

**kids
candidly**

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

**kids
cancer care**

in this Issue

Ryder & Sloan



page 4

SPRING/SUMMER 2014 ISSUE

CEO message



Look for our
spring fundraising
in the mail.

dear friends,



Spring is here and the signs of new life and hope are everywhere—especially here at Kids Cancer Care.

Every year, we are blessed with the joy of new life when hundreds of kids arrive at Camp Kindle, eager to experience the magic of summer camp. We have you to thank for this.

This year, with your generous support, we will complete our \$2.5 million commitment to the experimental and applied therapeutics (EXPAT) program at the Alberta Children's Hospital and University of Calgary.

Because of you, we were able to complete this five-year commitment a full year ahead of schedule, giving researchers the support they need to investigate the most difficult childhood cancers.

This vital research program is offering new therapies where conventional therapies have failed. For some kids, this means a second chance at life.

As the kids prepare for camp, we are heading into our busiest fundraising season. Please look for our spring fundraising appeal and give generously for children and families affected by cancer.

Please check out our fundraising events too. Fundraising events are integral to our work and they would not be possible without you.

Events also give us the opportunity to get out and meet you, so if you cycle, run, golf, ride a motorbike or just need a good haircut, I look forward to seeing you soon!

Thank you for giving so generously to support children with cancer.

Sincerely,

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

children's cancer research in Canada

SPECIAL REPORT

In 2013, the Canadian Cancer Research Alliance released a special report on pediatric cancer research in Canada. Pointing to the growing long-term costs associated with childhood cancer, it makes a powerful case for a stronger investment in research. What follows is a summary of its findings.

Higher survival rates

Survival rates for many childhood cancers have increased significantly over the past 30 years with an overall five-year survival rate of 82 per cent for kids diagnosed between 2002 and 2006.

As survival rates improve, the number of long-term survivors continues to grow. There are approximately 30,000 childhood cancer survivors living in Canada today.

Permanent after effects

Unfortunately, a significant portion of these survivors experience life-long adverse effects related to the cancer itself or the cancer treatments. Approximately 75 per cent of survivors experience at least one chronic medical problem in their lifetime and more than a third experience a late effect that is severe or life-threatening.

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news & media

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.

website



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

Bereaved Family Camp

Recognizing the unique needs of bereaved families, Kids Cancer Care is now offering a Family Camp for bereaved families, **May 9 through 11, 2014**. Please join us.

To register for the bereaved Family Camp, visit kidscancercare.ab.ca, call Mary at 403 984 1227 or email her at phillipo@kidscancercare.ab.ca.

Keep us in your inbox

Canadian e-communication laws are changing as of July 1, 2014. To comply with these regulations, in the coming months, we will send you an email, asking you to opt in to continue receiving email communication from Kids Cancer Care and Camp Kindle. Please check 'yes', so we can stay in touch!

Biological cancer therapies

Dr. Brian Mahoney left his position at the Children's Hospital of Eastern Ontario Research Institute in Ottawa to join the children's cancer team here in Calgary. As part of the experimental and applied therapeutics program in Calgary, Dr. Mahoney is investigating the use of biological agents such as oncolytic viruses as an alternative to drug-based cancer therapies. Non-toxic to humans, these viruses can be manipulated to target and destroy cancerous tumours, while also alerting the patient's immune system about the presence of cancer cells.

Compassionate Care Leave

Did you know that as of February 1, 2014 **Compassionate Care Leave** enables Albertans to take a temporary job-protected leave of absence to care for an ill family member?

