

Family thankful for the help they received from local kids

It's difficult for Lyem Magennis's family to put into words just how grateful they are to have something that they hope they will never have to use.

Lyem, who began attending Maple Grove Education Centre this school year, has Barth Syndrome. It's a rare genetic disorder that, among other things, weakens the heart muscle. For the Magennis family this is a frightening prospect because people with Barth Syndrome can suddenly, without warning, go into cardiac arrest.

But there is a device that can shock a heart to restart it. It's a defibrillator. And while Lyem has had one available to him at school, up until a few months ago he's never had one at home.

But then a group of kids stepped up to the plate to raise money to purchase one for him. Actually, they didn't really step up to the plate; rather they hip hopped, spun, flipped and danced their way there.

Last spring Kidzact – a local dance production group that raises money for children's charities through its performances – set out to raise \$2,500 to purchase a defibrillator for Lyem. It didn't take long for the young people to achieve their goal.

Even now months later, as the family has been living with the comfort of having a defibrillator nearby, Lyem's grandmother Debra Magennis is still in awe.

"I'm blown away by kids helping kids," she says.

The defibrillator is small enough that Lyem can carry it with him in his Children's Wish Foundation backpack. It goes wherever he goes, like when he visits family and particularly if he's going to be somewhere for an extended period of time, like the camping trip he took to Kejij.

Lyem was diagnosed with Barth Syndrome when he was 19 months old. He can't run and he's small for his age. The syndrome affects his fine motor skills and he has to be monitored closely and is on medication. But it's always been the possibility of cardiac arrest that his family has feared most.



Lyem Magennis sits next to a box of new kittens in his household while holding a defibrillator that the local Kidzact group purchased for him.

Having a defibrillator at home gives the family peace of mind. That is, as much peace of mind that a family can have living daily with such a situation.

"It's hard to describe," says his grandmother. "You can't say that you are more relaxed, but you are more relaxed."

"And it's scary with it, but it's scarier without it," says Lyem's mother Jasmine.

Lyem, meanwhile, has been planning a way to say thank you to the Kidzact group in his own special way. He's been saving his money, however we can't tell you what his plan is because it's a secret.

What isn't a secret, though, is how thankful this family is for the gift they've received.

"At first he was a little afraid of it," says Debra Magennis. "I said if we ever have to use it, it will help you, it will save your life. There is nothing to be afraid of."

Not anymore.