

CdLS FOUNDATION

Research Center of Excellence

Designation Application

Thank you for your interest in Research Center of Excellence designation with the CdLS Foundation. Designated Centers form the backbone of our Mission Possible network — connecting families to world-class expertise and advancing our shared goal of identifying treatments for Cornelia de Lange Syndrome. Please complete all sections and submit to both Bonnie Royster at Director@CdLSusa.org and David Litwack at DLitwack@CdLSusa.org.

SECTION 1: INSTITUTIONAL INFORMATION

Institution / Organization Name *

Department / Division

Institution Type (Hospital / University / Institute)

Street Address

City, State, ZIP

Institution Website

Primary Contact Email

SECTION 2: LEAD PRINCIPAL INVESTIGATOR

Full Name

Credentials / Degree(s)

Title / Position

Department

Phone Number

Email Address

Research Lab / Group Website (if applicable)

Brief Biographical Statement — Please describe your background and expertise as it relates to CdLS or cohesinopathies (3-5 sentences) *

Summarize relevant training, prior appointments, and CdLS-related research experience...

SECTION 3: RESEARCH PROGRAM OVERVIEW

Primary Research Focus Area(s) *

Select all that apply:

- Genetics / Genomics Molecular Biology Cell Biology
 Neuroscience / Neurodevelopment Biomarker Discovery Therapeutics / Drug Development
 Natural History / Epidemiology Behavioral / Developmental Research Other (specify below)

If Other, please specify:

Describe your current research program and how it relates to CdLS or related cohesinopathies. *

Include key questions being investigated, model systems used, and how findings may benefit CdLS individuals and families...

What is the current stage of your CdLS-related research?

- Early / Foundational Active / Ongoing Translational / Pre-clinical Clinical Trial Stage

List major ongoing or recently completed CdLS-related projects (title, funding source, dates): *

Project Title | Funding Source | Start-End Date...

Do you have an established research laboratory dedicated (in full or in part) to CdLS/cohesinopathy research?

- Yes — fully dedicated Yes — in part No — but in development No

SECTION 4: BIOSAMPLES, DATA & BIOBANKING

Do you currently hold or have access to CdLS patient samples or datasets?

- Yes No In Progress / Planned

If yes, describe what is available (e.g., blood, tissue, DNA, iPSCs, clinical records, imaging data):

Sample type | Approximate N | Data types | Consent/IRB status...

Are you willing to share samples or data with other CdLS Foundation–designated researchers under appropriate agreements?

- Yes No Case-by-case basis

SECTION 5: PUBLICATIONS & SCHOLARLY CONTRIBUTIONS

List up to five (5) key peer-reviewed publications related to CdLS, cohesinopathies, or directly relevant research (most recent first): *

Author(s), Title, Journal, Year, DOI — list each on a separate line...

Have you presented CdLS-related research at national or international conferences in the past three years?

- Yes No

If yes, list conference name(s) and year(s):

SECTION 6: COLLABORATION, TRAINING & FOUNDATION ENGAGEMENT

Describe your current or planned collaborations with other CdLS researchers, clinical centers, or patient registries. *

Include any existing partnerships with other COE-designated institutions or the CdLS International Network...

Do you mentor trainees (graduate students, post-docs, fellows) in CdLS-related research?

- Yes — actively Yes — occasionally No — but open to it No

How do you engage with or plan to engage with the CdLS patient and family community? *

e.g., participation in Family Conferences, Registry contributions, patient advisory input, community education...

Are you willing to participate in Foundation-organized research activities (e.g., Consortium for CARING, Annual Research Meeting, webinars)?

- Yes Maybe / Discuss No

SECTION 7: RESEARCH GOALS & 3-YEAR VISION

What are your primary research goals for the next 3 years as they relate to CdLS? *

Be specific about anticipated milestones, planned grant submissions, or translational targets...

What resources or support from the CdLS Foundation would be most valuable to your program?

- Access to patient registry data Collaboration introductions Grant/funding connections
 Family/community engagement support Scientific visibility (publications, conferences) Other

Additional comments on needs or goals:

SECTION 8: DESIGNATION CRITERIA – RESEARCH COE

The following criteria are used to evaluate Research Center of Excellence applications. Applicants are encouraged to ensure their responses above address each criterion.

#	Criterion	Expectation
1	Research Expertise	Demonstrated history of CdLS or cohesinopathy-related research; peer-reviewed publications and/or active funded projects.
2	Active Research Program	Ongoing laboratory or data-based research with clear scientific focus and methodology related to CdLS.
3	Biosamples / Data Assets	Access to or stewardship of CdLS patient samples, genomic data, or natural history datasets; willingness to share.
4	Collaborative Engagement	Active or planned collaboration with other CdLS researchers, clinicians, or patient registries; team science orientation.
5	Mentorship & Training	Evidence of training next-generation researchers in CdLS-related science.
6	Translation Potential	Research program has plausible pathway toward biomarker identification, therapeutic development, or clinical application.
7	Community Connection	Engagement with or openness to connecting with CdLS families, the Foundation, and the broader network.
8	Foundation Partnership	Willingness to participate in Consortium for CARING, Annual Research Meeting, and Foundation-led initiatives.

SECTION 9: CERTIFICATION & SUBMISSION

By signing below, the applicant certifies that all information provided is accurate and complete, and that the institution supports this application and the commitments described herein.

Principal Investigator Signature

Date

Printed Name

Title

**Department Chair / Division Chief Signature
(if required)**

Date

Submit completed application to both: Director@CdLSusa.org and DLitwack@CdLSusa.org.

Questions? Contact Bonnie Royster, Executive Director | 800-753-2357 | www.CdLSusa.org
Cornelia de Lange Syndrome Foundation, Inc. | Reaching Out. Providing Help. Giving Hope.