



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

## Parents, a Crucial Resource

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If you have children, you likely identify yourself first and foremost as a parent. Being a parent is an all-consuming, extremely tiring, always exciting, tremendously stressful, potentially thankless but incredibly rewarding job. For a parent of a child with a number of medical and/or developmental complications there are additional responsibilities, stresses and rewards. These are usually compounded by many necessary office visits and telephone calls.

From the professional point of view, the parental role in any interaction is crucial. There would be no other way to ascertain correct findings without an accurate medical and educational history.

Accuracy in characterizing the following information can often provide the most helpful insights:

- duration and frequency of symptoms
- amount of food or formula taken
- length of time in a specific therapy
- particular treatments used previously and whether or not they were successful
- clear description of pain and what may help it or make it worse
- behavioral differences in school compared to home
- which mood changes can be detected at certain times

It may be helpful to keep a diary, especially if observing your child for a specific symptom that could be affected by meals, household activities, bowel movements, or moods.

Please never underestimate the importance of this exchange of information. Even if you are unsure about the potential relevance to a specific entity, err on the side of sharing too much information rather than too little. It is also helpful to work with the professionals, as they should work with you: keep appointment times, cancel if an emergency arises and reschedule. Follow-up visits are vital to sort out persistent findings.

Being a member of this parent support organization, you are providing your children with a tremendous advantage. For example, you read newsletters and get together with other parents in similar situations, learn from each other's struggles and share successes. You have the best interests of your children at heart throughout their lives. This, in turn, enables your children to feel confident, cherished and strong. With these inherent feelings, they will be calmer in approaching therapy and school, and office visits. Your children will reflect your efforts. Your doctors, therapists, and educators will be better equipped to serve you and your child.

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