



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

**CdLS Foundation Contact:**

Brenda Shepard, (312) 912-7198

[bshepard@CdLSusa.org](mailto:bshepard@CdLSusa.org)

Cornelia de Lange Syndrome Foundation  
302 West Main Street #100 Avon, CT 06001

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## **5<sup>th</sup> Annual Brew & BBQ to Benefit Individuals with Rare Disorder**

Alpharetta, GA – (September 3, 2014) The Cornelia de Lange Syndrome (CdLS) Foundation, a national nonprofit family support organization, is hosting its 5<sup>th</sup> annual Brew & BBQ for CdLS at Jeckyll Brewing in Alpharetta, GA, on September 27.

Event organizers Fran Rissland and Suzanne Musial of Alpharetta, are both parents of children with CdLS, a little-known genetic disorder that causes a variety of physical, cognitive and developmental disabilities.

"As moms to children born with Cornelia de Lange Syndrome, we are honored to host this fundraiser benefitting the national CdLS Foundation that does so much for families affected by this syndrome like ours," said Musial, mom to Ella Grace (age 6).

Since 2009, the event has raised nearly \$20,000 to help people with CdLS live better, fuller lives. Admission includes a souvenir glass, beer sampling, barbeque dinner, live music, brewery tours and a chance to bid on fabulous silent auction items. All proceeds benefit the CdLS Foundation.

"We are also excited to host the Brew & BBQ for CdLS this year at Jeckyll Brewing in Alpharetta which is right in our backyards," said Rissland, mom to Riley (age 10). "We hope to increase awareness of this little-known syndrome and gain support within our own community."

For more information, visit [brewandbbq4cdls.com](http://brewandbbq4cdls.com). 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.

### 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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