May 14, 2011
Awareness Day
CdLS
Cornelia de Lange Syndrome Foundation

CdLS Foundation celebrates National CdLS Awareness Day, marks 30 years helping families affected by the syndrome

AVON, CT (April 6, 2011)—Just over 30 years ago, a group of moms and dads from across the country came together in a Maryland state park with one common goal: to make sure that no one caring for a child with Cornelia de Lange Syndrome (CdLS) would ever have to feel alone.

Back then, little was known about CdLS—a genetic syndrome causing a range of medical, physical and cognitive challenges. What was known painted a grim picture. Families caring for people with CdLS were often misinformed, isolated from one another and living with little reason to hope for a better future for their child. Doctors didn't know how or why CdLS happened. Many children were institutionalized.

"When our daughter was diagnosed, we were desperate to talk with other parents. *How are their children progressing? Do they have other children? How are they coping?*" says John of Virginia, father of Jocelyne, 33, and an attendee of that first picnic. "Parents stayed up all night talking, and the need and motivation for the establishment of a national organization took flight."

That first gathering of 19 families in a park turned into a second gathering and, in 1981, the formation of a national nonprofit that today supports thousands of families, relatives, professionals, and people with CdLS.

"The Foundation has changed the outlook for every child born with CdLS," says Pam, mother of Matt, 41, and a co-organizer of the first picnic. "We could never have imagined 30 years ago, the role the Foundation would play in the lives of so many people."

While the Foundation has grown from a grassroots, volunteer-run group to a professionally-staffed organization during the past three decades, there is much more work to be done. Researchers believe CdLS remains undiagnosed in thousands of men, women and children. And diagnosis and medical monitoring are critical since complications related to CdLS can be life-threatening.

Saturday, May 14, marks National Cornelia de Lange Syndrome (CdLS) Awareness Day, an annual opportunity to educate the public and health care professionals about the little-known syndrome.

"We can't help people if they don't even know they need us," says CdLS Foundation Executive Director Liana Fresher. "CdLS is not a one-size-fits all syndrome. Many children fall through the cracks because they don't fit the classic CdLS mold. So it's important to educate nurses,

therapists, teachers and others who work on the front lines with children every day," says Fresher.

"Once a child is diagnosed, we can make sure the family gets support and information, and, just as the founding families envisioned, make sure that family knows they are never alone."

More information about the syndrome is available from the CdLS Foundation Web site, www.CdLSusa.org or by calling the CdLS Foundation at 800-753-2357.

About CdLS

CdLS is a genetic syndrome occurring in about 1 in 10,000 live births. It affects males and females almost equally, and is found in all races and ethnic backgrounds. CdLS is not hereditary in most cases; rather, it is caused by a random change in one of three—so far—genes.

Common medical problems include gastro-esophageal reflux disease, hearing loss, heart defects, and feeding difficulties.

Although individuals with CdLS range from mildly to severely affected, most have similar physical characteristics: small size, hands and feet; eyebrows that meet in the middle; long eyelashes; upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms, and partial joining of the toes.

Behavioral issues, including self-injury and aggression, are not uncommon. More than half of people with CdLS are considered to be on the autism spectrum. Intellectual disabilities or learning difficulties are often present. With proper diagnosis and medical care, people with CdLS can live a full life, well into adulthood.

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