

Speech, language, and non-verbal communication in CLN2 and CLN3 Batten disease

Key terms

Batten disease, CLN2, CLN3, neuronal ceroid lipofuscinoses, childhood dementia, speech, language, communication

What this research is about



Speech and language difficulties are common in Batten disease. Batten disease is a group of childhood dementias. CLN2 and CLN3 disease are the most common types of Batten disease. Speech and language skills change as the disease progresses. However, speech and language had not been researched in a group of people with Batten disease.

We wanted to understand the speech and language features, support needs and strengths in Batten disease.

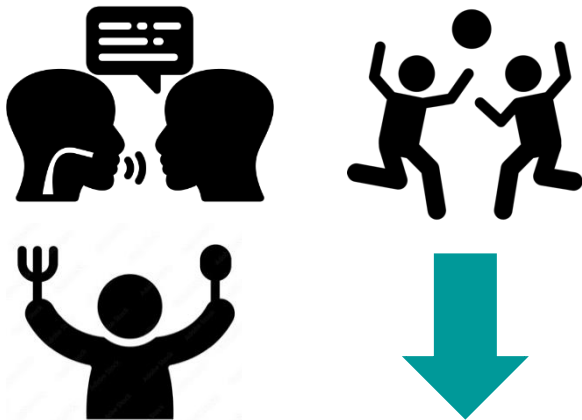
This research helps us to better understand Batten disease. This study also improves our understanding of what therapies and supports might be helpful for individuals with Batten disease.

What the researchers did



- 33 people with Batten disease took part.
 - 16 people had the CLN2 type of Batten disease.
 - 17 people had the CLN3 type of Batten disease.
- Online surveys assessed health and development, feeding, adaptive behaviour and communication.
- Speech was assessed via an online video call.

What the researchers found



- People with little speech could still often communicate to refuse things.
- People who were speaking had a speech disorder called dysarthria.
- Expressive language was stronger than receptive language (understanding skills) for people with CLN3 disease

- Many people had speech and language difficulties before they got a genetic diagnosis.
- Language, daily living skills, and feeding skills declined with age.
- Many speech features were different between people with CLN3 disease and people without CLN3 disease.
- Some people used augmentative and alternative communication (AAC, e.g., communication aids) as speech and language skills declined.

What this means for people with Batten disease and their families



- Clinicians should be aware that speech and language difficulties can be early signs of Batten disease.
- Tailored speech and language therapies are important to support speech and language skills, especially training communication partners.
- Many people with Batten disease would

also benefit from early AAC access to support communication for as long as possible.

Learn more here: Morison, L. D., Whiteman, I. T., Vogel, A. P., Tilbrook, L., Fahey, M. C., Braden, R., Bredebusch, J., Hildebrand, M. S., Scheffer, I. E., & Morgan, A. T. (2025). Speech, Language and Non-verbal Communication in CLN2 and CLN3 Batten Disease. *Journal of inherited metabolic disease*, 48(1), e12838. <https://doi.org/10.1002/jimd.12838>