



CORNELIA DE LANGE SYNDROME USA FOUNDATION
RESEARCH PROPOSAL –FACE PAGE

Title of Application: _____

Name of Applicant: _____

Post-Graduate Degrees of Applicant: _____

Title of Applicant at Present Institution: _____

Division/Department of Applicant: _____

Institution at which grant is to be held: _____

Applicant's Institutional Address: _____

Tel. No.: _____ Fax No.: _____ E-Mail: _____

Administrative Official to be notified if award is made:

Name: _____ Tel. No./E-mail: _____

Signature

Date

If human subjects are to be 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 to be 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 USA FOUNDATION
RESEARCH PROPOSAL

The Cornelia de Lange Syndrome (CdLS) Foundation is a family support organization which 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 others with similar characteristics make informed decisions throughout their lifetime.

Up to five grants of \$5,000 each are available to investigators at academic and research institutions in the United States; fellows and graduate students are encouraged to apply. Overhead or indirect costs are not supported in these funds. The format for submitting proposals is outlined below. Please limit applications (not including Face Page, Biosketch, Budget Page, and References) to three pages with one-inch margins using 12-point font.

Face Page

Complete attached face page with appropriate signatures.

Biosketch:

- . Name of Applicant and Degrees
- . Undergraduate and Postgraduate Education and Degrees Granted
- . Current and Past Positions
- . Relevant Other Funding
- . Relevant Publications

Budget:

Please include the dollar amount you will need to complete the different phases of your study. These phases may include, but are not limited to, the following:

- . Phase One: Data Collection
- . Phase Two: Data Analysis
- . Phase Three: Report Writing

Indirects and overhead costs are not supported by this grant mechanism. Clinical and Post-Doctoral Fellows are encouraged to apply.

Funding period is from June 1, 2005 through May 31, 2006.

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 CdLS population

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 CdLS children
 - . Number of non-CdLS children 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 Institutional Review Board (IRB) and/or IACUC and Animal Welfare Assurance approval for this study. (Please note that approval is required as indicated by the studies proposed in this application.)
- . References

Recognition:

The Foundation and its families are grateful for your study. Please indicate how the Foundation will be made aware of your findings, as well as the expected time frame for these reports. The CdLS Foundation also encourages the publication of new information updating the medical community about characteristics of CdLS and all treatments available for individuals with CdLS. 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 any article or presentation.

The Foundation encourages awardees to present their studies at a CdLS Foundation Scientific Symposium and write a brief summary 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.

The CdLS Foundation greatly appreciates the efforts of the Clinical Advisory Board and the medical community at large to better diagnose and understand Cornelia de Lange Syndrome. Each day, we enlist the expertise of professionals from many fields including genetics, medicine, speech and language, behavior, dentistry, alternative health, education, and psychology in our collective effort toward advancing global recognition and societal understanding of the Syndrome. We are especially grateful for your interest in our mission and your submission of this research proposal.

Please submit three copies of your Proposal no later than April 22, 2005 to:

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