For more information, visit the Alberta Government Compassionate Care Leave webpage: <http://tinyurl.com/ptvjvvn>

Thank you for providing hope

For years, **Joanne and Jonathan McDonald** have reached out to parents and families at our weekly Pizza Night program at the Alberta Children's Hospital. Having seen their own daughter Justine through cancer when she was just a baby, Joanne and Jonathan were able to offer hope and support to other parents. After 15 years of volunteer service to the Pizza Night program and close to 20 years of volunteer service to the foundation as a whole, Joanne and Jonathan have decided to step down from the Pizza Night program to give other parent volunteers a chance to give back in this capacity. **Thank you, Joanne and Jonathan, for your dedication and service. You will be missed.**

WANTED! Teens with cancer

If you are a teen or young adult who has or had cancer when you were between the ages of 14 and 20, a University of Calgary research team would like to hear from you. **Dr. Nancy Moules** is conducting a research study called, *Sexuality and Adolescents with Cancer*, to understand how teens navigate cancer and sexuality in order to help teens with cancer in the future.

For more information, contact **Dr. Nancy Moules** at 403 220 4635 or email her at nmoules@ucalgary.ab.ca.

Bright stars

Tierra Walter (right), a teen leader and cancer survivor, is a recipient of a 2013 *ConocoPhillips Youth of Distinction Advocacy Award* for her volunteer work with Kids Cancer Care's Teen Leadership Program.



KCC archives

Matthew Carrington, a bereaved sibling in the Kids Cancer Care community, was awarded a *Youth Philanthropist of the Year Award* from **Ronald McDonald House** for his fundraising and volunteer efforts.

feature
story

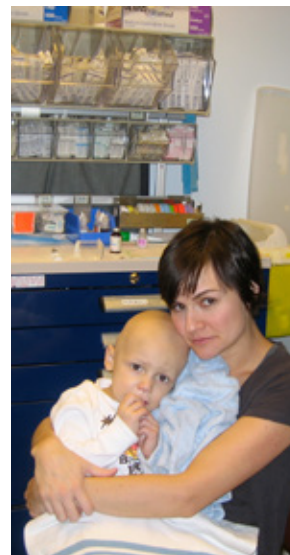


Cruz

Ryder

Sloan

TRANSPLANTS



Photos: Courtesy of the McGinn-Thompson family

Blood brothers

a story of two brothers and how, together, they survived a harrowing cancer journey

"It was like serving jail time. You're so isolated, you lose all your freedom."

— Karin McGinn

"They essentially take the child up to death's door and then start rebuilding him. It was gut-wrenching to see Sloan like this."

—Karin McGinn

Sloan and Ryder are blood brothers. They're not just best friends who nicked their palms with a jackknife and squeezed their palms together to mix their blood. No, these boys are blood brothers in the truest sense of the title.

Their mom had just given birth to their little brother Cruz when Sloan was diagnosed with acute myeloid leukemia. He was two. When Sloan relapsed after his fourth round of chemotherapy, his parents, Karin McGinn and Rodney Thompson, knew his only hope for survival was a blood stem cell transplant.

Blood and bone marrow transplants are extremely high-risk and life-threatening procedures that involve months of high-dose chemotherapy and radiation to wipe out the patient's white blood cells to replace them with healthy blood cells.

Still reeling from this heart-crushing news, the McGinn-Thompsons discovered that Sloan's brother Ryder was an identical donor match for transplant. In the turbulent world of cancer and transplantation, they had just hit the jackpot.

"The odds of a sibling match are only 25 per cent," says Karin, "but transplants with sibling donors have the best possible outcomes. There are fewer complications, like graft versus host disease, and the chances of long-term survival are much higher."

Still, it's a high-risk procedure that demands a huge commitment from the entire family.

"They essentially take the child up to death's door and then start rebuilding him," says Karin. "If it doesn't work, the child dies because there's nothing left of him, no immune system is left. It was gut-wrenching to see Sloan like this. He was so sick he

was vomiting his own stomach lining. It was horrible."

It was a gruelling experience that lasted well over a year.

"Rodney took a leave of absence from work and he and I did shifts at the hospital—three nights on and three nights off," says Karin. "Cruz was still nursing, so he was always right there with Sloan and I at the hospital. His bedroom became a playpen in the bathroom of Sloan's hospital room."

The intense chemo and radiation treatments left Sloan with a dangerously low immune system and required that he be isolated from the outside world for months afterwards. "Before transplant, Sloan spent 72 days without a break in the hospital. Then it was another full year before he recovered," says Karin. "Camp was the only thing Sloan could do that whole year."

