

HER TRICK IS CREATING AWARENESS

BY KYLE REA
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Like many children her age, Tatum Blackwell loves Halloween, particularly for the costume — and candy of course.

But when the four-year-old St. Thomas girl went out trick-or-treating this year, she took along more than a candy bag. She took along some bracelets to sell to raise money, and awareness, about epidermolysis bullosa (EB).

Tatum suffers from the disease — a genetic disorder which prevents the layers of her skin from adhering properly, making her skin prone to tears and blisters. It's a painful disorder and there is currently no cure.

But Tatum didn't do it for herself — she did it for other children who suffer from the same disease, her mom, Natalie, explained.

"(At a recent conference), Tatum had a chance to meet a lot of different families and kids who suffer from EB," Mrs. Blackwell said.

The conference was put on by dEBra, a research group that spreads awareness about the disease. "When we got back, Tatum and I had a talk (about the other children). Tatum said 'I want to help them.'"

So she decided to sell to sell bracelets while trick-or-treating.

And that's exactly what she did.

With the \$2 bracelets in



Tatum Blackwell, left, with Mom Natalie, went out looking for something a bit extra on Halloween — donations to help children who suffer from the same genetic skin disorder she does. (T-J photo)

hand, Tatum went to homes in her neighbourhood and raised \$92.

"That's not bad for a four-year-old," said her mom. That amount has since risen to \$250 through the support of family and friends. The money, Mrs. Blackwell explained, goes to dEBRa for research and support services.

The campaign didn't

end there, however — boxes are now in place at three businesses in town, including Herbal One, where people can buy a bracelet and support EB research.

The community has contributed toward the Blackwells' cause in other ways — including more than \$1,000 raised by the Supreme Rebekah Lodge 251 in St. Thomas.

"The community support has been great. Our family feels blessed."

Next year, Tatum's mom said they plan to hold a charity golf tournament for her, although the details are as-of-yet undetermined.

"I think that would bring out a lot of people and raise a lot of awareness."

Raising public perception of the disease is key, she explained, since the disease is relatively unknown and potentially debilitating.

And Mrs. Blackwell worries about Tatum's future — hoping that the scarring, which often accompanies EB, could leave her wheelchair bound at some point.

"I don't know what the future holds for Tatum," she said. "I really hope that some of the things we're doing (can help) other kids who are born having to fight the disease."

"I think a what a lot of people may not realize is that this little girl, who's happy-go-lucky all the time is such a good kid

and she goes through daily pain. And we barely hear anything from her," Mrs. Blackwell said.

"That she can get through this, that's where I draw my strength."

Those interested in

helping the Blackwells' cause can send cheques to St. Thomas Masonic District Foundation, care of Grant Hughson, 119 Metcalfe St., St. Thomas, N5R 3K6, or telephone Hughson at 519-631-0740.