



Services Provided by Family Service Department

Clinics

CdLS Clinics: Provide a multidisciplinary comprehensive evaluation of the individual with CdLS, a treatment plan is formulated for the family to share with their medical professionals, increase knowledge of CdLS in caregivers, providing strategies for handling the challenges their children face, and resources to call upon when needed.

Conference: Attendees receive free head-to-toe consultations with experts from a range of medical and educational fields; attend workshops on legal concerns, educational issues and medical/behaviors challenges; and have opportunities to meet other families facing similar challenges.

Professional Services

Professional Contacts: Family service coordinators address questions from professionals who are interested in learning more about CdLS, calling on behalf of a family to gather resources, or hope to be in contact with a CdLS expert.

Professional Packets: Professionals can contact the foundation and request packet of medical information. Can be tailored to specific specialties.

Publications: Families can download printable publications from the website, or contact foundation to request a copy of publications available only in hardcopy.

Ask the Expert: Our Ask the Expert service allows users to email their questions for response from members of our Clinical Advisory Board, Professional Development Committee and Education Advisory Group.

Outreach Services

New Parents: Family service coordinators personally respond to new parents who have contacted the Foundation. Coordinators welcome new parents, answer a multitude of questions about CdLS, review available services to the family, provide family with publications specific to their needs, encourage them to connect with regional coordinators and local families.

Family Service Cultivation: Family Service Coordinators reach out to families who have not been engaged with the Foundation for two years or longer.

Birthday Card Campaign: Birthday cards are sent to individuals with CdLS who are children of Foundation volunteers.

Connect with a Family: Connect with a Family provides families the opportunity to gain mutual support, provide information and share resources.

Regional Coordinator Outreach: Family Service sends a quarterly bulletin to educate Regional Coordinators of new information such as updated publications, upcoming events, resource highlights to share with families in their area.





CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

Grandparent Program: Grandparents program is based on the belief that grandparents are each other's greatest resource. Grandparents interested in the program receive our free grandparent booklet and information about CdLS and the foundation, and or connecting with other grandparents.

Information in Spanish: Spanish-language articles range from basic knowledge about CdLS to specialized articles on aging, behavior and treatment protocols. These articles can be accessed below.

Bereaved Parents Resources: The CdLS Foundation staff is here to provide guidance on the complicated journey you have ahead of you after losing a loved one with CdLS. Staff is here to listen, honor and remember your child. The Foundation has a network of caring families who serve as grief support volunteers whom we can connect you with when you are ready

Emotional Support: Calls placed to our support lines are answered by a caring professional who is willing to listen. Our staff is trained to answer questions personally and offer individualized support over the phone and via email to families

Family Gatherings

Family Gatherings: family gathering can consist of a picnic at a lake with five or six families or a catered luncheon for 100 people. When possible, a member(s) of the Foundation's Clinical Advisory Board or Professional Development Committee attend to consult with families.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

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