



Marjan Stolte and Brianna O'Donnell hope to encourage the community to ride for MD.

No holding back for Brianna

DISEASE DOES NOT SLOW HER DOWN

Pia van Straalen

AT 29 years old, Brianna O'Donnell has met just two people outside her family with the same rare form of Muscular Dystrophy (MD) as she has.

Brianna and her sister, Katie (33), both have severe childhood autosomal recessive MD.

The other siblings they met were also in their 20s and from an Indian background.

The condition is so rare, researchers say they could share 300-year-old genes - possibly from gypsies in Europe.

"I've been involved in Muscular Dystrophy WA since I was 14 and I've only just met someone with the same disease," Brianna said.

Brianna was diagnosed from a text book at four years old after her sister was found to have the early manifestations of the muscle wasting disease.

"It's a genetic disorder and my mum is a carrier; there were no early indicators that anything was wrong with us, but we did walk on our toes and have large calves," she said.

Despite doctors saying she would not need a wheelchair

until adulthood, she stopped walking at 13.

As she's aged she has needed more help, but that is the extent the disease affects her life.

"I certainly haven't let this hold me back; I've travelled the world and I get out and do stuff," she said.

In 2010 Brianna was one of the creators behind the MD Ride for Someone Who Can't, a 14km, 40km, 64km or 100km ride in the Act-Belong-Commit Dwellingup 100.

Bentley engineer Marjan Stolte is participating in the September 5 ride for the third consecutive year to represent Brianna.

She said taking on the 100km dressed as Batgirl was a way to bring attention to the disease.

"I want to feel tired by the end; a fundraiser should mean you have to put in a lot of effort, and feel it," she said.

"But it's nothing compared to what people with MD go through every day."

The ride aims to raise \$110,000 to support West Australian's living with MD.

Visit everydayhero.com.au/event/rideforwc2015.