



# CdLS Foundation

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

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**What – The 4<sup>th</sup> Annual Brew & BBQ for CdLS**

**When –** Takes place September 28 from 6:30 to 9:30 p.m.

**Where –** SweetWater Brewery in Atlanta, GA

## **Local Parents Bring Awareness, Raise Funds for Rare Genetic Disorder**

*Two area families affected by Cornelia de Lange Syndrome (CdLS) host the 4<sup>th</sup> Annual Brew & BBQ in September to benefit the national CdLS Foundation and help raise awareness for the little-known syndrome.*

Atlanta, GA – (September 12, 2013) The 4<sup>th</sup> Annual Brew & BBQ for CdLS takes place September 28 from 6:30 to 9:30 p.m. at SweetWater Brewery in Atlanta. The event is hosted by the Musials, parents of Ella Grace, 5, and the Risslands, parents of Riley, 9, both of Alpharetta, GA. Their children were born with CdLS, a rare genetic disorder that causes a variety of physical, cognitive and developmental disabilities.

"As moms to children with CdLS, Fran and I understand firsthand how critical it is to have the support and access to information that the Foundation provides," said Suzanne Musial. "Both of our families have benefited from the great work they do, and we are pleased to have the opportunity to give something back."

Guests will enjoy sampling locally-brewed SweetWater beer and food from Slope's BBQ, as well as live music, complimentary brewery tours and a silent auction. All proceeds benefit the national CdLS Foundation, a non-profit organization that provides vital information and support to families affected by CdLS in the Atlanta area and across the country.

Tickets are \$30 per person in advance and \$40 per person at the door, and may be purchased online at [www.brewandbbq4cdls.com](http://www.brewandbbq4cdls.com). For information regarding the event, contact the organizers, Suzanne Musial and Fran Rissland at [brewandbbq4cdls@gmail.com](mailto:brewandbbq4cdls@gmail.com). This is a 21+ event and is sponsored by Building Bridges Therapy, Franchise Gator and Tryst Hair Salon & Boutique.

For more information about CdLS, contact the CdLS Foundation at 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. Early diagnosis and intervention are 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.