AWARENESS

We are currently supporting close to 300 families across Canada; however, we have at least another 3,600 more families to find. We want every family impacted by CdLS to have access to support, resources, and specialized CdLS clinicians to ensure everyone has the opportunity to thrive. We are expanding our Canadian clinical expertise to offer CdLS Clinics and support clinicians caring for individuals with CdLS to provide specialized care to this complex and rare population. Accessing specialists when individuals with CdLS often do not present in the same way as typically developing individuals results in many challenges and avoidable complications. The most common issues in Canada where access and quality of care are challenging are in the areas of gastroenterology and behaviour. We aim to ensure early access to primary prevention, diagnostics and treatment across body systems at time of diagnosis versus as issues arise.

DIAGNOSIS

The diagnosis of CdLS is primarily a clinical one based on signs and symptoms; however molecular testing is becoming increasingly accurate as the field of genetics advances. Eighty percent of individuals can be diagnosed through genetic testing. If you suspect your family member has CdLS, geneticists can help. Genetic testing for CdLS is available throughout Canada.

SUPPORT

We provide a variety of resources, services and information to support families, educators and clinicians. We offer 7 days a week virtual support for families dealing with a diagnosis, struggling with the challenges of day-to-day life, accessing CdLS clinical experts and answering questions about CdLS.

Services Include:

- Home visits
- Virtual Welcome Session
- Family Gatherings
- CdLS Clinics
- Advocacy/education at School IEP Meetings
- Advocacy/education virtually at Care Team Meetings
- Bereavement Services
- CdLS App
- Connecting families to their local & national CdLS Community
- Funding to CdLS Clinics and Conferences

EDUCATION

We offer comprehensive education through webinars, one-on-one virtual education, resources to families, clinicians and educators. We send all of our CdLS families a welcome package with information and resources to help them on their journey. The CdLS Connections Podcast brings information and stories about CdLS and related topics in a easy and accessible format.

ABOUT THE CANADIAN CDLS FOUNDATION

The ***Canadian CdLS Foundation*** is the only national non-profit Registered Canadian Charity (#707263885-RR001) that serves individuals with CdLS, their families, clinicians, educators & community since 2019.

Our four core programs to achieve our mission are *Awareness, Diagnosis, Support & Education*.

Website:

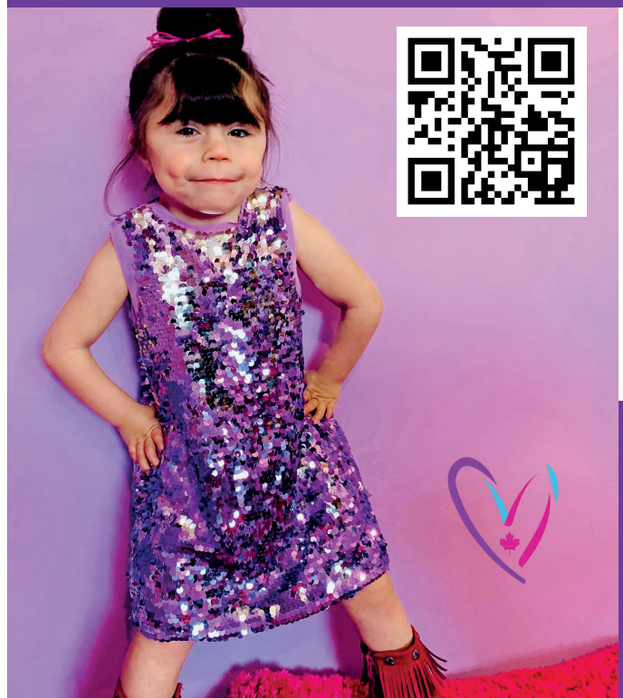
www.CanadianCdLSFoundation.com

Family, Clinician & Educator Support:

support@canadiancdlsfoundation.com

CHARITABLE FOUNDATION FOR CANADIAN INDIVIDUALS, THEIR FAMILIES, CLINICIANS, EDUCATORS AND THEIR COMMUNITY WHO ARE AFFECTED BY CORNELIA DE LANGE SYNDROME

Facts about CdLS & the Canadian CdLS Foundation



CANADIAN CDLS FOUNDATION

Our mission at the Canadian CdLS Foundation is to ensure every Canadian with Cornelia de Lange Syndrome thrives from birth to old age.

WHAT IS CORNELIA de LANGE SYNDROME (CdLS)?

CdLS is a rare genetic disorder present from birth. CdLS can cause a broad range of potential physical, cognitive, and medical challenges. Physical features and medical conditions occur along a continuum with varying degrees of severity. **No two individuals with CdLS are the same.** It is estimated that CdLS occurs in 1 in 10,000 live births, regardless of race, sex or economic status. CdLS presents with variable features and with varying degrees of severity.

MANAGEMENT GUIDELINES

Identifying concerns and initiating treatment to address medical and developmental issues are vital. The CdLS Management Guidelines outline necessary evaluations and tests recommended at different ages and intervals. Find them on our website

https://www.canadiancdlsfoundation.com/

CHARACTERISTICS OF CDLS

CdLS can cause a broad range of potential physical, cognitive, and medical challenges. Physical features and medical conditions occur along a continuum, with varying degrees of severity. No two individuals with CdLS are the same.

As with other syndromes, individuals with CdLS strongly resemble one another. Common characteristics include low birth weight (often under 5 pounds), slow growth, small stature, and small head size. Typical facial features include eyebrows that meet in the middle, long eyelashes, a short upturned nose, and thin downturned lips. Other features may include excessive body hair and small hands and feet.

Common medical issues include:

- Gastro-esophageal reflux disease (GERD)
- Heart defects
- Seizures
- Feeding difficulties
- Vision problems
- Hearing loss

Missing arms, forearms or fingers are also present in approximately 25% of individuals with CdLS. Behavioural, communication and cognitive challenges often exist and may vary in severity.

Not all individuals with CdLS will have all the signs and symptoms mentioned above.

support@CanadianCdLSFoundation.com

Donate Today!

Join us in making a difference! Your contribution to the ***Canadian CdLS Foundation*** enables us to provide vital support, education, and advocacy for individuals and families affected by *Cornelia de Lange Syndrome*. Together, we can empower families, raise awareness, and ensure a brighter future for those living with CdLS. Donate today and help us continue our important work!

Visit us at

www.canadiancdlsfoundation.com

Or Scan our QR code to visit our donation page:

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