and businesses, touched by one girl's courage, began sending donations and words of encouragement.

First it was a large donation from the Lion's Club of Olds. Then it was a call from Mortgage Alliance, who pledged to give one dollar for every Facebook "Like" they received. When the local paper ran a follow-up story on this fundraising challenge, the town of Innisfail caught fire.

Rowan was in demand, doing interviews with Olds radio stations Rock 104.5 and 96.5. More donations and accolades rolled in.

continued on page 10

photo: (above) Tara Jacques is proud of her daughter Rowan who inspired an entire community to give.

camp

with open arms

Will Mom see me graduate from high school? How will Mom cope if Dad doesn't make it? Will Mom get better? Is there anyone who understands what I'm going through?

These are some of the thoughts that consume a child who has a parent with cancer. For these kids, life is filled with uncertainty and anxiety as they stand by and helplessly watch Mom or Dad battle cancer. Paris (15) and Kasia (13) Kowicki know this reality all too well.

Once carefree teenagers, Paris and Kasia were busy with school, friends and the latest fashion trends. That changed in 2011, when their father was diagnosed with cholangiocarcinoma, an extremely rare and aggressive type of cancer. Their young lives are now fraught with worry, sorrow and fear.

Enter Camp SunHaven. "A friend of the family heard about Camp SunHaven and told our mom," says Paris. "Initially, I didn't want to go. I was really nervous and didn't want to talk about what I was going through."

Kids Cancer Care introduced Camp SunHaven in 2010 with young people like Paris and Kasia in mind. No child wants to meet the criteria to go to this camp, but for those who do, SunHaven is there to ease their burden and pain.

With a gentle nudge from their mom and dad, Paris and Kasia embarked on their first camp adventure. "When we first drove into Camp Kindle, it was like something you see in the movies," says Paris. "My sister and I both had such a good time and the experience made us realize that we're not alone, that there are other kids going through the same thing."

"The experience made us realize that we're not alone" — Paris



Unique Perspectives Photography

From the high ropes course, to the giant swing, to the laughs and friendships made, Camp SunHaven offered the girls the break they needed. "With their dad's health getting worse, we couldn't go on a family holiday and the girls needed an escape from cancer," says their mom Wendy. "Camp SunHaven gave my daughters a chance to be kids again and meet children in similar circumstances. When I picked them up they were so happy."

Paris and Kasia will be coming back to camp this summer. Now more than ever, they will need the support Camp SunHaven has to offer. This past November, their dad lost his courageous battle to cancer and the girls are learning to navigate this world without him. Camp SunHaven will be waiting for them with open arms.

photo: Paris (above) and Kasia (left) enjoyed their time at Camp Kindle and realized they are not alone in their struggles.

you can help kids heal

Thank you RBC Foundation for providing a healing place for children who have a parent with cancer. Your generous support for Camp SunHaven is helping kids with big worries heal.

Unique Perspectives Photography



talking about cancer with children

Cancer. Is there any other word that strikes as much fear? A diagnosis more unfair? How do you talk about cancer with your children?

we're here too

There is strong evidence to suggest that children do better if they can talk openly and honestly about cancer. Sometimes they just need a friend who understands what they're going through.

To learn more about our cancer camps, please contact Mary Phillippo at 403 984 1227 or phillipo@kidscancercare.ab.ca.

When facing a cancer diagnosis in the family, talking about it may be one of the hardest things you do—especially when it comes to your children. Although it may be frightening, being open and honest about cancer may be the best thing you can do to help your children cope.

10 reasons to talk

1. Children are sensitive to family dynamics and may sense something is wrong anyway.
2. Not knowing, but feeling something is wrong, may leave children feeling anxious and insecure.
3. With limited information, children may imagine things are worse than they are.
4. They may feel hurt or betrayed if they hear the news from someone else.
5. Pretending everything is fine, when it's not, teaches children to keep their worries inside.
6. Talking with your children will help you control the type and amount of information they receive and how they take it in.
7. Talking openly will build intimacy and draw the family closer.
8. Open communication encourages children to ask questions and share how they feel.
9. Talking openly gives you a chance to comfort your children and to check in, so you can correct any misinformation they may have about cancer.
10. Teaching children to talk openly helps them to grow emotionally and gives them valuable coping skills for life.

How to tell children

- Choose a time to talk when you're feeling calm.
- Have another adult present to show your children there are other adults they can talk to and who will support them. If you're a single parent, ask a close relative or friend to be there.
- Use words kids understand, i.e., doctor instead of oncologist or medicine instead of chemotherapy.
- Be prepared to repeat the information, perhaps many times. Keep checking in to see if they understand. You may need to take cues from their questions, eye contact and body language.
- Don't be afraid to share your feelings too. It may help them express theirs.

