



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

## Otolaryngology

- An individual with CdLS should have regular evaluations and immunizations with the primary care provider.
- Hearing evaluation (otoacoustic emissions, or brainstem auditory evoked response if audiology is abnormal).
- Audiology testing after birth or at diagnosis. Testing is recommended every two to three years if there is any concern about hearing or recurrent ear infections.
- Treat recurrent ear infections medically or if fails, with ear tube placement.
- Consider sinus infection as a possible source of hidden pain.
- Be aware that cochlear implants have been successful in improving hearing in some individuals if clinically indicated.
- If sleep problems develop, consider workup for obstructive sleep apnea and/or the use of weighted blankets
- Follow up with appropriate subspecialists as needed.
- Whenever any surgery is performed, all involved specialists should be consulted in order to maximize the use of anesthesia and so that the individual can undergo diagnostic or management studies as needed at the same time.

Support organization information should be given to the family whenever a diagnosis is made:

The CdLS Foundation

1-800-753-2357

[www.CdLSusa.org](http://www.CdLSusa.org).

- It is important that individuals with CdLS be evaluated and followed at some regular interval for gastroesophageal reflux (GER). Unexplained pain/discomfort or acting out may be due to an underlying medical condition. Management and treatment guidelines are available [www.cdlsusa.org](http://www.cdlsusa.org).

- Ensure that the family has the CdLS Medical Alert Card, available from the CdLS Foundation Web site, which would be helpful in an emergency situation (e.g. risk for volvulus).