



# CdLS Foundation

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

## Cornelia de Lange Syndrome Foundation Application for Research Study Approval

Title of application:

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Name of applicant:

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Post-graduate degree(s) of applicant:

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Title of applicant at present institution:

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Division/department of applicant:

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Applicant's institutional address:

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Tel.: \_\_\_\_\_ Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

If human subjects are used as part of this proposal: status of IRB approval (required):

not submitted  submitted, approval pending  approved/protocol number: \_\_\_\_\_

Name and Signature of IRB-official:

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Name

Signature

Date

If animals are used as part of this proposal: Status of IACUC approval:

not submitted  submitted, approval pending  approved/protocol number: \_\_\_\_\_

Name and Signature of IACUC official:

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Name

Signature

Date

Please check the category that best fits the area of focus for your study:

Clinical  Developmental biology  Molecular biology  Behavior  Education

Other (specify) \_\_\_\_\_

Name and signature of Applicant:

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Name

Signature

Date

## **Cornelia de Lange Syndrome Foundation**

### **Research Approval Application**

The format for submitting proposals for approval by our Research Committee is outlined below. Please limit applications (not including face page, bio-sketch, budget page, and references) to three pages. Please note there is no funding associated with this application. If you are applying for a CdLS Foundation grant, please use the Research Grant Application.

#### **Face page**

Complete attached face page with appropriate signatures.

#### **Bio-sketch**

- Name of applicant and degrees
- Undergraduate and postgraduate education and degrees granted
- Current and past positions
- Relevant other funding
- Relevant publications

#### **Summary and Need for Study**

##### **For clinical projects, please indicate:**

- Percentage of CdLS children affected, if known
- Comparison of your area of focus between children affected with CdLS and those unaffected
- Ages at which your area of focus is most significant and/or originates
- What the study will measure and what question(s) the study will answer
- How these findings can be valuable to the overall CdLS population

##### **For basic science projects, please indicate:**

- Relevance to understanding the pathophysiology of CdLS
- Samples and/or systems to be used to address hypothesis
- What the study will measure and what question(s) the study will answer
- How these findings can be valuable to the overall population of people with CdLS

#### **Study design**

Following your study summary, please detail the steps in your study design:

- Hypothesis
- Specific aims
- Background and significance of study
- Preliminary results

- Research design and methods, including:
  - Duration of the study
  - Number of participating people with CdLS
  - Number of people without CdLS or other individuals participating
  - Animals to be used
  - Methodology for sample collection (if applicable)
  - Methodology for clinical/behavioral/educational assessments (if applicable)
  - Status of the IRB and/or IACUC and Animal Welfare Assurance approval for this study. (Please note that approval *is required* before starting your study).

## References

- Literature Cited

## Recognition

The Foundation and the families it serves are grateful for your study. Please indicate how the Foundation will be informed of your findings, as well as the expected timeframe for these reports.

The CdLS Foundation also encourages the publication of new information that updates the medical community about characteristics of CdLS and available treatments. Please indicate plans for publication of your findings in scientific or medical journals. We do ask that, where possible, you include contact information for the CdLS Foundation in related articles or presentations.

The CdLS Foundation requires researchers to present findings at a CdLS Foundation Scientific Symposium (held bi-annually in even-numbered years) and write a summary article for the CdLS Foundation newsletter, *Reaching Out*.

## Additional Information

Please also include any additional information that you believe would be helpful to the members of the CdLS Foundation in reviewing your proposal.

Please submit **three** copies of your proposal to:

Research Committee  
c/o Ms. Liana Garcia-Fresher, Executive Director  
Cornelia de Lange Syndrome Foundation  
302 West Main Street, #100  
Avon, CT 06001-3681

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The CdLS Foundation appreciates the efforts of the scientific community to better diagnose and understand CdLS. Each day, we enlist the expertise of professionals from many fields including genetics, biology, behavior, dentistry, and education in a collective effort toward advancing global recognition and understanding of the syndrome. We are grateful for your interest in our mission and your submission of this research proposal.