

Twins and CdLS

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Twin pregnancies account for a small percentage of all births; however, over the past few decades the rate of multiple pregnancies has been rising. According to the National Center for Health Statistics, in 2012 the overall twin birth rate was 33.1 per 1,000 total births in the United States which has risen by over 70% since 1980, due to the use of assisted reproductive technologies.

Identical twins (monozygotic twins) develop from a single embryo, which is created from the union of a single sperm from a man and single egg from a woman, then divides into two embryos. Monozygotic twins are mostly genetically identical, thus being very similar in looks, physiology and development. Fraternal twins (dizygotic twins) result from two separate eggs that are fertilized by two separate sperm. Fraternal twins on average share half of their genetic material, which is the same amount shared between any two siblings with the same biologic parents.

The occurrence of Cornelia de Lange Syndrome in twins is rare but possible. Though CdLS is a genetic diagnosis, it is rarely inherited from a parent to a child, but rather is the results of a sporadic mutation of a gene related to the cohesin complex. These mutations could occur during the formation of the sperm, the egg or after the embryo is formed.

Coping with twins can be challenging, and raising twins of whom one has a significant disability can be even more stressful, depending on the level of resources available to the family. The differences in development and behavior from an early age will be much more obvious to a parent in a twin pair, similar to the differences seen when siblings are close in age. One study showed that most parents in these situations consider their twins to be siblings rather than twins. Such differentiation likely helps parents accept each child for who they are, rather than having unrealistic expectations of either.

Coping then becomes similar to how families cope with any sibling group in which one has significant challenges. Coping strategies include:

- Consider each child as unique, recognizing their strengths, and needs. This means having different expectations, based on their individual capabilities, not the exact same expectations.
- Encourage siblings to see the strengths in each other and find activities that all family members can enjoy together and make this a regular part of the week.
- Arrange for each child to have their own activities independent of the other. The difficulty with twins or siblings who are close in age is the expectation that they will do everything together and not allowing for individual differences.
- Give each child time alone with a parent. Arrange to divide and conquer if they are in a two parent household. In a single parent household, use relatives, family friends, play dates, or babysitters to do this.



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- Allow each child his/her own space in the house, which is off limits to other siblings. This can be a bedroom, but if you don't have the space, it could be a desk, or a cordoned off area in a common living area.
- Avoid making the typical child the 'grown up' too early. They can and should take part in helping their sibling, but not to the point of giving up their own childhood.

Coping with Twins Discordant for Intellectual Disabilities: The Mothers' View.

De Vos B. Jacobs N. Vandemeulebroecke L. Derom C. Fryns JP. *Twin Research*. 5(3):227-30, 2002 Jun.

Sarah Noon serves on the Foundation's Clinical Advisory Board; Mary Pipan serves on the Professional Development Committee.

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