



CdLS Foundation

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

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Cornelia de Lange Syndrome Foundation
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21st Annual Charity Golf Tourney to Benefit Those with Rare Disorder

Ipswich, MA – (May 6, 2013) The Cornelia de Lange Syndrome (CdLS) Foundation, a national nonprofit family support organization, is hosting its sold out 21st annual New England Golf Tournament for CdLS at Ipswich Country Club in Ipswich on May 20.

Tournament organizers Shelly Champion of Andover, Ava Frank and David Molzan of Sudbury, Stephen Igoe of Grafton, Dianne Lessa of Littleton, Patrick Lyons of Portsmouth, NH, Brian O’Keefe of Salem, and Frank and Denise Teixeira of Hingham are parents of children with CdLS, a little-known genetic disorder that causes a variety of physical, cognitive and developmental disabilities.

“What makes the event so special is my relationship with Brian and his family, especially his daughter, Meaghan, who has been a patient of mine for many years,” said Donald Sadoski, DMD, who has been participating in the New England Golf Tournament for more than 20 years. “It’s a great cause and very enjoyable tournament.”

Since 1993, the tournament has raised \$482,000 to help people with CdLS live better, fuller lives. Inspired by their children affected by CdLS, New England parents, like the O’Keefes, and their friends have made the event an annual success. All proceeds benefit the CdLS Foundation.

The tournament is sponsored by RBC Capital Markets, BMO Capital Markets, KeyBanc Capital Markets, Macquarie Capital USA, Inc., SIG, ISG Insurance Surogation Group, Renaissance Macro Research, and Samuel Adams Brewery.

Ipswich Country Club is one of New England’s premier private golf clubs and is reserved exclusively for the event. The day begins with a deli lunch and registration at 11 a.m., followed by a shotgun start at 12 p.m. Dinner is at 6 p.m., and raffle and silent and live auctions begin at 7 p.m. \$210 per player includes greens fee, cart, lunch and dinner.

For more information, call Gail Speers at 800-753-2357. For more information about the CdLS Foundation or to make a donation, call 800-753-2357 or visit 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 is 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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