

**Cornelia de Lange Syndrome Foundation
Research Study Application**

Title of application:

Name of applicant:

Post-graduate degree(s) of applicant:

Title of applicant at present institution:

Division/department of applicant:

Applicant's institutional address:

Tel.: _____ Fax: _____ Email: _____

Administrative official to be notified if approval is made:

Name: _____ Tel. /email: _____

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:

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:

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:

Name Signature Date

Cornelia de Lange Syndrome Foundation

Research Study 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 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.

Additional Information

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

Please submit a copy of your proposal via email to director@CdLSusa.org.

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.