



Educating Young Children with Fragile X Syndrome

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What is Fragile X syndrome?

- The single most common inherited cause of autism and intellectual disabilities
- Prevalence estimates vary greatly
 - 1 in 2500-6000 boys and 1 in 6000-11,000 girls have Fragile X
 - 1 in 200-400 women and 1 in 400-800 men carry Fragile X [source: CDC](#)





Major Symptoms

- Anxiety
- Intellectual disabilities
- Attention deficit and hyperactivity
- Unstable mood
- Behaviors seen in autism
- Sensory integration problems

[Learn more](#)

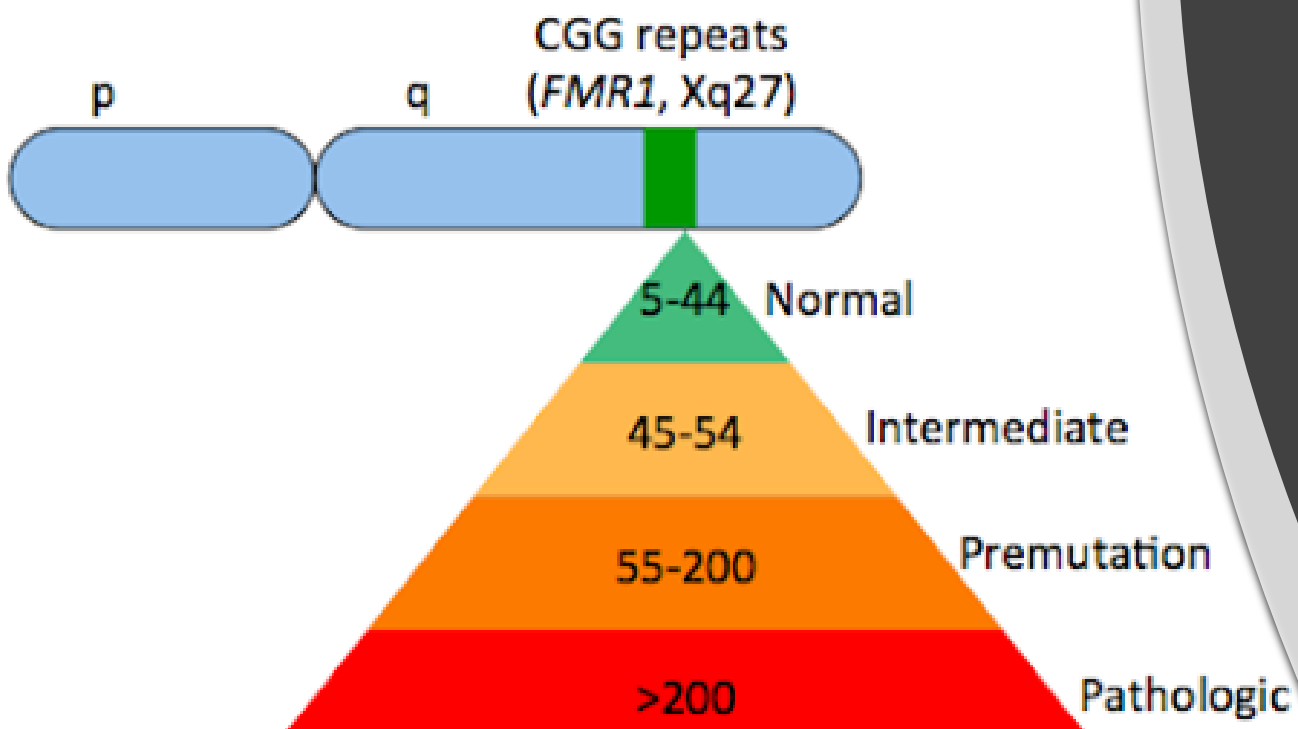


Physical Signs

- Long face, prominent ears, flat feet
- Hyperextensible joints, especially fingers
- Low muscle tone
- Seizures (epilepsy) affect about 25%

Girls are Often Less Affected than Boys

[Learn more](#)

