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BARRHAVEN Independent

YEAR 33 • ISSUE 9

FREE

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FRIDAY • APRIL 28 • 2023

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For Hannah Otto, even the darkest cloud can have a silver lining

BY JEFF MORRIS

It's not that the memories are fading.

There are just not enough of them.

"When you think about it, we were only together for a few years," Hannah Otto said. "I have memories, and I miss her, but we were both so young. We didn't have a lot of time together as sisters."

Hannah was seven when her little sister, Maddy, passed away at Roger Neilson House at the age of five. She thinks about what Maddy would be like as a younger sister. She would be 21 now, and the special bond they had would only be deeper and stronger. But in Hannah's thoughts and memories, Maddy is forever five.

Maddy's Gala, which has become one of the marquee philanthropic events of the year, takes place Sat., April 29 at the Infinity Centre. The event is in its 14th year and has been the cornerstone of the Otto family's legacy fundraising work for Roger Neilson

House. The Otto family recently surpassed the million dollar mark for the children's hospice, located adjacent to CHEO.

While Dean and Jeanine have been front and centre telling their story over the years, Hannah will be sharing her story and her memories Maddy at this year's gala.

Each year since Maddy's passing, family and friends gathered at the Pinecrest Cemetery to do what they have done every year since January, 2008. They gather at Maddy's grave, they sing happy birthday, and they release balloons into the sky. Many of them were superhero balloons with Batman or Spider-Man on them. Maddy loved superheroes.

"I remember sometimes my friends and I would be dressed up like princesses and we would all be wearing pink," Hannah recalled with a smile. "And then Maddy would always be there in her Batman costume."

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Sixteen years ago, Hannah Otto lost her little sister, Maddy, to an inoperable tumour. Since then, her family has created a legacy for Maddy by raising more than a million dollars for Roger Neilson House, the children's hospice adjacent to CHEO. KAREN JOYNER PHOTO

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Maddy had been with her family at the cottage when she awoke from a nap and her parents noticed something was wrong. She was taken to CHEO. Maddy had an inoperable tumour on the stem of her brain, and it was bleeding. The doctors told Maddy she had about 48 hours to live.

Two days later, Maddy passed away peacefully, surrounded by her family and closest friends, at Roger Neilson House.

Dean and Jeanine Otto, and Maddy's older sister, Hannah, had their world turned upside down.

But somehow, these two shocked parents and a devastated little girl seized Maddy's spirit and used it to better the community. In an effort to create a legacy for their daughter, the Otto family began one of the greatest philanthropic journeys of courage and strength that Barrhaven, and Ottawa, have ever seen. They have also touched the lives of many other families who have grieved, passing on some of that hope and inspiration.

While Dean and Jeanine Otto have become pillars of strength and inspiration both in the community and for other families grieving a lost child, Hannah has been right beside them. She has grown up working on the gala, and listening to

her parents deliver a message of hope that has touched countless people. Hannah spoke in a video at the 2020 Maddy's Gala, the last gala that was held before the COVID-19 pandemic.

It is a story that begins the same way as the one told by her parents.

"We were at the cottage, about an hour-and-a-half outside Ottawa," Hannah recalled. "Maddy was having a nap and we were playing a board game. When she woke up and came out of her room, we saw that something was wrong."

The Otto family packed up their car and headed back to Ottawa to go to CHEO. They did not know the severity or urgency of Maddy's condition. They dropped Dean off at home in Barrhaven and then Jeanine and the girls headed to CHEO. Dean took everything in the house and then he headed to CHEO behind them.

"Maddy was put in a room and was in a coma, and my mom left the room for a few minutes to go to the wash-room," Hannah said. "When she was gone, Maddy had a seizure. I was scared. I was only seven so I didn't really know what a seizure was, but I knew something wasn't right. I ran to find a nurse as quickly as I could."

Before long, Dean and

Jeanine learned the news no parents could ever imagine hearing. Maddy's tumour was inoperable. She had about two days left to live. They contacted family and friends from all over Canada.

"I still didn't really know what was going on," Hannah recalled. "But we had family from across Canada arriving, and everyone was hugging so I knew it must have been serious."

On July 17, 2007, Maddy Otto passed away peacefully at Roger Neilson House.