What to say

- Begin with basic information, such as the name of the cancer, the body part it affects, the treatment and its possible side effects.
- Be honest about the chances of recovery. Balance hope with reality by assuring them doctors are doing everything possible.
- Tell your children that cancer is not contagious.
- Tell your children it's not their fault. Nothing they did caused the cancer.
- Cancer treatments disrupt routines, so tell them how their lives will change, i.e., schedule changes in school, sports, music lessons, meals, chores and so on.
- Encourage your children to come to you (your partner or another trustworthy adult) with their worries and questions. Promise that you too will be open and honest with your feelings.

Above information abridged and summarized from cancer sites: cancer.ca; cancervic.org.au; cancercouncil.com.au; and cancer.org.



sneak-a-peek

camp kindle

Construction at Camp Kindle is almost finished. The newly renovated Camp Kindle will open its gates to kids and families on July 9, 2012.

Become a fan on Facebook and see the final stages of construction unfold at Camp Kindle.



Breaking ground for Kris's maintenance shop



The new dining centre



Water treatment and mechanical building



Indoor activity hall and future BBQ site



Dogwood lodge - camper dorm

it takes a town continued from page 7

On December 2, 2011 Rowan and four students and the vice principal of Ecole John Wilson Elementary School shaved their heads for children with cancer before an excited audience of students and guests. When they announced that, together, they had raised \$10,154 and beat their \$2,500 fundraising goal four times over, ear-piercing screams rose from the bleachers.

What started as a glimmer of kindness in a seven-year-old girl ignited an entire community to take action in the fight against children's cancer. Rowan's mother Tara is still in awe of the experience. "It was one of the most life-affirming experiences I've ever had. Seeing my little girl inspire such passion in so many people, who gave their heart and

soul to a cause that will affect all of us in some way, was, in a word, priceless."

you can inspire great things

Seven-year-old Rowan ignited a community and helped raise \$10,154 for children with cancer. Thank you Rowan and Ecole John Wilson Elementary School and the Innisfail community for your generosity and courage.

how you can help

september is childhood cancer awareness month

5 ways you can help kids this September

wish list

We need new appliances for our staff & volunteer lodges:

- 2 fridges
- 2 stoves
- 2 dishwashers
- 2 kettles
- 2 toaster ovens
- 2 toasters

Appliances must be new.

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



1. Donate

Our annual fall fundraising appeal will be out in September. Show the kids they're not alone by making a donation during Childhood Cancer Awareness Month.

2. Host a fundraising event

Kids Cancer Care has set an ambitious goal of ensuring that there is a community fundraising initiative every day in September with a goal of raising \$100K in one month. You can be one of the many Albertans to host a fundraising event for the kids. It doesn't take much to organize an initiative. Please contact us for ideas.

3. Cycle in the National Inside Ride

Coast to Coast Against Cancer is rolling into Calgary again this September for the National Inside Ride. Enter a team in this high-powered cycling event and raise money for children with cancer. Last year, this national fundraising initiative raised \$2M for children's hospitals and cancer charities across Canada.

4. Shave Your Lid for a Kid®

Nothing says "I care" better than shaving your head for a child with cancer. It's a strong visible statement that draws attention to the cause, while raising much-needed funds that have the power to change lives.

5. Tune-in, talk & tweet

Tune-in to Astral radio stations—Virgin 98.5, CJAY 92 and Country 1060—and to CTV Calgary this September to find out what's on for Childhood Cancer Awareness Month. Volunteers from CTV, Albi Renova and Albi Homes are heading to Camp Kindle for a week in September for a special edition of CTV Operation Renovation with Albi Renova. Tell your friends and family to tune-in and tweet it too.

If you can help, please contact us at 403 216 9210 or staff@kidscancercare.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

Survivor Day

Sunday, June 3, 2012
Calaway Park

High Hopes Challenge

presented by Citytv
Saturday, June 16, 2012
Camp Kindle

Ride for a Lifetime

presented by Brookfield Homes
June 22 – 24, 2012
Calgary -> Fernie -> Nakusp -> Calgary

Camp Kindle Grand Opening

Friday, July 13, 2012
Camp Kindle

Tour for Kids - Alberta

July 13 – 15, 2012
Rocky Mountains

Don & Joanne Golf a Kid to Camp tournament

presented by Trico Homes & XL103 FM
Thursday, August 9, 2012
Cottonwood Golf & Country Club

Dad & Daughter Butterfly Gala

presented by Dilawri Automotive Group
Saturday, October 20, 2012
TELUS Convention Centre
Tickets on sale June 18

It's all for the kids



Don & Joanne Golf a kid to camp 2012 Tournament

Thursday, August 9
Cottonwood Golf
& Country Club

Call 403.984.1223 or
[go to kidscancercare.ab.ca](http://go.to/kidscancercare.ab.ca)
to register!

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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