

Foix-Chavany-Marie Syndrome

What is Foix-Chavany-Marie Syndrome?

FCMS is a disorder of the brain resulting in the inability to control muscles for feeding and speech. Children can be born with FCMS, usually from an illness or stroke suffered in-utero, but a small number of cases are genetic. Children can also acquire FCMS at a young age from an illness or epileptic disorder. Some children with epileptic disorders may suffer from transitory FCMS.

How do FCMS and accompanying symptoms affect communications?

Each child is different, and must be assessed by an interdisciplinary team including a speech language pathologist (SLP)

- Children may have a learning disability, cognitive impairment, hyperactivity, hearing loss or hemiparesis (difficulty controlling one arm or one half of their body).
- Children who have FCMS may have normal cognition. They can understand language, but often don't have the physical ability to speak. The few who have some speech can sound slurred, have a creaky and/or nasal voice, and be very difficult to understand.
- The children who have average nonverbal intelligence but can't speak usually rely on sign language or an AAC device to communicate. All too often, unfortunately, these children do not reach their full expressive potential.



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For more information, visit:

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Swallowing: <http://www.asha.org/public/speech/swallowing/>

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What can be done to help?

Even if a child has had a lifetime of being able to understand language, without the ability to freely express themselves, the child will fall behind peers in many ways, such as:

- Vocabulary
- Grammar
- Pragmatics (social norms)
 - Initiating conversation
 - Turn taking
 - Interacting with peers

THE SLP: A speech language pathologist (SLP) can assess and address the child's communication needs, whether they involve: speech, using Augmentative and Alternative Communication, pragmatic (social) communication, language remediation, literacy or other functional goals.

Other Concerns

Feeding:

- These children cannot use the muscles controlling their mouth, jaw, or throat. Many of these children require a special puree diet and/or suffer from malnutrition. Difficulty with swallowing can lead to food or liquid entering the lungs and can ultimately be deadly.

Drool:

- Many children with FCMS cannot voluntarily close their mouths and experience near-constant drooling. This can lead to negative social effects.

Making decisions: who is involved?

Interdisciplinary IEP Team, Family, Child

For the team to make the right decision about what educational environment would suit the child best, if an AAC system is needed, and what professional services would help the most, the child must be properly assessed in all areas:

- Hearing, speech and language
- Cognitive level and functioning
- Physical condition (especially paresis, epilepsy, status of feeding, drool)



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