

Gottsleben chooses to beat the odds

Memoir chronicles her life with MPS



Kendra Gottsleben signs a copy of her book, *“Live, Laugh, Lemonade: A Journey of Choosing to Beat the Odds,”* during an event held in June at Nook ‘N Cranny in Vermillion.

If there’s one thing Vermillion native Kendra Gottsleben has, it’s a positive attitude.

“My philosophy is, no matter who we are or what we look like, we all have hurdles to overcome,” she said. “It’s just how we get through those with the attitude that we have, the outlook, the determination.

“You just have to make the best lemonade possible,” she said.

Now, with the publication of her memoir, *“Live, Laugh, Lemonade: A Journey of Choosing to Beat the Odds,”* Gottsleben is sharing her story and her sunny philosophy.

Gottsleben was born with Mucopolysaccharidoses (MPS) Type VI, a genetic lysosomal storage disorder caused by her body’s inability to produce a specific enzyme.

“That enzyme that I’m not making cleans my cells, so the difference from you to me is, you have cells and you have that enzyme that goes in there and cleans them. Mine don’t,” she said. “So they build up in my connective tissues, my vital organs, my eyes.”

As a result, Gottsleben is less than three feet tall and has to undergo a treatment once a week at the Sanford Children’s Specialty Clinic in Sioux Falls.

Approximately one in 25,000 people have the broad type of MPS, Gottsleben said.

MPS Type VI is much more rare, affecting one in 250,000, she said.

The effects of the disorder are not always the same, she said.

“There are some people that are five feet tall, but like everything, there’s mild, moderate and severe,” she said.

Gottsleben said her MPS would fall under the mild-to-moderate range.

“For me, it’s been pretty good, because there are some people that have more heart complications. I have a leaky valve, but other than that my heart is pretty healthy,” she said.

Her book is the result of two years’ work, starting with an outline in March 2010 through to the official release date of May 15, 2012 – which also was National MPS Awareness Day.

“I thought that would coincide pretty well,”

Gottsleben said. “It was really cool. The company that creates the drug for my treatment wrote a story about me for their employees to announce it, and there’s a magazine for the national MPS Society that did a little piece. It’s been fun.”

Gottsleben also promoted the book with a signing at Nook



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