



Frequency is 1:10,000-1:30,000 live birth affecting both males and females

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## ABOUT CDLS

It is a **genetic condition** present from birth. It affects the child's body and brain development. Because of this, children **may look a little different and may grow, learn, or develop more slowly than other children.**

## DIAGNOSIS

Doctors make the diagnosis by carefully

- **examining the child**
- **doing special blood tests to check the genes**
- **sometimes using X-rays or scan findings.**

## GENETIC COUNSELLING

Usually a child with CDLS is born in a family without any member with CDLS. The risk of recurrence in the sibling of the affected child is usually very small. The family should consult a genetics specialist before planning next pregnancy.

## PATIENT SUPPORT GROUP

World Federation of CdLS Support (International) – information and links to national CdLS groups around the world:

<https://www.cdlsworld.org/>

ORDI (Indian) –

<https://ordindia.in/>



## CAUSE

This condition happens because of a **changes in any of these gene** (NIPBL, RAD21, SMC3, BRD4, HDAC8, SMC1A) that controls early growth and development. 10-20% cases of CDLS remain undiagnosed so the overall diagnosis rate is 80-90%. Most of the time, this gene change happens by chance. 1% of individuals have an affected parent.

## SIGNS

Not all children have the same problems, but common features can include:

- **Slow growth** before or after birth
- Distinct facial features (such as joined or thick eyebrows, long eyelashes, small nose)
- **Delayed development**
- Learning difficulties or intellectual disability
- **Feeding problems, reflux, or poor weight gain**
- **Hand or limb differences** (small hands, missing/joint fingers in some children)
- More body hair than usual for child's age and sex
- Some children may not have classical features of CDLS, they may just present with intellectual disability.

## TREATMENT AND MANAGEMENT

- There is no **curative treatment**
- Medical problems like **feeding difficulty, reflux, heart issues, hearing or vision problems can be treated.**
- **Early therapies** (speech, physical, and occupational therapy) help with learning and daily skills.
- **Nutritional support** is important for proper growth and weight gain.
- **Behavioral support and special education** help improve communication and behavior.
- **Regular follow-up** with a pediatrician and specialists is needed.