



UNDERSTANDING MED13L SYNDROME AT SCHOOL



A guide for teachers and school staff from The MED13L Foundation

MED13L EXPLAINED

Our genes are like instructions that tell our bodies how to grow and develop. MED13L is part of a system that helps the body read and use those instructions at the right time. When MED13L does not work as expected, it can affect development in many different ways, including communication, movement, learning, and sensory processing.



EVERY PERSON WITH MED13L SYNDROME IS DIFFERENT



These are common areas of challenge, not a checklist. A student may experience some, all, or none of them. With the right supports, students with MED13L Syndrome learn, participate, make progress, and build real friendships at school. The boxes below show what you may see and what helps.



COMMUNICATION AND SPEECH

May experience: Speech and expressive language can be significantly more difficult than understanding language. Some individuals have childhood apraxia of speech or other motor speech differences, and some use AAC.

How to build success: Presume competence. Talk to the student directly and allow extra response time. Use visuals and modeling. Ensure AAC is always available and respected as the student's voice. Understanding is almost always ahead of speech.



MOVEMENT, MOTOR PLANNING, AND ENERGY

May experience: Low muscle tone, motor planning differences, balance and coordination challenges, and fatigue.

How to build success: Allow extra time and movement or rest breaks. Demonstrate new physical tasks and break them into steps. Recognize that fatigue may affect performance, and that effort on a hard motor day is still effort.



VISION, HEARING, AND SENSORY PROCESSING

May experience: Vision differences, including strabismus (eyes not aligned) and CVI (cortical visual impairment, a difference in how the brain processes what the eyes see, not an eye problem alone). Hearing differences, balance difficulties, and sensory processing differences may also occur.

How to build success: Follow the student's individual vision and hearing recommendations. Gain the student's attention before giving directions. Consider seating, positioning, visual clutter, contrast, noise, and sensory demands.



LEARNING AND PROCESSING

May experience: Developmental and learning differences vary widely. Processing can take longer, and the ability to speak or physically respond may not reflect everything a student understands. Attention differences and autism related differences may also occur.

How to build success: Give extra processing time. Use repetition, visuals, modeling, and hands on learning. Provide multiple ways for the student to show what they know, and measure understanding by what works for this student, not by speech alone.



HEALTH AND STAMINA

May experience: Some individuals have respiratory, hearing, sleep, feeding, immune, or other medical concerns. Some students become fatigued more easily, get sick more frequently, or need additional time to return to baseline after illness.

How to build success: Expect day to day variability. Be flexible following illness, and communicate with the family about significant changes from the student's baseline.