

Boo-boos a fact of life

**Fragile skin cause
for painful wounds**

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Natalie Blackwell smiles when she recalls the little girl at the service station in Barrie, Ont., who pointed to her daughter and wondered why Tatum Blackwell had so many boo-boos.

"Her mother pointed to her daughter's leg and

said, 'You have lots of boo-boos, too!'"

It was a light-hearted moment for a St. Thomas woman who wants to raise awareness — and understanding — of epidermolysis bullosa, the genetic disorder which means Tatum's life is one painful boo-boo after another.

The five-year-old girl, daughter of Blackwell, an Herbal One health counsellor, and husband Chris, a builder, has fragile skin which lacks the usual anchors to connect its layers.

Minor trauma, even rubbing, can cause painful wounds.

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Tatum Blackwell and her mother, Natalie. Tatum's skin has been damaged by a rare genetic disorder. (T-J photo)

'Amazing' support for Tatum

**Motorcyclists
ride in with gift**

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wounds which resemble serious burns.

Her condition means ongoing medical expenses for bandages and dietary supplements to boost her immune system and to promote healing, and Tatum's story has resonated in the community.

There is no cure for EB.

Expenses, which average \$150 to \$200 a week, aren't covered by health insurance, nor are they deductible — ironically, because the bandages and the supplements ensure Tatum isn't disabled by her disorder. If she were, there would be assistance.

"If she was in a wheelchair ... but that's not what we want," Blackwell says.

No, the Blackwells want their daughter to live as normal a life of any five-year-old, as she can.

That includes a camping trip this summer and the stop at the Barrie service centre. The family's northside home is ruled by a cat and puppy, though the cat is declawed and the puppy trained — hopefully — to not jump up.

It doesn't include a bicycle. There's too great a risk to Tatum of injury. But she has a toy four-wheel car to drive — and

it's motorized so she can make the trip to the park.

In September, Tatum will enter French Immersion kindergarten at Wellington Street Public School, with the help of an educational assistant. Natalie, who grew up in a French first-language home in Windsor, Ont., is grateful to Thames Valley District School Board for recognizing Tatum's special needs.

The Blackwells don't want to spoil their daughter. But they don't want to deny her, either.

Blackwell explains, quietly but matter-of-factly, "Some of the realities of the future can be very grim."

In addition to immediate concerns arising from her wounds, including infection, long-term scarring can immobilize hands and feet. And EB can lead to life-shortening complications.

Community support has included Tatum's "adoption" by local Freemasons, who accept donations through a tax-receipting foundation.

On Sunday, about two dozen motorcyclists from the Toronto area raised close to \$2,000 in a charity ride from North York to St. Thomas.

It was organized by a



Participants hold a flag they signed at a charity motorcycle ride for Tatum Blackwell. That's Tatum with her parents, Natalie and Chris, kneeling in front, and ride organizers Laura Gardash and Michael Snider holding the ends of the banner. (Contributed)

co-worker of Blackwell's sister's husband and the woman's father, after they heard Tatum's story. Laura Gardash also has created a website, www.tatumbhope.org

"It was so amazing when they rode in on Sunday," Blackwell says.

"It was overwhelming. They had never met Tatum, they had no idea who she was — other than a little girl they wanted to help."

The ride tied up at Dowler-Karn, one of several local supporters.

There is a new national week for epidermolysis bullosa in the last week of

October. Blackwell hopes to organize participation in 2008.

There's a website for information about EB: www.debracanada.org.