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# HOME AWAY FROM HOME



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**Roger's House to mark a decade helping families of sick kids**

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Left: Jenny and Jonathan Doull pose with daughter Mae, 7, and Phoebe Rose, 5. Centre: Julie, Kate, Brian and Jack, front, Drury. Right: Family photos of parents Jeanine and Dean Otto with their daughter Hannah and Maddy, 5, who died at Roger's House in 2007.

# ROGER'S HOUSE FILLED

PAULA MCCOOEY

## Family support facility marks 10 years of serving Ottawa

As Roger's House prepares to mark its 10th year of supporting the families of children with life-threatening illnesses, those families are praising a place that provides not just a warm bed, but also a safe haven to connect with others who understood their pain, anger and loss.

"We went there every single Wednesday night, broken," says Jeanine Otto, after her five-year-old daughter Maddy died suddenly in 2007. "We would dread going there ... because we knew it was going to be rough and crying."

"It took three or four months to actually smile. I remember one of the other couples saying, 'You're going to smile again, you just don't believe it until it happens.'"

Those families will be sharing their stories at the Roger's House community builders celebration on June 16 — Roger Neilson's birthday. Roger's House was created in honour of the Hockey Hall of Fame coach, who died in 2003, by the Ottawa Senators Foundation in collaboration with the Children's Hospital of Eastern Ontario and the ministries of Health and Children and Youth Services.

It was expected that Roger's House would take five years to build, but the community was quick to mobilize and the home

opened its doors on Smyth Road on May 15, 2006, within two years of the idea's conception.

"The anniversary celebration is really an opportunity for us and our board at the Sens Foundation, the CHEO Foundation, to bring back all of those people who helped donate services or supplies, inviting them back to see the house and see what they contributed to," said Megan Wright, Roger's House executive director.

The team provides respite, end-of-life, transition-to-home support, pain and symptom management, perinatal care and bereavement care. The physical, emotional and spiritual needs of young patients and their families are met through staff support, but also with the help of more than 320 volunteers who keep the house running and growing.

"Certainly the number of referrals have increased significantly, about an 86 per cent growth in numbers, patients (from) that first year compared to last year," said Wright. "And we've added a number of services to keep up with the patient and family needs."

Those programs include enhanced bereavement and "SIBS" — for Spectacular Incredible Brave Siblings — which

offers emotional support for the brothers and sisters of those in palliative care. It's an opportunity to meet other children in similar situations. Wright says kids often "grow and blossom" in the supportive group environment.

"They can talk about their feelings, they can do play therapy, they do a lot of art, they do music and games."

A new program also sends volunteers to a family's home for a few hours a week to help the parents, doing their laundry or cooking to "give moms and dads a little break in the house."

Roger's House offers comfortable home-like atmosphere but there's also an emphasis on fun, and through activities like arts and crafts, cook and baking, recreation therapists make that happen.

"The kids have fun when they come to Roger's House," says Wright. "They like being here, when they come for respite it's a welcome break for them too, they play and have fun and can just be kids."

### Family stories

Julie Drury's family developed an intimate relationship with the Roger's House team over the past eight years. Their first visit was on Mother's Day when

they spent the weekend in the family suite with their daughter, Kate, who was very sick and had yet to be diagnosed. Drury said the staff was quick to help them through the emotional and confusing time.

"We had a child who was having multiple hospitalizations and no one knew what was wrong," says Drury, who will be speaking at the anniversary celebration. "The palliative care team stepped in as support to us, co-ordinating the complicated meetings and visits of the specialists (from CHEO) who were involved."

Kate was eventually diagnosed with Sideroblastic Anemia Immune Deficiency (SIFD),

a rare mitochondrial disorder. As she got older and her condition became more complicated, the family kept receiving respite services and consultation from the pain and symptom management program to keep her comfortable. Then came end-of-life care in their home where, on Nov. 30, 2015, eight-year-old Kate succumbed to the disease, following complications from a bone marrow transplant.

The entire family receives bereavement support, and Kate's brother Jack, who was just three when his sister first became ill, attends Roger's sibling counselling program.

"He doesn't say much. He's a quiet little boy and he got into the car and he said, 'Wow, those kids are just like me. They have the same thing going on in their house.' Pretty powerful from a little kid. So he enjoyed it, he made friends and he got to do silly games," said Drury, who organizes a group of charity runners during Ottawa Race Weekend in support of mitochondrial disease research.

The children at Roger's House might be medically fragile, but Drury says it's also a place with a lot of life, laughter and comfort.

"That place is happy, and there is joy there and fun and creativity, and it's a home," she

said. "When you walk in, it's cosy and you feel safe and you feel supported."

■■■■■

Roger's House came into Jenny and Jonathan Doull's lives after the loss of their young daughter, Phoebe Rose, in November 2015.

She was diagnosed with infantile leukemia at nine months old, and was sent for clinical trials at St. Jude Children's Research Hospital in Memphis. Unfortunately, Phoebe Rose died after a relapse in May 2015 before they had a chance to bring her home.

