



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

## Development & Early Intervention

- An individual with CdLS should have regular evaluations and immunizations with the primary care provider.
- Developmental assessment in infancy and continuing every one to three years.
- Ongoing developmental services, with school placement and therapy issues individualized. It is likely that most individuals will benefit from physical, occupational and speech therapy.
- The use of sign language is encouraged since this will help facilitate oral communication, as will communication boards and other tools.
- Follow up with appropriate subspecialists as needed.
- Discuss job training or work issues, higher education.
- 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).

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).