

Roxana family hopes to win a life-changing ride

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Like many 9 year olds, Layne Twigg of Roxana enjoys going outside, watching his little brother, Aiden, play baseball, spending time at the beach and watching “Spongebob Squarepants.”

But Layne was born with a rare, unnamed disorder, in which part of his 11Q chromosome is deleted and another part of it is duplicated. As a result, he doesn’t communicate verbally — aside from forming a few words — and has a developmental delay, in which he has the capabilities of a 6 month old, according to his mother, Danielle.

He also suffers from hip dysplasia, leaving him wheelchair-bound. He has gone through four hip surgeries since he was 3, in attempts to help him gain the strength needed to walk.

In order to travel, Twigg, a single mother, must take Layne out of his wheelchair and lift him into her Chevrolet Tahoe truck, chosen in part to get onto the beach. It’s a routine that is done on a daily basis and can add as much as half an hour to any trip, no matter how short a distance.

She pushes his wheelchair up to the

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FYI

To visit Danielle Twigg’s National Mobility Month local hero page and vote for her, go to <http://www.mobilityawarenessmonth.com/entrant/danielle-twigg-frankford-de/>.



STAFF PHOTO BY JON BLEIWEIS

Danielle Twigg escorts her 9-year-old son, Layne, down a walkway outside. Danielle has entered into a contest with the hopes of winning a wheelchair-accessible van.

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side of the door, takes him out of the chair and lifts him into the car. Then she fastens him up. After that, she must put his custom-made wheelchair — which doesn't fold and weighs nearly 100 pounds — into the car and fastens that down.

It's a labor of love that happens daily, rain or shine. But it gets tedious, she said.

It's a process that has worked for years. But as a result of a recent growth spurt, Layne now weighs about 64 pounds, and it's putting a physical toll on his mother. She developed bursitis in her hip about three years ago. It will flare up suddenly — even as she carries her son.

She previously looked into converting her vehicle to add a swivel chair to ease the process but it came with a steep price tag — close to \$15,000.

While Twigg browsed Facebook one day, she came across MobilityAwarenessMonth.com, home to the The National Mobility Equipment Dealers Association's annual local hero campaign, in which the nonprofit will give away four custom wheelchair-accessible vehicles. May is National Mobility Awareness Month.

"It was just kind of random. I hadn't



STAFF PHOTO BY JON BLEIWEIS

Nine-year-old Layne Twigg, right, plays catch with his brother, Aiden, 8. Their mother, Danielle, has entered into a contest with the hopes of winning a wheelchair-accessible van.

even liked their page or anything. It came up as a suggested thing," she said. "I clicked on it and I was reading through some of the stories and I thought, 'I could do this.'"

So she created an entry to share her story, with the hopes of winning that life-changing van.

Having a vehicle with a built-in wheelchair lift would mean no more of

that strenuous half-hour routine every time she wanted to take her son somewhere.

"It would mean the world to me," she said. "I never win anything so I'm not really expecting it. But if we do, it would just be the most amazing thing. But if we don't, I'm still raising awareness."

As of Thursday, May 21, Twigg's page has received more than 1,400 votes of support and she's received many kind words from locals.

"It's amazing," she said. "It's more than what I expected."

Voting ends May 31. Winners will be announced in the end of June.

In the meantime, Twigg is thinking about starting a nonprofit, Layne's League, which would help bring awareness to children with rare chromosome disorders, like her son.

"You see a lot of organizations that have to do with autism and Down's syndrome and specific disorders, but Layne doesn't really fit in any of those categories," she said. "So it's really important that we raise awareness for children just like him."

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