"We actually tried to get her home because we wanted her to be able to be at a place like Roger's House," said Jenny. "But we weren't able to and pretty much as soon as we got home we heard from a social worker at Roger's House offering support."

Overwhelmed and devastated, the family started attending bereavement counselling for her parents and Phoebe's seven-year-old sister Mae.

"Mae was with her sister when she died, she was with her for every step of her illness," said Jenny. "(Phoebe Rose) was sick pretty much from birth, and she passed away when she was five, so she and Mae were best friends, so it was really impor-

### BY THE NUMBERS

- 8 beds at Roger's House
- 20,661 days of care provided in the past 10 years
- 6,000 families have stayed at Roger's House with their children
- 581 families and children have received support through bereavement counselling
- 163,700 hours offered by volunteers



# WITH LOVE

tant to us that Mae get some kind of counselling.”

The couple appreciated how Roger's House focused on play during the child counselling sessions. Jenny said it helped Mae talk about her sister and to share the “good times and the bad times” in a safe environment.

The couple says grieving with other parents who understand their pain helps the healing process. Jonathan is also involved with the 57 Ride for Roger's House to help make the outdoor space at Roger's House more accessible and comfortable.

“For my husband and I, it's sort of the same thing, about being able to talk about Phoebe in a safe environment with people who really understand,” said Jenny. “Because really at the end of the day, the only people who truly understand what it's like to lose a child are people who have also lost a child. And so we've

made some good friends, it's been a good experience.”



Jeanine and Dean Otto were at their cottage on a sunny summer day in July 2007 when their five-year-old daughter, Maddy, awoke from a nap with what appeared to be partial paralysis from a seizure.

The family rushed her to CHEO where she experienced a second seizure and were soon given the devastating news she had an inoperable brain tumour and only had 48 hours to live.

Representatives from Rogers House reached out to see if the family wanted Maddy to spend her final hours there. They said yes.

“It was just so much more comforting (than a hospital),” said Jeanine. “There's a king-sized bed, and it's more of a room than a ward, so we did

go there. I think we left CHEO around 3 p.m., walked through a little garden on the way to Roger's House and stopped in the garden and took a couple of pictures, and then she passed away around 6:20 that evening with so many friends and family there.”

With the sudden loss, the family, including their daughter Hannah, attended bereavement counselling.

With the help of the social workers and other families, the Ottos have been able to pick up the pieces. To keep Maddy's spirit alive, they started Maddy's Gala. So far they have raised more than a half a million dollars for Roger's House.

“There's not a day that goes by that we don't think of her,” said Jeanine. “We're good, but it doesn't mean that our heart is healed. There's a part of us that will always be missing.”

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# Get Hip on the Hill, band's fans cry

AEDAN HELMER

A campaign urging Ottawa's Canada Day organizers to add The Tragically Hip to the roster of Parliament Hill performers is picking up steam on social media.

A Facebook page titled Let's Get the Hip on the Hill surfaced this week, with nearly 1,000 fans already pledging their support.

The Tragically Hip announced their farewell concert tour in May, at the same time it was announced iconic frontman Gord Downie had been diagnosed with terminal brain cancer.

Doctors and the band's management team said Downie, 52, is expected to be healthy enough to perform on tour, though they said he would be taking precautions to avoid exhaustion while he battles the cancer that was discovered in December.

The tour begins July 22 in Victoria, and rolls through Ottawa's Canadian Tire Centre Aug. 18, before

what is expected to be the band's final concert in their Kingston hometown Aug. 20.

Outrage spread from coast-to-coast as tickets went on sale, and were quickly snapped up, with many appearing on ticket reseller sites, such as StubHub, for wildly inflated prices.

“The more (Facebook) likes and shares, the better our chances of putting the screws to the scalpers, as well as to see one of Canada's most special bands,” wrote Rich Bowie, who organized the Canada Day campaign. Whether the initiative succeeds remains to be seen.

While the Hip would have had their first choice of any Canadian venue on this summer tour, they opted for the climate-controlled and relatively secure environment of indoor hockey arenas over larger outdoor stages in every stop along the tour.

And if the Hip play the Hill, it would be a first.

The band that, to many fans, is synonymous with Canada has seldom made a spectacle of Canada Day concerts, and only once, way back

in 1991 at Lansdowne Park, have they played Canada's capital on the country's big day.

They've performed on July 1 only four times since the mid-90s, each time in the Toronto area.

And the proposed Canada Day concert would have the band starting their tour a full three weeks ahead of schedule.

Still, several similar fan-driven campaigns have popped up in recent weeks, with varying degrees of support.

Popular petition site Change.org hosts several petitions to Canadian broadcasters to air the band's final shows, with one such petition collecting more than 31,000 signatures. Another petition urges the band to play the Grey Cup halftime show – in late November at Toronto's BMO Field – and another calls for a free concert at Downsview Park, where the band attracted nearly 30,000 fans to a 2011 Canada Day concert.

The movement with the strongest support is a petition to Gov. Gen. David Johnston to invest Gord Downie with the Order of Canada. That petition has garnered nearly 70,000 signatures in three

weeks.

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