

Littleton woman helps raise awareness of Cornelia de Lange Syndrome

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awareness," Lessa said.

National CdLS Awareness Day was created in 1989 to raise awareness about those diagnosed with the syndrome and their families, and what people m

Sue Anthony and Carol Welsh, two mothers whose children were born with in 1977. It began as a grassroots support group, with a newsletter as its o at a state park in Maryland, and in 1981 the Foundation was incorporated Jackson, a geneticist at Jefferson Medical College in Philadelphia, as its fir

The Foundation provides support for families and exists to make sure chil accurately. The Foundation also supports research of CdLS and helps peop and their families. Lessa has been on the Foundation's Board of Directors s

About Cornelia de Lange Syndrome

Dr. Cornelia de Lange first identified the syndrome in 1933, after noticing medical conditions. In 1941, Dr. de Lange presented a third case to the An de Lange Syndrome was officially recognized. She died in 1950.

According to the CdLS website, people with the syndrome strongly resembl thin eyebrows that meet in the middle, long eyelashes, a short upturned n

Other characteristics include low birth weight (often under five pounds), s Other features may include excessive body hair and small hands and feet. esophageal reflux disease, heart defects, seizures, feeding difficulties, visic including missing arms, forearms or fingers, are seen in about 25 percent c communication issues and developmental delays often exist.

Early diagnosis and intervention is crucial to ensure proper management

For information about CdLS, the CdLS Foundation or to make a donation to support individuals with CdLS, call the Foundation at 800-753-2357 or visit cdlsusa.org.

Littleton — Diane Lessa of Littleton is joining families across the country to raise awareness of Cornelia de Lange Syndrome or CdLS on National CdLS Awareness Day, Saturday, May 11.

Lessa's 33-year-old daughter, Valerie, was diagnosed with Cornelia de Lange Syndrome at birth.

Compared to some children diagnosed with the syndrome, Valerie's symptoms are relatively mild, Lessa said.

"Her size -- her hands and feet are small. She has the facial features that go along with it and she is learning disabled. She has had some sleep problems," Lessa said. "We're so lucky with her. Some kids have pretty severe problems."

Valerie graduated from high school when she was 22, where she learned valuable life skills. She can read and write and has been working since the age of 15. She has a job at K-Mart and is living in an apartment in Concord. Social Security payments supplement her income, allowing Valerie to live on her own, Lessa said.

From the beginning, Lessa said, they pushed V

"I've always been a believer that you have to e you get," Lessa said.

Cornelia de Lange Syndrome occurs in about c that about 20,000 people in the U.S. have CdL

"It's such a rare thing; doctors will find somet

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