Constantly spelling each other off at the hospital or at home, Karin and Rodney hadn't spent any time together in over a year. "Camp was *our* first break too," Karin laughs.

Sloan and his family survived the transplant, but not without enduring its traumatic aftershock. Although Sloan has been cancer-free for five years, he still goes for baseline testing every year. While many of the long-term side effects are still unknown, what is certain is that Sloan is infertile and at high-risk for certain heart conditions. Fortunately, Sloan hasn't shown any signs of cognitive impairment. He's a strong student in both reading and math.

After the family's cancer crisis, Karin suffered from severe insomnia and anxiety and was eventually treated for post-traumatic stress disorder. "When your child's in treatment,

Blood and bone marrow transplants are high-risk, life-threatening procedures that involve months of high-dose chemotherapy and radiation to wipe out the patient's white blood cells to replace them with healthy blood cells.



About the Artwork

Karin McGinn exhibited her work, *Blood Brothers* (above), at the Marion Nicoll Gallery and the +15 at the Epcor Centre for Performing Arts throughout February and March. The individual life-size figures in this fiber work commemorate the special bond shared by her two sons Sloan and Ryder. When Sloan (2) was diagnosed with a highly aggressive blood cancer in 2008, Ryder (4) donated his blood cells to save his brother's life. The transplant was successful and the two boys and their baby brother Cruz are thriving today.

"Camp was the only thing Sloan could do that whole year."

—Karin McGinn

you feel like you have a purpose and that you're actively treating the cancer," says Karin. "But when you're released from the hospital you feel like your safety net has been taken away. The daily blood cell counts are no longer happening and you no longer know if you're on top of it. I was plagued with fear that it would return."

Today, the McGinn-Thompsons have regained their stride, along with a healthy appreciation for life. "I have no illusions about death," says Karin. "We don't know what Sloan's life expectancy is, or ours, so

we try to embrace our life now and enjoy each other while we can."

Dad is working at his business, Vogogo, and Mom is doing a fine arts degree at the Alberta College of Art and Design. And the boys? They are growing like wildflowers, endlessly rough-housing and teasing each other as brothers do.

"When Ryder gets in trouble for teasing his brother now, he'll say, 'Mom, I saved his life; give me a break.'" ■

Eunice's last stand: a legacy of love

"She was a tiger lily, not a shrinking violet." —Melinda James

An orchestra of colour animates Melinda James' yard. Tiger lilies, irises, daisies and brown eyed Susans—each one carefully chosen and planted with love.

"When my Aunt Eunice passed away, I wanted to keep something of her," says Melinda. "She loved to garden, so I looked out at her garden and knew exactly what to do. I went out and dug up some of her flower bulbs and planted them in my garden. Tiger Lilies were her favourite. Now, every spring, when I see those flowers bloom, I know she is still with me. They are my living memory of Aunt Eunice, my memory garden."

Melinda's Aunt Eunice will also live on in the lives of many others through a bequest she made in her will to Kids Cancer Care and the Calgary Emergency Women's Shelter. Her legacy gift speaks to the life she lived and the people she cherished most.

"Eunice was a very strong woman, who lived life on her own terms," says Melinda. "But she always had a soft spot for the underdog and she made no bones about it. She had strong convictions and she wasn't afraid to speak her mind."

Although Eunice chose not to marry, she loved children. She adored all her nieces and nephews and their children.

Often hiding behind a gruff exterior, Eunice had a gentle playful side, tobogganing in the winter and hiking in the summer with Melinda and her boys Tyne and Taylor. She was the fun aunt who dressed up as Santa at Christmas just to see the wonder in her great nephews' eyes.

Eunice spent many Christmases with Melinda and her boys and they shared numerous family dinners together. "Eunice loved to cook! She was the person who inspired my passion for cooking," says Melinda. "I love opening cookbooks she gave me with special little messages scribed to me in her handwriting. She was the kindest person."