"When it really hit me was when they put her in the vehicle and she was taken away," Hannah said. "That's when I realized I would never see my sister again, and that she was gone. I cried and kicked and screamed. It was awful."

Although Maddy's stay in Roger Neilson House only lasted for a few hours, her passing marked a starting point for the Otto family to become connected with the children's hospice for life. They were in bereavement groups and had access to counselling. A year after Maddy's passing, the Otto family became ambassadors for the first ever Barrhaven Run for Roger Neilson House. The first Maddy's Gala, organized by some close family friends, was held at the Monterrey Inn on Prince of Wales Drive with



Maddy Otto has inspired her family to raise more than a million dollars for Roger Neilson House through Maddy's Gala and other initiatives.

a goal of raising \$10,000 for Roger Neilson House. Little did they know that their work for Roger Neilson House was just beginning.

"After Maddy's passing, we spent a lot of time at Roger Neilson House," Hannah said. "There were support groups and I met other kids who were going through similar things. I didn't realize it then, but looking back, it really helped me get through some difficult times."

One of the toughest challenges for Hannah was to return to Jockvale Public School after the tragedy.

"I felt like everyone was

looking at me, waiting for something to go wrong," Hannah recalled. "It was a difficult situation for them. They would have me seeing counsellors and doing the things they thought were best for me. But even though I was young,

I just wanted to show them I was strong. I really missed my sister, and I still wish she was here with us, but I had not changed as a person."

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Maddy and Hannah shared a bedroom. As you would expect, the room felt empty for Hannah.

“We shared a room and had



Friends and family gather before releasing balloons at Pinecrest Cemetery for Maddy Otto's birthday.

BARRHAVEN INDEPENDENT FILE PHOTO

bunkbeds,” Hannah said. “She was on the bottom bunk, and I was on top. We were always talking and laughing. I remember I would be just about to fall asleep, and Maddy would kick my bed from underneath, and she would be giggling and laughing. I would get really mad, but then I would do something to her when she was about to fall asleep, and I would be giggling and laughing.”

Through the years, Hannah also has some keepsakes. She still has a few pieces of Maddy's clothing in her drawers. She also has something very special.

“One day a friend of my mom's asked if she could have some of Maddy's clothing,” Hannah said. “We gave her some things, not really knowing what she was doing. Eventually, she showed up with a quilt she had made out of Maddy's clothing. It was so beautiful and so thoughtful.

I slept with it every night for years. I'm trying to save it and keep it safe and in good condition.”

While Maddy's Gala has grown through the years, Hannah has grown with it. Children were not at the first few galas, but eventually, Hannah became a part of the event.

“I think during the first one I went to, I fell asleep after dinner and slept on a chair beside my grandparents most of the night,” she said. “But through the years there are things that really jump out. I remember walking into the room with my parents the music playing as we were introduced. And we see the same people back every year. They come every year to support us and to remember Maddy, and we are so thankful for them and for the gala's sponsors.”

The gala has grown into one of the largest events of the year for the Sens Foundation and Roger Neilson House. But it is

still as raw and emotional as it was in its first year. It may not be Ottawa's biggest event of the year, but it is certainly the most powerful.

“I am so proud of my parents for everything they have done and how hard they have worked on the gala,” Hannah said. “Sometimes I can't believe that they have been able to keep it going and for it to keep growing. But I think a lot of it has to do with Maddy. She was such a magnetic person. Everyone is so drawn to her, just like I was.”

Hannah believes her sister would be pleased with the legacy they have created for her.

“I think she would be proud of us,” Hannah said. “My mom and dad have been able to take the darkest moment of our lives and create a silver lining. You can never turn what happened into something positive, but something good has come out of it.”

Hannah said that raising a



Hannah Otto places flowers at the grave of her sister, Maddy. Hannah was seven when Maddy passed away.

KAREN JOYNER PHOTO

million dollars seems unthinkable, but there is something even more important than the money.

“Through the gala, we have given hope to a lot of people who need it,” Hannah said. “That's a lot more important than any amount of money we have raised. I know what I went through and what we went through as a family. Making it

easier for the next people who have to go through what we did is more important than any amount of money we could raise.”

And that's why Maddy's Gala has become the light at the end of so many dark tunnels.

For ticket information to this year's Maddy's Gala, visit www.maddysgala.com.

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