

# Tatum's world

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TIMES-JOURNAL STAFF

Like any happy, fun-loving, and very energetic four-year-old, Tatum Blackwell loves to play with her toys, spend time with her friends and, most of all, tear around outside.

But, unlike other little girls, the slightest trip and fall could cause Tatum's skin to easily tear and blister — making regular child-play a hazard.

"Our parks are very safe, but not so much for Tatum," said Tatum's mother Natalie Blackwell, a St. Thomas resident. "Little kids don't realize they have to be careful with her."

Tatum is afflicted with severe form of a rare genetic skin disorder called epidermolysis bullosa (EB) — a genetic defect that does not allow the layers of her skin to adhere properly, leaving areas of her skin structurally weak and making her very susceptible to injury.

Although only four years old, Tatum's body bears the scars from cuts and blisters that have plagued her body since birth. She is prone to blisters on her hands and feet (sometimes they appear spontaneously all over her body) and there is scarring as a result.

Potentially, Tatum could end up in a wheelchair one day if her scarring is extensive enough to restrict her mobility. "It's debilitating," said Mrs. Blackwell.

Due to the disorder, Tatum has lost most of her finger nails — she only has two left — and is also at greater risk of developing skin cancer.

And although Tatum rarely voices her discomfort, the disorder can be



Four-year-old Tatum Blackwell sits in front of a playhouse her family was able to purchase thanks to a \$2,500 donation from Formet Industries. (T-J photo by Krista McFadden)

very painful. "Think of the pain, the burning sensation caused by a blister that broke ... there are open sores on her body, that's a big part of the pain," said Mrs. Blackwell.

Unfortunately, there is no cure for EB.

"Tatum rarely complains, she's taught us a lot about courage and

strength," said mom. "We just had to jump right in because our daughter needed us."

Both Tatum's parents practice as much preventative care as they can in the home.

Every single night, usually for about an hour, the Blackwells bandage her little feet to protect them

from blisters. In her short lifetime, Tatum has gone through about 3,000 bandages.

Thanks to generous donations from members of Port Stanley's St. Mark's Lodge 94 and several other lodges in the St. Thomas Masonic District, the Blackwells were able to purchase supplies and bandages, as well as a special \$2,500 pressure-relieving mattress for Tatum.

"The costs are on-going. It's everything from bandages, to shoes, to the type of clothing we have to buy for her," said Mrs. Blackwell.

Formet Industries has also helped the family by donating \$2,500 for a playhouse that now sits in Tatum's backyard.

"We've had an amazing amount of support from members of the community," said Mrs. Blackwell.

With the help of family, friends and community members, the Blackwells hope to make an EB-friendly world for Tatum here in St. Thomas so that she can live a long, healthy, happy life.

"I don't expect her to live in a bubble," said Mrs. Blackwell. "We just want to give her the best that we can give her. She's who she is for a reason and I think she has a lot to show us."

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.