



CdLS Foundation

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

FOR IMMEDIATE RELEASE

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Parents host 17th annual CdLS Charity Golf Tournament to benefit children with rare genetic disorder

GEORGETOWN, MA (May 14, 2009) – The Cornelia de Lange Syndrome (CdLS) Charity Golf Tournament takes to the fairway for its 17th year on Monday, May 18, at the Georgetown Club on Andover Street. This event is sponsored by RBC Capital Markets.

Tournament organizers Stephen Igoe of Grafton, Dave Molzan of Sudbury, and Brian O'Keefe of Salem are fathers of children with CdLS, a little-known genetic disorder that causes a variety of physical, cognitive and developmental disabilities. All proceeds benefit the CdLS Foundation, a national family support organization near Hartford, CT.

“When your child is diagnosed with CdLS, it’s important that you receive the resources and support provided by the CdLS Foundation,” says Denise Teixeira of Hingham, tournament volunteer, lunch sponsor and mother to seven-year-old Sofia, who has CdLS. “Raising money for the Foundation helps support the production of materials, like the newsletter *Reaching Out*, which has been an invaluable resource to my family over the years,” Teixeira says.

“My family is constantly trying to make a difference, not just for Sofia, but for all children and families affected by CdLS.”

Since 1993, the CdLS Charity Golf Tournament has raised more than \$325,000 to help people with CdLS live better, fuller lives. Inspired by their children affected by CdLS, New England parents, like the Teixeiras, and their friends have made the success of this tournament an annual labor of love.

The tournament tees-off with lunch and registration at 11:30 a.m., followed by a shotgun start at 12:30 p.m. Dinner is at 6 p.m. and a silent auction begins at 7 p.m. \$175 per player includes greens fee, cart, box lunch, dinner, and prizes. For more information, call Brian O’Keefe at 978-745-7794.

What is CdLS?

CdLS is a genetic syndrome that 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.

Although individuals with CdLS range from mildly to severely affected, most have similar physical characteristics: 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, and partial joining of the toes. Common medical problems include gastroesophageal reflux, bowel malrotation, hearing loss, 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 make informed decisions throughout their lifetime. For more information, call 800-753-2357 or go to www.CdLSusa.org.