

## The disease

NCL2 (the full name is "late-infantile neuronal ceroid lipofuscinosis") is a so-called neurodegenerative disease. The brain cells of the child can no longer degrade a certain substance and thus die off gradually.

However, because children are still building new brain cells, there is a constant ups and downs of skills. For example, the child will forget to walk - then take a few steps in the next few weeks - just to lose this ability again.

Little by little the child loses all previous skills and becomes as helpless as a newborn baby.

Depending on the course of the disease, this is supplemented by epileptic seizures, myoclonios (twitches similar to those of Parkinson's disease), progressive blindness and a reduction of the swallowing reflex, so that the children have to be artificially nourished. The immune system becomes weaker and colds and other infections become more and more dangerous.

At some point, usually between the ages of 8 and 12, the primary life functions fail and the child dies.

The NCL Group is a self-help organization that represents the interests of children and their parents who are suffering from NCL.

Further information on the self-help group and, of course, on NCL in general can be found on our homepage:

**[www.NCL-Deutschland.de](http://www.NCL-Deutschland.de)**

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Can you help us support affected parents and children?

NCL Group Germany e.V.  
IBAN: DE 2720 0100 2000 0195 0208  
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Hamburg)

We issue donation receipts for donations of 50 euros or above.

## Information for family and friends

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**NCL2**



In your circle of friends or family, a child was diagnosed with NCL2 - probably a shock for the parents, for whom a lot will change now. Perhaps the expected result of the long-drawn-out search for a diagnosis. But not only parents and the child must learn to live with this diagnosis.

You too, as relatives and acquaintances are often unsettled. What does this mean for the child? How should I behave towards the parents and the child now? Frequently, this insecurity causes the circle of friends (both the child's and the parents) to retreat slowly.

To avoid this, we have gathered some information about the **disease** - and especially tips on **how to deal with the child itself** - which will hopefully help you.

## Dealing with the child

First and Foremost:

**The child is and will remain a person, not an object coincidentally being present in the same room and without any awareness.**

NCL children are **not deaf**. On the contrary, by the diminution of vision, they often hear all the better. The fact that they can no longer express themselves does not mean they do not understand what you are saying.

**It is difficult to assess what they still notice in the case of older children - but in case of doubt, it's always more than you would expect.**

The more the child is promoted, the longer his abilities will be maintained. The more satisfied it is and the more it feels respected, the better it will do:

- ❖ Welcome the child when you visit the family - just as you would welcome healthy siblings or other children of the same age.
- ❖ The fate of the child may be cruel: Its daily life is not. It may have good and bad days, like everyone else. But you do not need to speak with sad voice. The children are very sensitive to the mood in their surroundings. Therefore, better try to make them smile.
- ❖ Please pay attention to what you tell in the presence of the child. Ask the parents what the child knows about the disease. Would you want to hear in a subordinate sentence that you are going to die soon?
- ❖ Do not talk about the child in its presence. How would you feel when people are talking about you in the same room without being able to express yourself?
- ❖ Do not be afraid to speak directly to the child.
- ❖ Because of the poor vision, the child does not know who is entering the room or why it clatters when you take a cup out of the closet - tell him or her!
- ❖ The same is true when you wrap, change clothes, and so on: "I'm combing your hair now", binds the child into the process and ensures that it doesn't startle when being touched by the brush.
- ❖ If you are in doubt: Ask the parents. They will be glad that someone takes their child's needs seriously and will gladly explain what you should look out for.
- ❖ Most children with NCL2 love to be with other children. And many healthy children get along more easily with the affected child than

most adults do. A simple "he / she is sick" is any explanation they need. NCL is not contagious and there is absolutely no reason to keep the children away from each other

- ❖ Even with children, who cannot move themselves, one can play – just like it is done with infants. Finger plays, "cycling" with the legs, just hugging, crackling together with a rescue cover, rattling or even painting together with a pen. Massage the child with a massage ball or similar. Let it touch and feel a variety of materials. Flowers and spices can also be experienced through their smell. Joint cutting out of cookies where you guide his or her hand and explain what you are doing, is just as possible as strumming on the piano.
- ❖ If you are in doubt, please guide yourself on how you would deal with healthy children - although somewhat younger ones.

**One forgets too easily what NCL-children are above all: children who are as happy as everyone else, if they are taken seriously and given someone's full attention.**