Now, her kindness and strength of conviction will touch the lives of countless others.

In Eunice's world, a child with cancer or a woman mistreated by her partner was wrong—things worth taking a stand for. And so, with a \$109,785 bequest each to Kids Cancer Care and the Calgary Emergency Women's Shelter, Eunice took her last stand, one that will help Alberta women and children for years to come. ■

Eunice Yvonne Marie McLaughlin

(1952 to 2012)

Eunice McLaughlin was the youngest of eight children born and raised on the family farm in Mannville, Alberta. She left the homestead in 1970, bound for Edmonton, where she began a career with Revenue Canada. Eunice later moved to Calgary, which she called home the rest of her life. When Eunice passed away in August 2012, she left a legacy of love for Alberta children with a \$109,785 bequest in her will to Kids Cancer Care. Her generous gift will be there for kids affected by cancer for years to come.



Left: Eunice enjoys a special moment with her great nephew Clark.
Above: Eunice with her great nephews Tyne (right) and Taylor (left) on a hike near Blue Rock, west of Turner Valley.
Photos courtesy of Eunice's family.

camp

you are giving them a safe place to be

"It was so unreal because he's so little. It was like a slap in the face and it just kept hitting us harder and faster—surgery, cancer, chemotherapy. There was no time to think or feel. We were in survival mode."

—Inge van Galen

"These camps and programs are the only thing we can do."

—Inge van Galen

Finn is 14 months old and the only world he knows is cancer—central lines, needle pokes, chemo ports, dressing changes and hospital stays.

Finn has spent his first year of life fighting for it.

His parents' only reference point is a cheerful, but sick little boy in need of constant medical care. They do not know what it's like to have a healthy child nor are they familiar with the sense of peace this brings.

Amid the frightening and clinical world of childhood cancer, you reached out and helped give Finn and his parents their first real break from cancer. With your generous donation, you helped give the van Galen family the gift of respite at Family Camp.

"At first we were hesitant," says Inge van Galen, Finn's mother, recalling the moment they were first invited to Family Camp at Camp Kindle. "We were about five weeks into Finn's treatment and I think we were just terrified of committing ourselves to the idea of a children's cancer community. It seemed like such a final stand, so absolute."

In the end, Inge and Martjin van Galen decided it would be good to connect with others on this path, so they packed their bags for the weekend and headed to Camp Kindle.

The entire Family Camp weekend was about relaxation and fun—building birdhouses, enjoying meals with other parents, hiking trips and drumming circles.

"We had a fantastic time at camp! It was so well-organized and the staff and volunteers were amazing," Inge says. "After Family Camp, we became instant regulars. We started going to all the events at Camp Kindle—Mother's Day Brunch, Survivor Day."

Kids Cancer Care's family camps and family programs, offered year-round, are often a lifeline for families forced into isolation because their child's immune system is compromised by chemotherapy.

"I think people can underestimate the impact of forced isolation on the child and the family," says Inge. "You're literally housebound because visiting a grocery store or meeting a coughing child, as you come around the corner, can be fatal. These camps and programs are the only thing we can do."

Still on chemotherapy, Finn was sick for much of that weekend at Family Camp. He and Mom spent a lot of time in the ReKindle Clinic, where volunteers administered tender loving care 24/7.

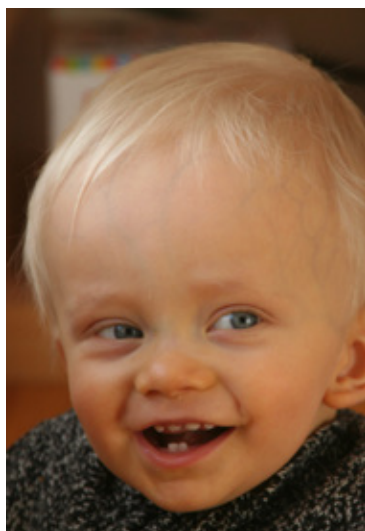
"They were so wonderful," recalls Inge. "One evening, the volunteers actually sat on the floor by Finn's bed, while he slept, so we could join other parents in the evening activities. It was an amazing break for us."

