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Cornelia de Lange Syndrome Foundation
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FOR IMMEDIATE RELEASE

25th Annual Charity Golf Tournament Raises More Than \$70,000 for Rare Disorder

IPSWICH, MA – (June 1, 2017) Avon-based national nonprofit organization the Cornelia de Lange Syndrome (CdLS) Foundation held its 25th annual CdLS Foundation New England Charity Golf Tournament at Ipswich Country Club on Monday, May 22.

Inspired by their children affected by CdLS, a rare genetic disorder, New England parents and their friends have made the success of this event an annual labor of love. Since 1992, the Charity Golf Tournament has raised over \$875,000 to help people with CdLS live better, fuller lives. This year, the event raised an impressive amount, adding to the total.

“We were able to raise more than \$70,000 through the 2017 golf outing,” said Kristi Larson, Development Manager for the CdLS Foundation. “It was a great event for golfing, making connections and supporting individuals with CdLS. We’re thrilled with its success.”

Tournament organizers included Dianne Lessa, of Littleton, MA; Ava Frank and David Molzan, of Sudbury, MA; Patrick Lyons, of Portsmouth, NH; Shelly Champion, of Ipswich, MA; Brian O’Keefe, of Salem, MA; Denise and Frank Teixeira, of Hingham, MA; Anders Johnson, of Danbury, CT; and Mike Christie, of Sutton, MA.

For more information about the tournament, call 860-676-8166 or visit <http://www.cdlsusa.org/events/NE-golf.htm>. To make a donation, visit <https://donate.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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