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Hospice for kids enhances quality of life

Parents will 'treasure every moment'

EVA FERGUSON
CALGARY HERALD

Five-year-old Cassandra Patterson has battled a debilitating genetic disorder every day of her young life, preventing her from learning to walk, sit, talk and at times even smile on her own.

But when she enters the unique sensory room of the new Rotary Flames House hospice for children, surrounded by transparent pillars filled with flowing fluorescent bubbles, she lights up.

"She really loves this place. It's like a theme park for her," says her mother Illisha Patterson.

Families like the Pattersons, gripped with the anguish and exhaustion of dealing with their child's life-threatening illness on a day-to-day basis, will now get some much-needed respite and support in the \$12.5-million hospice facility adjacent to the Alberta Children's Hospital site.

The two-storey house, the first of its kind in Alberta and one of only six in North America, is filled with comfortable sitting rooms with stars on the ceiling, play rooms with unique toys and games, bedroom suites, and an open dining and kitchen area, including a large outdoor barbecue.

Families with kids facing a poor prognosis in their illness can stay and relax, connect with other families and get support from trained health-care professionals.

Kids can also stay overnight so their parents can take some time out with each other, take siblings on special trips or just get some much-needed

sleep at home.

A series of unique play areas and multi-sensory rooms offer a variety of touch, feel and hear activities for kids with limited abilities, such as the sound beam motion sensor, which plays a soothing pan flute to anyone who moves nearby.

"Families will love this. Children who can't play in the same way as other children will get so much enjoyment out of these areas," said Christina West, clinical nurse specialist for pediatric palliative care and grief support.

"To be able to enhance the quality of life for these children, facing these challenges, you cannot underestimate it.

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CHRISTINA WEST, NURSE

"Not only will the families treasure every moment, but if their child dies, they will treasure the moments as memories that will bring a deep comfort in their grief later."

As well, West adds, families will be able to meet with other families dealing with the same challenges.

"One of the greatest comforts for parents is meeting and knowing other parents in the same situation.

"They understand each other in ways that others cannot, even their closest friends or family."

And with health-care professionals close at hand, parents can relax and just be parents for a time, instead of having to also be doctors and nurses to their own children at home.

After spending the first two years of her life at the Alberta Children's Hospital, Cassandra

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Patterson's homecoming was overwhelming for her parents, who became medical experts in her complex care.

They would often face up to 70 seizures in a day, round the clock medications, and recurring infections.

A study authored earlier this spring by Lillian Rallison, a PhD candidate in the University of Calgary's nursing faculty, found families with terminally ill children stable enough to be cared for outside of hospital are in critical need of in-home care and out-of-home respite.

With much of the palliative care being done at home, families are overwhelmed by the demands of round-the-clock caregiving, and doing much of the medical care themselves, the study said.

But the hospice's respite and end-of-life care hopes to help with that transition from hospital to home.

"Some families will still choose to keep their children at home. But the hospice offers them that choice for a break," said Dr. Marli Robertson, lead physician for the Rotary Flames House.

"There's a big responsibility for these parents, in having to make difficult decisions around the care of their child.

"This is a place where their precious child is safe and they can have fun with unique activities — it's enormous for them, because it validates them, their children and that they deserve a good quality of life."

The Rotary Flames House is set to open in November, offering services for anywhere between seven and 12 families needing support.

The Rotary Clubs of Cal-



Christina Ryan, Calgary Herald
Ian and Illisha Patterson enjoy a quiet moment with their five-year-old daughter Cassandra at the Rotary Flames House, Alberta's first hospice for children.

gary and the Flames Foundation for Life provided a \$2.5-million donation. Several private donations came

from corporate and individual sponsors.

Alberta Health Services will foot the \$2-million annual bill

for operating costs.

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RECEIVERSHIP LIQUIDATION

PRESS RELEASE

In the matter of the receivership of Russell Ventures Ltd. operating as The Living Room and The Bedroom Shoppe, the sale of all remaining inventory has been authorized by the Receiver, Hudson & Company, Insolvency Trustees Inc.

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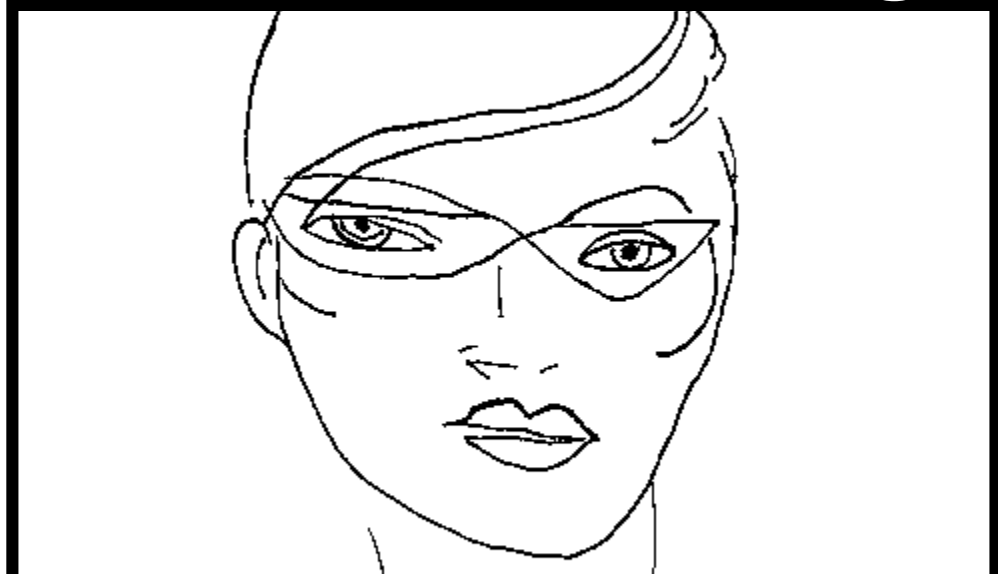
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