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Asheville to observe National Cornelia de Lange Syndrome (CdLS) Awareness Day

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By Caitlin Byrd on 04/25/2013 05:58 AM

TAGS: blogwire, health, asheville, Wellness, .

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Press release Cornelia de Lange Syndrome (CdLS) Foundation

Asheville, NC – Through a proclamation by Mayor Terry Bellamy, the City of Asheville joins cities, states and individuals nationwide in observing May 11th as National Cornelia de Lange Syndrome (CdLS) Awareness Day.

It's not a rare sight to imagine: families, friends and neighbors uniting for one cause. What you may not see as often, are individuals with the rare genetic disorder, CdLS. While it is rare, it makes a huge impact on the lives of those affected.

"Raising a awareness of CdLS is so important, as countless individuals are still undiagnosed and therefore, not getting the proper medical attention or support they desperately need," said Jody Light, mother to Dean, who was diagnosed with CdLS at 11 months old. "The doctor put us in touch with the CdLS Foundation and I can't express what a lifeline they were, providing hope, education, and getting Dean referred to the appropriate specialists."

Since 1989, National CdLS Awareness Day has been observed on the second Saturday of May, in order to spread the word about CdLS, how it affects those with CdLS and their families, and what the general public and medical professionals may need to know about this often misdiagnosed genetic syndrome.

CdLS occurs in about 1 in 10,000 live births and an estimated 20,000 people in the U.S. have CdLS but remain undiagnosed and/or without support services.

Individuals with CdLS often have similar physical characteristics including small size, hands and feet; thin eyebrows that meet in the middle, long eyelashes; an upturned nose, and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms. Early diagnosis and intervention is essential to ensure proper management of related medical issues.

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

About the CdLS Foundation

Founded in 1981, the Cornelia de Lange Syndrome Foundation is a national 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.

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