

## Jackson's Zest for Life Shines

To look at Jackson Ferguson, an active Grade 3 student who loves playing hockey and golf, you'd never know he's been through nine surgeries and eight shunt revisions for hydrocephalus, including emergency ambulance trips to the hospital with flashing lights and sirens.

"Jackson has the most amazing zest for life," says his mother, Tammy Trimble. "It amazes me every day how strong and resilient he is. He has a very big and passionate heart and a larger than life personality!"

Jackson was diagnosed with hydrocephalus at the age of four months. Two months later doctors operated on him to implant a shunt to drain the dangerous build-up of cerebral spinal fluid from his brain. Tammy says the uncertainty around hydrocephalus is one of the greatest challenges. "Every day of Jackson's life a surgery could happen," says Tammy. "It's tough to walk on egg shells all the time. Jackson had been surgery-free for almost four years when we were rushed down to SickKids (The Hospital for Sick Children) in Toronto last March. It never gets easier. But I take it day by day and try to remember it could always be worse."

The family has made several emergency trips by ambulance from their home in Orangeville to Toronto, "Jackson told me that his last surgery was the scariest one for him because he could feel so much pain – something he has never expressed before," says Tammy. "That was really tough to hear. He also said he knows that his shunt keeps him alive, which, again, was really tough to hear, as a mom."

Tammy says Hydrocephalus Canada, formerly SB&H, has been a great support to the family through its literature about hydrocephalus, children's books that help Jackson understand and cope with the condition and toll-free phone line. Connecting with other families in the same situation has also helped. "I have an amazing friend whom I bounce



Jackson almost always wears a smile. Especially on the Golf Course where he has been happy to support the work of Hydrocephalus Canada. Thank you Jackson!

things off of all the time. Jenn Fraser and I met through our boys. Her son Quinn has hydrocephalus as well, and we've been bonded through that ever since. Any time one of the boys has an issue or concern we lean on each other."

## Inspired by Experience

The family's experience inspired Tammy to start Jackson's Hope Fore Hydrocephalus Golf Tournament which benefits HC and SickKids. She is passionate about increasing awareness about hydrocephalus. "The general public should know how common it is and how often it happens to children and families every day in Ontario," says Tammy. "They should also know that these children live normal, happy and healthy lives. This is not to say they don't have bumps along the way but, truthfully, what kid doesn't?"

Tammy advises families who are starting their journey with hydrocephalus to connect with Hydrocephalus Canada and others who are on the same journey. "Take it day by day. Don't believe everything you see and read. And reach out, talk to as many people as you can so you can feel comfortable about the information you receive. My son is 8 years old and I am still learning new things about hydrocephalus.

**Hydrocephalus Canada is the voice of Canadians living with hydrocephalus. Every day we strive to empower those impacted by the condition to experience the best life possible. We do this by establishing environments that protect, support and enhance the lives of those living with, or at risk of developing,**