Communication in KIF1A-associated neurological disorder

Key terms

KIF1A-associated neurological disorder, KAND, speech, language, communication

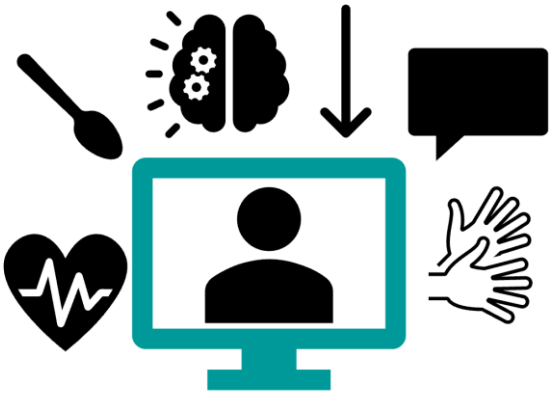
What this research is about

Speech and language difficulties are common in individuals with KIF1A-associated neurological disorder (KAND). These difficulties impact individuals' ability to socialise and self-advocate. However, speech and language had not been researched in a group of people with KAND. For some people, KAND is also a progressive condition.

We wanted to understand the speech and language features, support needs, and strengths in people with KAND.

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

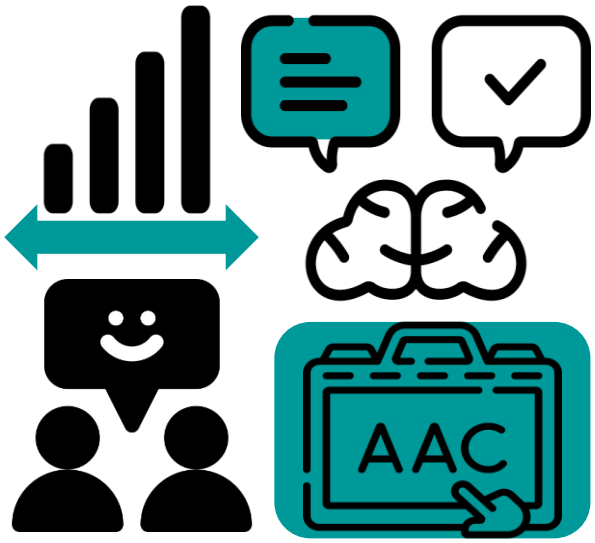
What the researchers did



- 44 people with KAND took part from 13 countries.
- Participants ranged from 1 year old to 60 years old.
- Speech was assessed via an online video call.
- Online surveys assessed health and development, feeding, adaptive behaviour, language and social communication.

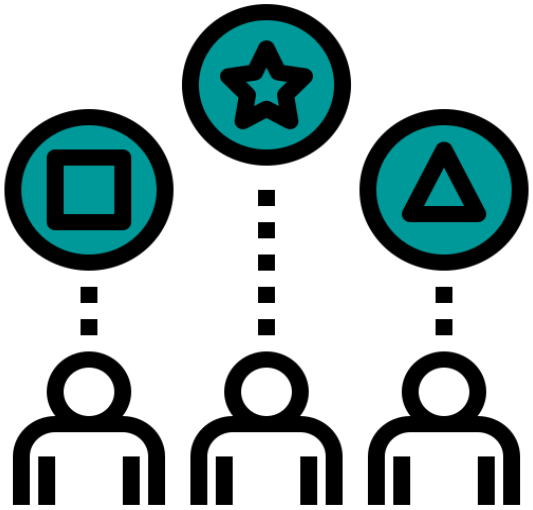
This summary was created following guidelines from Gasparini et al. (2025) *IJLCD.* https://doi.org/10.1111/1460-6984.13142

What the researchers found



- There was a **big range of speech and language ability** in the group.
- All people who were speaking had a motor speech disorder called **dysarthria**.
- Most people had **delayed speech and language milestones**.
- Expressive language was stronger than receptive language (understanding skills).
- People were very **socially motivated**.
- Some people used **augmentative and alternative communication** (AAC, e.g., communication aids like key word sign or speech generating devices).

What this means for people with KAND and their families



- **Individualised speech and language therapies** are important to support speech and language skills, including literacy.
- **AAC** should be able to be adapted to visual and motor impairments (e.g., alternative access, high contrast symbols).
- Relative **strengths** such as social motivation and determination should be used to support success in therapy.
- Many people with KAND would benefit from **early access to AAC** due to delayed speech and language milestones and dysarthria.

Learn more here: Morison, L.D., Vogel, A. P., Christodoulou, J., Gold, W. A., Verden, D., Chung, W. K., Braden, R., Bredebusch, J., Kaur, S., Scheffer, I. E., Morgan, A. T. (2025). Understanding Speech and language in *KIF1A*-associated neurological disorder. *European Journal of Human Genetics.*

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