But things are about to change for Finn and his parents. Finn finished his last chemo treatment in January. He's responded well to treatment and his prognosis is excellent.

"The world is going to open up for Finn in 2014!" says Inge. "As soon as he's ready, I'm going to take him everywhere—Heritage Park, Calaway Park, the Calgary Zoo."

And, of course, Camp Kindle.

It's been a full year since their first Family Camp and Inge is electric with excitement: "This time, we'll be the ones with the good cancer story to share." ■



Photos: Courtesy of the van Galen family

Helping families through transplant

“Transplant is a high-risk, life-threatening procedure that brings with it a host of complicated decisions and challenges for families. It impacts the psychosocial life of the entire family.”

—Wendy Pelletier

With funding from the Alberta Children’s Hospital Research Institute for Child and Maternal Health, Wendy Pelletier, Dr. Fiona Schulte and their colleagues are conducting a multi-year study that is seeking to understand the psychological impacts of transplants. Interviewing families at key points in the transplant experience—before, during and after—the research team is trying to determine whether there are critical points in the experience that are especially challenging and put the patient and family at greater risk for psychological difficulties. Arming health care professionals with a deeper understanding of the psychological implications of this experience, this research will be instrumental in designing intervention programs and services to support families through the transplant experience.

Blood and bone marrow transplants are intense procedures for children and families to navigate. It’s not only the extreme physical demands it places on the child—although these are plentiful and severe. It’s also the sheer emotional and mental strain it puts on the family that makes it so tough.

“Transplant is a huge commitment,” says Wendy Pelletier, an oncology social worker at the Alberta Children’s Hospital. “Families often travel long distances to Calgary for transplant and must remain here for many, many months. The emotional and financial burden on families is enormous.”



After finding a donor match and facing a battery of medical tests to determine whether the child and donor are physically capable of undergoing the procedure, the family must face a storm of difficult decisions, hypothetical situations and ethical questions:

- Will my child be able to cope emotionally and physically with a transplant given that my child has already experienced significant therapy before even moving into transplant?

- What if the donor backs out at the last minute?
- What if we can’t find a new donor?
- What if the transplant doesn’t take and the child’s body rejects the donor’s blood?

The ethical questions become even more complicated when the donor is an under-age sibling:

- Can an under-age child really give consent?
- Do they understand what they are agreeing to?
- Is it right to put another healthy child, as donor, through such an experience?
- What happens if the patient doesn’t survive? How does the surviving child integrate such a traumatic outcome?

Sometimes sibling transplants are incredibly life-affirming and creates deep emotional bonds between siblings, as was the case for the McGinn-Thompson boys (pp 4–6).

Sometimes it is not a positive experience. Some sibling donors feel coerced and resentful about it. While the sibling donor may enjoy the extra attention leading up to the transplant, once the transplant is finished and the focus returns to their sick sibling again, some children feel used and neglected. If the sick child doesn’t survive, some sibling donors feel guilty and responsible for their death.

And the barrage of troubling emotions, challenging decisions and ethical questions doesn’t even begin to touch the physical demands to come—forced isolation, dangerously high levels of chemotherapy and radiation and serious short- and long-term side effects. ■

Permanent late effects may include impaired growth and development, neurocognitive problems, compromised heart and lung function, infertility, endocrine dysfunction, kidney impairment, gastrointestinal problems, musculoskeletal disorders, metabolic syndrome and secondary cancers.

Certain groups of childhood cancer survivors are also at high risk for psychological distress, neurocognitive dysfunction and poor health-related quality of life. Lower levels of education and poorer employment outcomes have also been reported among childhood cancer survivors.

Cost of care

As this population of long-term survivors grows, so too do the costs associated with care. A 2013 study out of Australia estimates that:

- The average lifetime financial cost for households with a child with cancer ranges from \$150,000 to \$300,000.
- The average overall lifetime cost per childhood cancer survivor, including personal household, productivity and health care costs range from \$1.7 million to \$2.1 million.

