

## The disease

NCL3 (the full name is "juvenile neuronal ceroid lipofuscinosis") is a so-called neurodegenerative disease. The brain cells of the child or adolescents can no longer degrade a certain substance and thus die off gradually.

The classic juvenile NCL usually begins at early school age. The first signs of the disease are visual problems which cannot be improved by a pair of spectacles because they are due to a change in the retina. The loss of vision is slowly worsening to the point of total blindness.

Later, their ability to concentrate and their mental activity are increasingly deteriorating, which is also reflected in a decline in school performance. In addition, there is the occurrence of seizures and movement disorders, which later necessitate a wheelchair. The child's language becomes increasingly difficult to understand. Some children also develop mental problems such as depression or anxiety with hallucinations.

Despite all these problems, many of these patients live until the age of 30 or more.

You can find detailed information on NCL3 on our homepage.

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)**

### **Juliane Sasse (Chairman)**

Graacher Str. 6,  
13088 Berlin,  
Tel.: 030 / 25 04 49 16  
[Juliane.Sasse@ncl-info.de](mailto:Juliane.Sasse@ncl-info.de)

### **Christian Thulfaut (2nd Chairman)**

Emil-Haag-Str. 2  
71263 Weil der Stadt  
Tel. 07033 / 52 39 914  
[Christian.Thulfaut@ncl-info.de](mailto:Christian.Thulfaut@ncl-info.de)

### **Sabine Kohlwey (Secretary)**

[Sabine.Kohlwey@ncl-info.de](mailto:Sabine.Kohlwey@ncl-info.de)

Can you help us support affected parents and children?

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

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



## **Information for Family and Friends - NCL3**

Is in your family or circle of friends a child or adolescent that was diagnosed with NCL3?

First of all, you are likely to encounter shocked and shattered parents. On closer inspection, however, perhaps also relieved parents - because the long-term search for causes, connected with endless investigations, wrong diagnoses, doctors without advice or ideas is now over. The diagnosis is established, and a new life begins. Now comes the time when parents, siblings, the entire family and the child must learn to LIVE with this diagnosis.

In this life situation, you are at least as important to families as the treating doctors.

Questions you will probably ask yourself now: What does the diagnosis mean? How should I behave towards the person concerned? And how should I deal with its parents? How can I help?

Frequently, these questions remain unanswered and lead to a gradual withdrawal of the circle of friends – the children's as well as the parents'.

To prevent this, we have collected a few tips that we would like to introduce you to!

### A plea in advance:

#### **Treat the affected person as normal as possible!**

They were, are and remain independent personalities with their own preferences, hobbies, abilities, wishes, dreams and needs. They are not objects that just happen to be present in the room and don't have any awareness.

Even if their ability to see and speak diminishes, and the need for help and support from others grows, this does not mean that they do not hear and understand what is said.

Even if they can no longer express themselves verbally, this does not mean that they can't do this in a different way. The more time you spend with those affected and the longer you know them, the better you will understand them, in whatever way.

#### **Should you ever be in doubt - always act per to the motto: The affected person does understand everything!**

Me and the affected person...

- ❖ It is important that the person concerned takes part in the normal life and is not excluded. Joint activities are a great enrichment for all parties involved.
- ❖ Welcome the affected person just as you welcome the other family members.

- ❖ Due to the poor vision, those affected often do not know who is in a room or is going to enter - just tell him / her. Even though it may be difficult for you to begin with, behave as usual!
- ❖ Speak directly to the affected person, even if they do not answer and can't see you. A blind person too deserves eye contact when being spoken to!
- ❖ Plan activities together. With a bit of creativity you can do countless leisure activities, such as cooking together, swimming pool visits, trips to the zoo, shopping tours, concerts, cinema, etc.
- ❖ Creative handicrafts with sufficient support are a nice way of spending recreational time together, depending on the state of the disease. You may just include the siblings as well.
- ❖ Make sure you explain and announce new situations. Give the affected person sufficient smelling, hearing, touch or feel experiences. Many excursions can be designed and give you too an insight in different sensory perceptions.
- ❖ The fate of the affected person may be cruel: his / her daily life is not. Both good and bad days occur. Try to emphasize positive things, have fun together and laugh together.
- ❖ Give positive feedback to the person concerned, e.g. If you have enjoyed a trip or if something has been made "on his/her own" during doing handicraft - this strengthens the self-confidence of those affected and helps them to deal better with their illness.

- ❖ Stay calm and act with serenity! Especially in the later stages of the disease.
- ❖ Please take care when talking about the disease itself in the presence of a person suffering from NCL. Ask the parents, siblings and/or carer what the person does and should know about his/her illness.
- ❖ NCL is not contagious! So you do not need to be afraid of touching the person.

If you are still unsure, just ask the parents, siblings or a caregiver (or - depending on the stage of illness - the affected person). Everyone will be glad that someone takes the needs of the person concerned seriously. They will be happy to explain what you should look out for. And with your compassion - which you have no doubt, otherwise you wouldn't have read this flyer this far - many big, seemingly insurmountable hurdles can be overcome together and turn out to be quite small!

Because the more a person suffering from NCL is encouraged and involved, the longer his/her abilities are maintained and his/her self-confidence is strengthened. Just bring a piece of normality into the everyday life of parents, siblings, families and affected persons.

They will thank you, and together you can draw new strength!