



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

## CdLS Foundation Contact:

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Cornelia de Lange Syndrome Foundation  
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**FOR RELEASE BEFORE SEPTEMBER 16, 2013**

**WHAT:** 25<sup>th</sup> Annual Madison County Wood Products Golf Tournament

**WHEN:** September 16, 2013

**WHERE:** Pevely Farms Golf Club in St. Louis

## **25<sup>th</sup> Annual Charity Golf Tourney to Benefit Individuals with Rare Disorder**

St. Louis, MO – (August 28, 2013) On September 16, Madison County Wood Products (MCWP) and Pallet Logistics Management are celebrating the 25<sup>th</sup> Annual Madison County Wood Products Golf Tournament at Pevely Farms Golf Club in St. Louis, which benefits the Cornelia de Lange Syndrome (CdLS) Foundation.

The tournament was inspired by the daughter of Madison County Wood Products co-owner, Doug Gaines. Gaines' daughter, Amber, 32, has CdLS, a little-known genetic disorder that causes a variety of physical, cognitive and developmental disabilities. Tournament organizers include co-chairs Bryan Kesting and Jim Morton, and Steve Snodsmith and Jim Kesting, who have been involved with the tournament for many years.

Since 1989, the event has raised more than \$420,000 to ensure that people with CdLS, a genetic condition causing a range of physical, medical and developmental challenges, live better, fuller lives.

The tournament is sponsored by Madison County Wood Products and Pallet Logistics Management, Crown Machinery, Gallagher Benefit Services, UHY Certified Public Accountants, Weiss Attorneys at Law, and many other local businesses.

Pevely Farms Golf Club is a championship golf course located in the natural beauty of the Meramec River Valley. The day begins with registration at 11:30 a.m., followed by a shotgun start at 1 p.m. Participants will enjoy 18 holes of golf, lunch, dinner, beer, soda and snacks on the course along with the opportunity to win both skill and door prizes.

For more information about sponsorships or to join the tournament, call Gail Speers at 800-753-2357 or Jim Morton at 800-325-0158 ext. 211. For more information about the CdLS Foundation or to make a donation, call 800-753-2357 or visit [www.cdlsusa.org](http://www.cdlsusa.org).

### About CdLS

Cornelia de Lange Syndrome occurs in about 1 in 10,000 births. 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 in the middle; 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, hearing loss, and congenital heart defects. Early diagnosis and intervention are essential to ensure proper management of related medical issues.

About the Foundation

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.

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