



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

## CdLS Foundation Media Contact:

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Cornelia de Lange Syndrome Foundation  
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## FOR IMMEDIATE RELEASE

### Cornelia de Lange Syndrome Foundation Awards Research Grants

*Three researchers will share \$24,447 funding awarded by national nonprofit*

Avon, CT – (June 7, 2019) As part of the 2019 Research Grants Program, the Cornelia de Lange Syndrome (CdLS) Foundation has awarded \$24,447 to researchers studying various aspects of CdLS. The goal is to have these research projects provide insight into the causes of CdLS as well as evaluate potential ways to improve the lives of individuals and families affected by this syndrome. “We are hopeful that the combined efforts will result in findings that ultimately create a higher quality of life for individuals with CdLS and the ones who love them,” stated Bonnie Royster, Executive Director of the CdLS Foundation.

The recipients of the grants are:

**Stephenson Chea, Graduate Student Researcher, University of California, Irvine, Center for Complex Biological Systems:** *Investigating Cell Fate Misallocation as a Source of Developmental Defects in Cornelia de Lange Syndrome.* This study will determine whether and how cell fate allocation of brain and gut stem cells differs between wildtype and Nipbl-haploinsufficient mouse embryos, by characterizing the single-cell landscape of embryos from late gastrulation to late head-fold stages (onset of organogenesis). As well as, characterize the transcriptional landscape of brain and gut stem cell populations across developmental time, from late-gastrulation to late head-fold, in wildtype and Nipbl-haploinsufficient mouse embryos.

**John Michael Falligant, MS, BCBA, Kennedy Krieger Institute, Maryland:** *Behavioral Assessment and Treatment of Problem Behavior in Children with CdLS.* This study will improve our ability to effectively treat problem behavior in CdLS, as well as identify key variables associated with problem behavior in CdLS which may be examined in future studies and clinical practice to foster early intervention and prevention efforts.

**David F. Smith, MD, Children's Hospital Medical Center, Cincinnati:** *Characterization of Sleep Patterns in Patients with CdLS.* The aim of this study is to use objective measures to characterize the sleep patterns of patients with CdLS by sleep logs, validated sleep surveys, and actigraphy in order to better characterize the sleep disturbances noted to be prevalent in these patients. We also aim to correlate these findings with patient phenotypes (using quality of life surveys and a review of previous medical records) as well as assess their sleep patterns against familial controls.

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Researchers will present their findings at the 2020 CdLS Scientific and Educational Symposia. For more information about the CdLS Foundation, the research into CdLS or to make a donation, call 800.753.2357 or visit [www.cdlsusa.org](http://www.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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