

A different kind of family life

Written by Elizabeth Barrett
Friday, 22 June 2012 13:15 -



Newbreds live with several disabilities

Watching as he plays trucks with his brother on the floor of his home, it's not apparent that 7-year-old Brennan Newbrey has several disabilities.

Both Brennan, and his 4-year-old brother, Brayden, have osteogenesis imperfecta, also known as brittle bone disease. Their father, Dan, also has the condition although has not yet encountered problems.

In addition, Brennan has been diagnosed with hereditary spastic paraplegia (HSP), a neurological disorder that causes progressive spasticity and weakness of the leg and hip muscles. The Dudley Elementary second grader also has scoliosis, or abnormal curvature of the spine.

Brennan and Brayden's mother, Elissa, also has HSP and walks with a limp. Brennan uses a wheelchair, walker and crutches to get around and wears braces on his feet and ankles for support.

"With HSP, you don't know how you're going to walk each day," Elissa said about the neurological disorder that tightens muscles so walking is difficult.

HOW TO HELP
There are several ways to help make the Newbrey home wheelchair and walker accessible.
An account for monetary donations has been set up at Gothenburg State Bank under the Benefit Fund for the Newbrey Boys.
Carpentry skills, supplies and other ways to volunteer are also welcome. Contact Caroly Evenson at 308-695-1888.

Because of brittle bone disease, both boys—at different times when they were toddlers—broke legs and were placed in body casts to their chests for eight weeks.

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“That was the worst,” Elissa said, noting that they can fall and break bones doing somewhat normal activities. “Brayden broke his leg falling over a Tonka truck and slipping on a kitchen floor.”

Although the family is not looking for pity, they do need help in making the boys’ bedroom and a bathroom handicapped accessible.

Elissa said it’s an independence, dignity issue for Brennan, whose walker doesn’t fit into the rooms.

“He has to crawl into them using his arms and can’t lift himself to get into the bathtub which is an accident waiting to happen,” she said.

Brennan has a collapsible wheelchair that doesn’t fit in the house. It’s stored for outside activities or to take where needed.

At the moment, Elissa and Dan are trying to get estimates of the cost to make the needed renovations.

The Newbreys discovered something wasn’t normal with Brennan when he was 2.

“Up until then he was running around until he broke his femur and after the cast was off, we noticed a limp,” she said.

After testing, they discovered he had HSP and brittle-bone disease.

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Brayden, who like his Dad has a mild form of brittle-bone disease, was diagnosed as a baby.



If either boy breaks a bone, he is taken to a Kearney specialist. Four times a year the children travel to a speciality clinic at the Children’s Hospital in Omaha for checkups.

“It could be worse,” Elissa said. “We’re very fortunate because osteogenesis imperfecta (brittle bone disease) can cause dwarfism, death, deafness, problems with teeth and other things.”

Some children are confined to a wheelchair.

“The doctors told us that Brennan would end up in a wheelchair but we’re to the point we want to prove them wrong,” she said.

Elissa, a 2002 graduate of Gothenburg High School, was diagnosed with HSP at age 4 when she started walking on her tiptoes.

Now she has good and bad days—times she’s angry both she and Brennan have HSP and that Brennan has brittle bone disease.

“I blame myself sometimes because I gave it to him,” she said.

Having HSP has also made her more compassionate toward anyone with a disability she sees.

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“Because I know what they feel like and I wish I could fix it,” she said.

For the most part, Brennan can do anything any other kid can do but “he has to do it in his way.”

Brennan said he likes to play basketball at school in his wheelchair, read and swim.

Still, she and Dan often hold their breath when either of the boys is doing something like jumping on inflatables.

Dan, a 2001 graduate of Brady High School, works in receiving at Frito-Lay. Elissa is a receptionist for local attorney Steve Windrum.

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