A Closer Look at Speech

By Ciara Duggan, Communications Intern

It is exciting when a baby says his or her first words. For parents of children with CdLS, those first words may take years to hear, if ever at all. Felicia of Connecticut waited four years before her daughter, Rayven, uttered her first words.

When Rayven was diagnosed with CdLS at age one, doctors told Felicia they had no idea how Rayven’s verbal communication would develop. [However, based on Dr. Goodban’s predictors (see Will My Child Speak? on previous page), one would expect Rayven to talk at some point: she has no limb differences, was more than five pounds at birth, is responsive to people, and had no significant delays in motor skills.]

“Rayven was so frustrated because no one could understand her,” says Felicia. “But once we sought out help and she learned to communicate better, her temperament drastically improved.”

At age four, she began saying single words. Now, at age 10, she communicates through limited speech (single words rather than complete sentences), sign language and gestures.

Not only has Rayven been learning to use sign language, but her entire family attends a signing class at the American School for the Deaf in West Hartford, CT. “Now that we are all learning to communicate with each other, things have become a lot easier,” says Felicia.

When Rayven is at school, she uses some verbal skills and sign language. Her special education teacher helps the other students learn sign language so they can communicate with Rayven. Rayven also enjoys teaching her classmates how to sign different words.

When Rayven is not learning sign language or working on her speech, she loves to ride her bike and has been taking tap dancing lessons for the past two years. Although CdLS can impair a child’s speech, it does not stop them from living his or her life.