

# CdLS FOUNDATION

## Clinical Center of Excellence

*Designation Application*

*Thank you for your interest in Clinical Center of Excellence designation with the CdLS Foundation. Designated Centers serve as trusted anchors for families navigating CdLS — providing expert, coordinated, multidisciplinary care. Please complete all sections and submit to both Bonnie Royster at [Director@CdLSusa.org](mailto:Director@CdLSusa.org) and David Litwack at [DLitwack@CdLSusa.org](mailto:DLitwack@CdLSusa.org).*

### SECTION 1: INSTITUTIONAL INFORMATION

Institution / Hospital / Medical Center Name \*

Department / Division / Program Name

Institution Type

Street Address

City, State, ZIP

Institution Website

Patient Referral Contact / Intake Email

### SECTION 2: LEAD CLINICIAN / PROGRAM DIRECTOR

Full Name

Credentials / Degree(s)

Specialty (e.g., Clinical Genetics, Pediatrics)

Title / Position

Phone Number

Email Address

Years of experience caring for patients with CdLS or related conditions: \*

Less than 2 years    2–5 years    6–10 years    More than 10 years

**Brief Biographical Statement — Describe your clinical background and CdLS patient experience (3-5 sentences): \***

*Include training, prior appointments, and relevant expertise in rare or genetic conditions...*

**SECTION 3: MULTIDISCIPLINARY CLINIC STRUCTURE**

**Does your center offer a dedicated CdLS or rare genetics multidisciplinary clinic?**

- Yes — dedicated CdLS clinic    Yes — integrated rare genetics clinic    No — but individual specialists coordinate    In development

**Clinic Frequency:**

- Weekly    Bi-weekly    Monthly    Quarterly    By appointment / as needed

**Does your clinic have dedicated genetic counselor support?**

- Yes — dedicated to CdLS/genetics    Yes — shared with other programs    No — referral model  
 In development

**Multidisciplinary Specialist Roster — Please indicate available specialties: \***

*List the staff member(s) for each specialty, whether it is available on-site, and any relevant notes.*

Specialty / Service	Staff Name(s)	Available?	Notes / Frequency
<b>Clinical Genetics</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Genetic Counseling</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Developmental Pediatrics</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Gastroenterology / GI</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Neurology</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Cardiology</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	

<b>Orthopedics</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Ophthalmology</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Audiology / ENT</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Speech / Language Therapy</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Occupational Therapy</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Physical Therapy</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Psychology / Behavioral Health</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Endocrinology</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	
<b>Other (specify)</b>	Name(s):	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Referral	

## SECTION 4: PATIENT POPULATION & CARE APPROACH

**Approximate number of CdLS patients currently followed at your center: \***

- 1-5    6-15    16-30    31-50    More than 50

**Geographic catchment — patients primarily travel from:**

- Local / Regional (within 50 miles)    State-wide    Multi-state / Regional referral center    International referrals

**Describe your center's approach to coordinated care for CdLS patients: \***

*Include how specialists communicate, how care plans are created, and how families are supported across appointments...*

**Does your center offer or connect families to the following support services? (check all that apply)**

- Social work / case management    Patient navigation support    Transition to adult care program  
 Telehealth / virtual consultations    Family education and resources    Interpretation / language access services

## SECTION 5: RESEARCH & REGISTRY ENGAGEMENT

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**Does your center participate in or contribute to the CdLS Foundation Natural History Study or Patient Registry?**

Yes — actively    Yes — occasionally    No — but interested    No

**Does your center engage in clinical research related to CdLS?**

Yes — actively recruiting for trials or studies    Yes — retrospective/observational studies    Interested but not currently active    No

**Describe any current clinical research, quality improvement, or educational activities related to CdLS at your center (if applicable):**

*Include study names, IRB status, or relevant publications if applicable...*

## SECTION 6: FAMILY & COMMUNITY ENGAGEMENT

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**How does your center currently engage with or support the CdLS family community? \***

*e.g., participation in CdLS Family Conferences, educational webinars, connections to support groups, family advisory roles...*

**Are you willing to participate in Foundation-organized clinical activities (e.g., Annual Symposium, webinars, family resource referrals)?**

Yes    Maybe / Discuss further    No

**Does your center proactively share Foundation resources (e.g., CdLS Atlas app, family guides, registry information) with newly diagnosed families?**

Yes — routinely    Sometimes    Not currently — but open to it    No

## SECTION 7: FUTURE COMMITMENTS & FOUNDATION PARTNERSHIP

**What are your clinical program goals over the next 2–3 years for CdLS care? \***

*e.g., expanding specialist roster, increasing patient volume, launching a transition clinic, establishing a multidisciplinary conference...*

**What support from the CdLS Foundation would most benefit your program or families?**

- Patient referral pipeline   
  Educational resources for clinical team   
  Connection to research centers  
 Family support materials / CdLS Atlas app training   
  Participation in Consortium for CARING   
  Other

*Additional comments:*

## SECTION 8: DESIGNATION CRITERIA – CLINICAL COE

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

#	Criterion	Expectation
1	<b>Clinical Expertise</b>	Lead clinician has demonstrated experience with CdLS or rare/complex genetic conditions; recognized within the medical community for this expertise.
2	<b>Multidisciplinary Team</b>	Access to a coordinated team of specialists across key areas relevant to CdLS care; evidence of team-based care planning.
3	<b>Patient Volume</b>	Sufficient CdLS patient volume to maintain clinical expertise and demonstrate meaningful impact on families.
4	<b>Coordinated Care Model</b>	Structured approach to care coordination across specialties; genetic counseling support; care plans developed collaboratively.
5	<b>Family Support</b>	Active engagement with families; connection to CdLS Foundation resources, support groups, and educational materials.
6	<b>Registry Participation</b>	Contribution to or willingness to participate in CdLS natural history studies, patient registries, or clinical research.
7	<b>Community Engagement</b>	Participation in or openness to Foundation events, family conferences, webinars, and outreach activities.
8	<b>Foundation Partnership</b>	Commitment to collaborate with the Foundation and with other COE-designated centers to strengthen the network.

## SECTION 9: CERTIFICATION & SUBMISSION

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*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.*

**Lead Clinician Signature**

**Date**

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**Printed Name**

**Title**

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

**Date**

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**Submit completed application to both: [Director@CdLSusa.org](mailto:Director@CdLSusa.org) and [DLitwack@CdLSusa.org](mailto:DLitwack@CdLSusa.org)**

Questions? Contact Bonnie Royster, Executive Director | 800-753-2357 | [www.CdLSusa.org](http://www.CdLSusa.org)  
*Cornelia de Lange Syndrome Foundation, Inc. | Reaching Out. Providing Help. Giving Hope.*