

Schools raise awareness for student with rare disorder

Journal Review | Posted: Saturday, May 2, 2015 1:15 am

In honor of National Cornelia de Lange Syndrome (CdLS) Awareness Day, and also a special little girl named Addison, two Crawfordsville schools are celebrating Friday, each in their own special way.

Teachers at Hose Elementary School, Addison's school, have planned a Dress Down Day for CdLS, and students are participating in lessons about diversity and disabilities. At Nicholson Elementary School the school in which Addison's mom, Angela Brown, teaches, students are putting on a play about the same topic in order to learn important lessons about acceptance and understanding.

"It is important to me that the students understand that we all have challenges, whether or not they are visible, and we can all learn, work, and play together in the school and the community with understanding and acceptance of everyone," Brown said. "In raising awareness about CdLS, it is my hope that children learn about CdLS, but more importantly to be encouraged to have open minds and hearts to include all kids no matter their challenges. I also hope the students and adults will know it is okay to ask questions and be curious because the more knowledge they have the more likely they are to accept all people with disabilities in their lives."

National CdLS Awareness Day is observed the second Saturday of May each year in order to shed light on this often misdiagnosed, little-known genetic syndrome. Since CdLS is unfamiliar to many, including professionals in the medical community, Awareness Day—celebrated since 1989 — is an opportunity to educate all segments of the population.

An estimated 20,000 people in the U.S. have CdLS but remain undiagnosed and/or without support services. Individuals with CdLS range from mildly to severely affected, though most have similar physical characteristics including small size, hands and feet; thin eyebrows that meet; long eyelashes; upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms. Common medical problems include GERD, bowel obstruction and congenital heart defects.



Addi Leslie

Founded in 1981, the Cornelia de Lange Syndrome Foundation is a family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS and their families make informed decisions throughout their lifetime.

For more information, call the CdLS Foundation at 800-753-2357 or visit www.CdLSusa.org.