

Press release

Eurofins Genomics donates to rare disease foundation NCL on Batten disease

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Eurofins Genomics is proud to donate on behalf of the Eurofins Foundation to the NCL Foundation's research project "Dissecting the CLN3 function". It has been found that Batten disease in children is linked to a mutated *CLN3* gene. The provided funding supports the development of a *CLN3* assay for a proposal at the National Center for Advancing Translational Sciences (NCATS). This would form the basis to implement an approved diagnostics tool for Batten disease. To achieve that, the charity organization is now able to create a PhD position that focuses exclusively on the research of the Batten disease. Dr. Emyr Lloyd-Evans will oversee the research and the newly created position will be part of his team (s. picture below).

Rare diseases affect around 300 million people around the world. There are around 7,000 rare diseases and most of them are caused by genetic alterations such as the Batten disease. The symptoms of this neural disease manifest early in life and turn children blind at school age. The affected children also develop dementia, motor problems and are plagued by epileptic seizures. Usually, they die in their twenties.

Until now, Batten disease, which encompasses a group of disorders called neuronal ceroid lipofuscinoses (NCLs), has hardly been researched. However, the NCL Foundation committed itself to initiating, supporting and funding research on NCLs. It also brings together professionals and groups from different fields to allow for an easier exchange of expertise and research findings.



Dr. Emyr Lloyd-Evans
Research Group Leader
Senior Lecturer at Cardiff University

About NCL Foundation

The non-profit NCL Foundation was founded in 2002 and is dedicated to national and international research funding, with the objective to give children with NCL (Neuronal Ceroid Lipofuscinosis aka Batten disease) a perspective for a long-needed treatment. Children turn blind at school age, develop seizures and motor problems as well as dementia. They usually die in their twenties. The NCL Foundation initiates, supports and funds research projects around the globe and encourages exchange of scientific expertise by connecting professionals and research groups from the respective fields. An extensive, sustainable network of NCL specialists, well established research cooperations and purposefully selected projects, form a strong underlying basis to facilitate a future without childhood dementia. In Addition, the NCL Foundation does important work to raise awareness for the rare disease, in the general public as well as in the medical environment, with the aim to enable an early diagnosis for affected children and offer support for the families. Also to be highlighted is the NCL Research Award, which is awarded regularly to projects that contribute to curing NCL and the Neurodegeneration Award that has the aim to foster and improve synergies in research into NCL childhood dementia and age-related neurodegeneration.



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Notes to Editors:

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