Nicholson raises awareness for CdLS

Tina McGrady tmcgrady@jrpress.com | Posted: Saturday, May 11, 2013 1:15 am

As Addison Brown made her way into Nicholson Elementary School on Friday morning several children swarmed around the tiny girl with bouncy brown curls and a huge smile.

Several students called out, “Hi, Addison,” “How are you?” and “You look so pretty” as she and her mother, Angie Brown, and her grandmother made their way toward the gymnasium where students and staff were gathering to recognize the Crawfordsville child.

Addison, 4, is afflicted with Cornelia de Lange Syndrome, a congenital condition caused by a mutated gene. Today marks National CdLS Awareness Day. Since 1989, the second Saturday in May has been designated as such in order to focus attention on this obscure genetic condition.

Common characteristics of those with CdLS include low birth weight, slow growth and small stature and head size. Individuals with CdLS typically have thin eyebrows that usually meet in the middle, long eyelashes, short, upturned noses and thin, down-turned lips. They also may have excessive body hair, small hands and feet, partial joining of the second and third toes, in-curved fifth fingers or cleft palates. They may suffer from gastroesophageal reflux, seizures, feeding difficulties, eye problems, hearing loss, behavioral issues or developmental delays. Some may have missing limbs or portions of limbs

(typically fingers, hands or forearms).

Most people with CdLS have some degree of mental retardation, which usually ranges from mild to profound. The majority fall in the mild to moderate range.

Addison has many of these physical features. She also has a hearing impairment. She wears braces to help straighten her legs and uses a walker.

Her mother, Angie, is a former teacher and reading interventionist at Nicholson Elementary. She resigned her position a two years ago to care for Addison.

“They are very near and dear to our hearts,” said Ellen Rooze, a third grade teacher.

Students and staff have spent a lot of time discussing Addison and learning about CdLS. On Friday, many students at the school wore purple, the signature color for CdLS awareness.

“Our students have heard announcements every day this week about Addison’s condition and they’ve signed a banner for her,” Rooze added.

Rooze has witnessed more students gravitating toward those with special needs this week in response to the daily announcements and increased awareness.

“Everyone has a challenge,” Angie told the students at the assembly. “Some are just more visible than others.”

She explained that Addison’s condition is extremely rare, and that there are less than 50 people in Indiana who have been diagnosed with CdLS.

“This means there aren’t many doctors who have seen this condition and it’s our goal to increase awareness so that more children can be diagnosed and receive the help that they need.”

Angie and her husband, Sean, were already the parents of two sons when Addison joined their family on Aug. 30, 2007. Until Addison made her appearance, they had no idea their daughter had any sort of medical problem.

After her birth in Crawfordsville, she was taken to Riley Children’s Hospital in Indianapolis, where doctors quickly made their diagnosis. Addison still receives care from a variety of doctors at Riley, but also attends preschool classes and receives physical, occupational and speech therapy.

CdLS individuals typically have normal lifespans, and there is no reason to believe Addison won’t live well into adulthood.

For more information on CdLS or the CdLS Foundation, visit www.CDLSusa.org.