



Beyond the Beads photo

Jessica Damiani (left) and Kayla Hillier, founders of Beyond the Beads support network for parents, families and friends of hospitalized children.

MAKING MOTHER'S DAY SPECIAL FOR SICKKIDS' MOMS

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Georgetown's Jessica Damiani knows firsthand what it's like to be a worried mother with a child in the hospital, fighting for their life.

That's why she and fellow SickKids parent, Kayla Hillier of Orangeville, are teaming up to pamper moms staying at the Ronald McDonald House (RMHC) in Toronto this Mother's Day.

The two women — who founded Beyond the Beads to provide support and resources for parents, families and friends of hospitalized children — are raising \$5,000 to provide RMHC families with a catered Mother's Day dinner that will be delivered to each room.

Damiani and Hillier are also donating gift boxes to the mothers filled with a variety of goodies from local makers and small businesses.

"We can't imagine going through our (SickKids) experience during COVID," said Damiani. "With Mother's

Day approaching, we thought how can we make it really special for these moms that are going through so much right now?"

The women first met about three years ago when their children were both in the NICU at the Hospital for Sick Children. Hillier's son was born with esophageal atresia, which causes the esophagus to end in a pouch, rather than connecting normally to the stomach, while Damiani was there for the second time with her youngest son. Both of her children were born with gastroschisis, a non-genetic condition where a baby is born with the intestines sticking out through a hole in the stomach wall.

"We connected over the fact there really is no support for parents of medically-complex, hospitalized, critically-ill children, and we needed that," said Hillier.

From there, Beyond the Beads was formed as a community for parents to come together, share information and gain support.

"We found a lot of people

assume that when you're discharged from the hospital, you're OK and your child is OK. But usually you're discharged with feeding tubes and lots of medication," said Damiani. "We struggled way more when our kids were at home. And once things kind of settle, the trauma of the hospital comes up."

The name is a play-off of SickKids bravery beads, which is a literal bead that children collect for every single procedure, test, scan, operation, feed, etc. that they undergo during their stay.

"It's to represent their bravery and what they've gone through," said Hillier. "Some kids have 10 beads, some kids have 10,000. It depends on each child's individual journey."

Those interested in donating to the Mother's Day dinner can do so at rmhccanada.ca/fundraisers/beyondtheboxes. Contributions are tax deductible and go directly to RMHC.

For further details on Beyond the Beads, including links to their social media feeds and podcast, visit beyondthebeads.ca.

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