



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

Neurology

- An individual with CdLS should have regular evaluations and immunizations with the primary care provider.
- Monitor development and use the CdLS
- No specific or routine brain studies are recommended unless clinically indicated.
- Seizures should be managed by standard medical recommendations.
- If sleep problems develop, consider workup for obstructive sleep apnea and/or the use of weighted blankets.
- 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.
- 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.