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

**FOR RELEASE BEFORE November 30, 2016**

**Parents Host “One Love, One Heart 5K” to Benefit Rare Disorder, Daughter**

**WHO:** Local Family Holds Road Race for CdLS Foundation

**WHAT:** One Love, One Heart 5K Walk/Run

**WHERE:** Medlock Park, 874 Gaylemont Circle, Decatur, GA 30033

**WHEN:** Saturday, December 3, 2016, 10:00 a.m.

DECATUR, GA (November 2, 2016) — Jim and Jen Pomfret are preparing to mark the twelfth year of what is called the hottest 5K of December. As the One Love, One Heart 5k slogan reads, “One love refers to the universal love and respect expressed by all people for all people.” At the event, this love is directed towards those who have a rare genetic disorder called Cornelia de Lange Syndrome (CdLS). This includes their daughter, Maya.

“It’s a way for Jim and me to do something positive for the CdLS Foundation. It helps to have the community and your friends and family when you do something like this. Sometimes it can be tough having a child with CdLS, so we put a lot of energy in here,” Jen says.

All profits raised go to the CdLS Foundation, which provides free services and support to families, like the Pomfrets. And while the event benefits the Foundation financially, Jen emphasizes that it is emotionally rewarding for families as well.

“When we first did it, it was a way for us to meet new families. Now Maya is 13. If there are new families, we can let them know they have a community close by. You can tell people are here for a purpose; not just to run and leave,” she continues.

Refreshments will be provided and the top male and female runners overall and in each age group will be awarded. Long sleeve t-shirts are guaranteed for all pre-registered runners, and while supplies last on race day.

[Registration](#) is \$25, but increases to \$30 on race day. Immediate family members—moms, dads and siblings of an individual with CdLS—receive free entry, but still need to register. The event will be held rain or shine.

For more information on the race, contact Jim or Jen Pomfret at [pomfretj@comcast.net](mailto:pomfretj@comcast.net) or 404-228-3915. Race Coordinator Ed Williams can be reached at [roadraceservices@comcast.net](mailto:roadraceservices@comcast.net).

For any additional information or to make a donation, call the CdLS Foundation at 800-753-2357 or visit [www.cdlsusa.org](http://www.cdlsusa.org).

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# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

## 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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