Children are still die

Despite huge advances in research and care, certain children's cancers still have very poor survival rates. Cancer remains the number one disease-related cause of death in children worldwide.

Strong research investment needed

Although childhood cancer represents a small proportion of the overall cancer cases in Canada, early-life cancers have formidable impacts on the children, their families and our health, economic and social systems.

The immediate and long-term costs associated with childhood cancer and its late effects present a compelling argument for an increased investment in childhood cancer research:

1. Understand its causes;
2. Improve cure rates; and
3. Reduce the burden of treatment toxicities and late effects.

While investment in childhood cancer research in Canada rose by 71 per cent between 2005 and 2010, this investment represents only three per cent of the total cancer research funding in the country. The upward trend is a positive sign but it must continue to grow. ■

Abridged and adapted from the Investment in Research on Childhood Cancer and Adolescent Cancers, 2005 – 2010: A Special Report from the Canadian Cancer Research Alliance's Survey of Government and Voluntary Sector Investment in Cancer Research.

what's up
at kindle?

Ignite! a new camp program

This summer, for the first time, Kids Cancer Care is offering a camp program to children outside the cancer community.

Ignite! is a five-day overnight camping adventure that runs June 30 to July 4 at Camp Kindle. It is open to Alberta youth, ages seven to 17, who are looking for fun and adventure.

Ignite! encourages young people to explore the outdoors, develop new skills, push their limits and make new friends, all while learning the importance of teamwork and leadership. Activities include swimming, archery, hiking, challenge course, arts and crafts, drama, dance, campfire sing-a-longs and much more!

Ignite! a child's summer, register today!
Registration is \$550 + GST per child.
Visit campkindle.ca or call
403 637 3975 for more information.

Proceeds generated through Ignite! registrations support Kids Cancer Care camp programs. ■

Ignite! is not a children's cancer camp.

The extensive nursing and medical support available at our oncology camps is not available at Ignite! so it is not suitable for children on active cancer treatment.



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JASPER

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km

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For more information, please contact Renée at
mactavish@kidscancercare.ab.ca or 403 984 1225



Brookfield
Homes



Funny
1060 AM



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.



Cover photo courtesy of the van Galen family. All other photos by Unique Perspectives Photography unless otherwise noted.

save the date

Bereaved Family Camp

May 9-11, 2014
Camp Kindle

Mother's Day Brunch

Sunday, May 11, 2014
Camp Kindle

Spring Family Camp

May 30-June 1, 2014
Camp Kindle

Survivor Day

Sunday, June 1, 2014
Camp Kindle

High Hopes Challenge

Presented by City
Saturday, June 14, 2014
Camp Kindle

Camp volunteer and staff training

June 20-22, 2014
Camp Kindle

Ride for a Lifetime

The Final Ride!
*Presented by Remington
Development Corporation*
June 20-22, 2014
Calgary > Jasper > Kamloops > Calgary

Tour for Kids Alberta

July 18-20, 2014
Canadian Rocky Mountains

Don, Joanne and the Coach Golf a Kid to Camp

Presented by Trico Homes and XL103
Thursday, August 7, 2014
Cottonwood Golf and Country Club

The Sears Great Canadian Run – The Relay to End Kids Cancer

Saturday, August 23, 2014
Bears Paw to Camp Kindle

Childhood Cancer Awareness Month

Join the movement!
Get involved now for September!

Indy Bike Challenge

Sunday, September 14, 2014
Glenmore Velodrome

Fall Family Camp

September 26-28, 2014
Camp Kindle

National Inside Ride

Sunday, October 19, 2014
Eau Claire Market

Fall Teen Camp

October 24-26, 2014
Camp Kindle

Dad and Daughter Gala

Presented by Dilawri Group of Companies
Saturday, October 25, 2014
BMO Centre, Hall D
Stampede Park

Cool Yule – A Christmas Carol

Sunday, November 23, 2014
Theatre Calgary

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.

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