



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

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Cornelia de Lange Syndrome Foundation

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26th Annual Charity Golf Tourney to Benefit Individuals with Rare Disorder

St. Louis, MO - (September 8, 2014) The Cornelia de Lange Syndrome (CdLS) Foundation, a national nonprofit family support organization, is hosting its 26th annual CdLS Charity Golf Tournament at Pevly Farms Golf Club in St. Louis, MO, on September 15.

Tournament organizers Jim Morton, of Fenton, MO, and Brian Kesting of Chesterfield, MO, host the event in honor of friend Doug Gaines, father of Amber, 33, who has CdLS, a genetic disorder that causes a variety of physical, cognitive and developmental disabilities.

Since 1988, the tournament has raised much needed funds to help people with CdLS live better, fuller lives. Inspired by children affected by CdLS, local families and friends have made the event an annual success.

The tournament is sponsored by Madison County Wood Products, Pallet Logistics Management, Crown Machinery, Cass Commercial Bank, Peco Pallet, The Daniel and Henry Company, ILM, LPS Equipment & Acquisition, Montgomery Bank, Magnum Fasteners, UHY LLP, and Weiss Attorneys at Law

Pevly Farms Golf Club is an 18-hole championship golf course located in the natural beauty of the Meramec River Valley in Eureka, MO. Participants will enjoy 18 holes of golf, lunch, dinner, beverages and snacks on the course along with the opportunity to win both skill and door prizes. Registration begins at 11:30 a.m. and a four-person scramble format is scheduled for a shotgun start at 1:00 p.m. \$155 per player includes greens fee, cart, lunch and dinner. All proceeds benefit the CdLS Foundation.

For more information, call the CdLS Foundation at 800-753-2357 or register for the events at <http://www.cdlsusa.org/events/MO-golf.htm>. To make a donation, call 800.753.2357 or visit www.cdlsusa.org.

About Cornelia de Lange Syndrome

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, and congenital heart defects.

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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