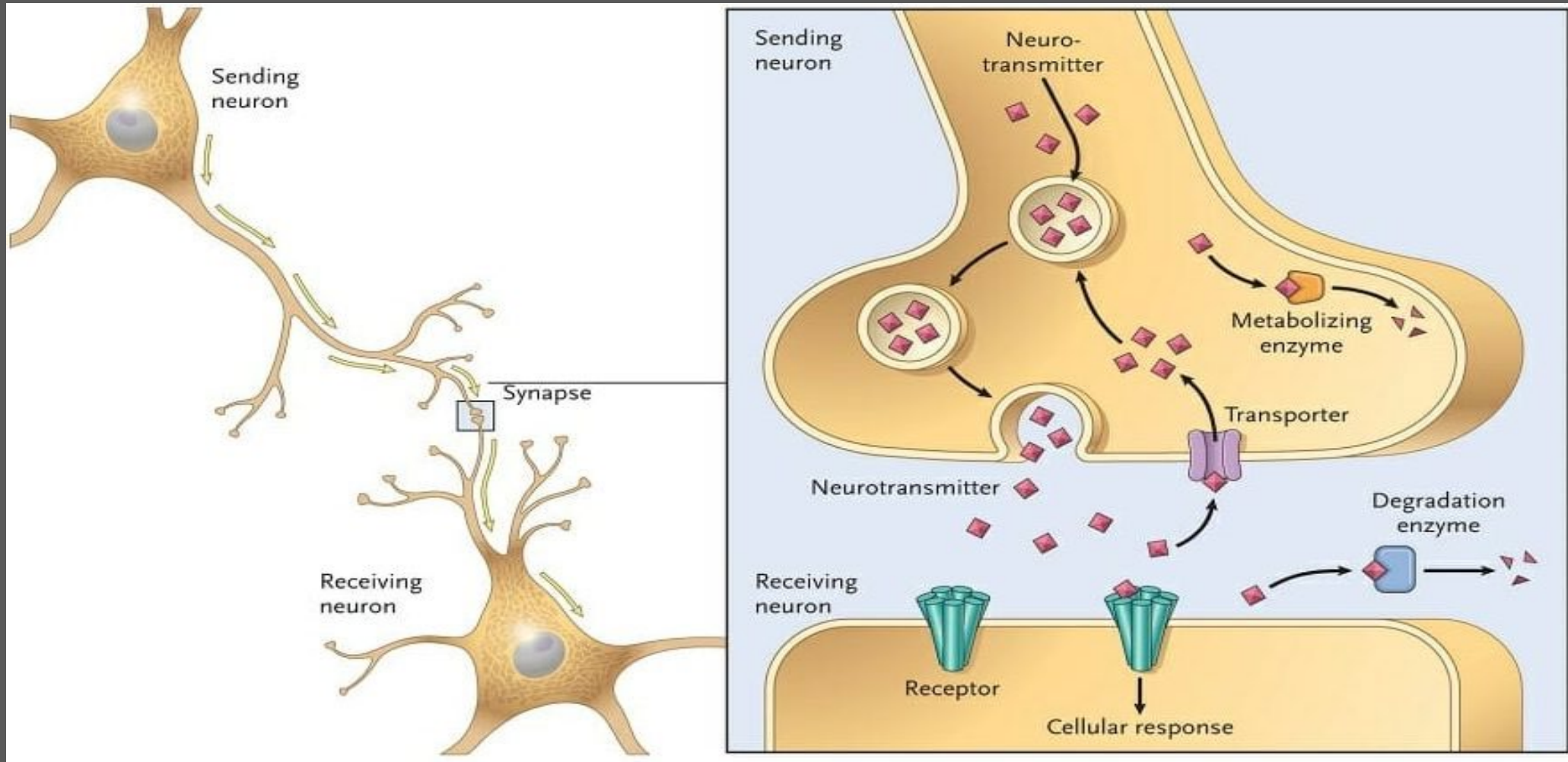


What Causes Fragile X Syndrome?

- FMR1: a single gene on the X chromosome shuts down
- FMRP: a protein vital for brain development is lacking
- Diagnosed by blood test
- Most children with Fragile X are not yet diagnosed

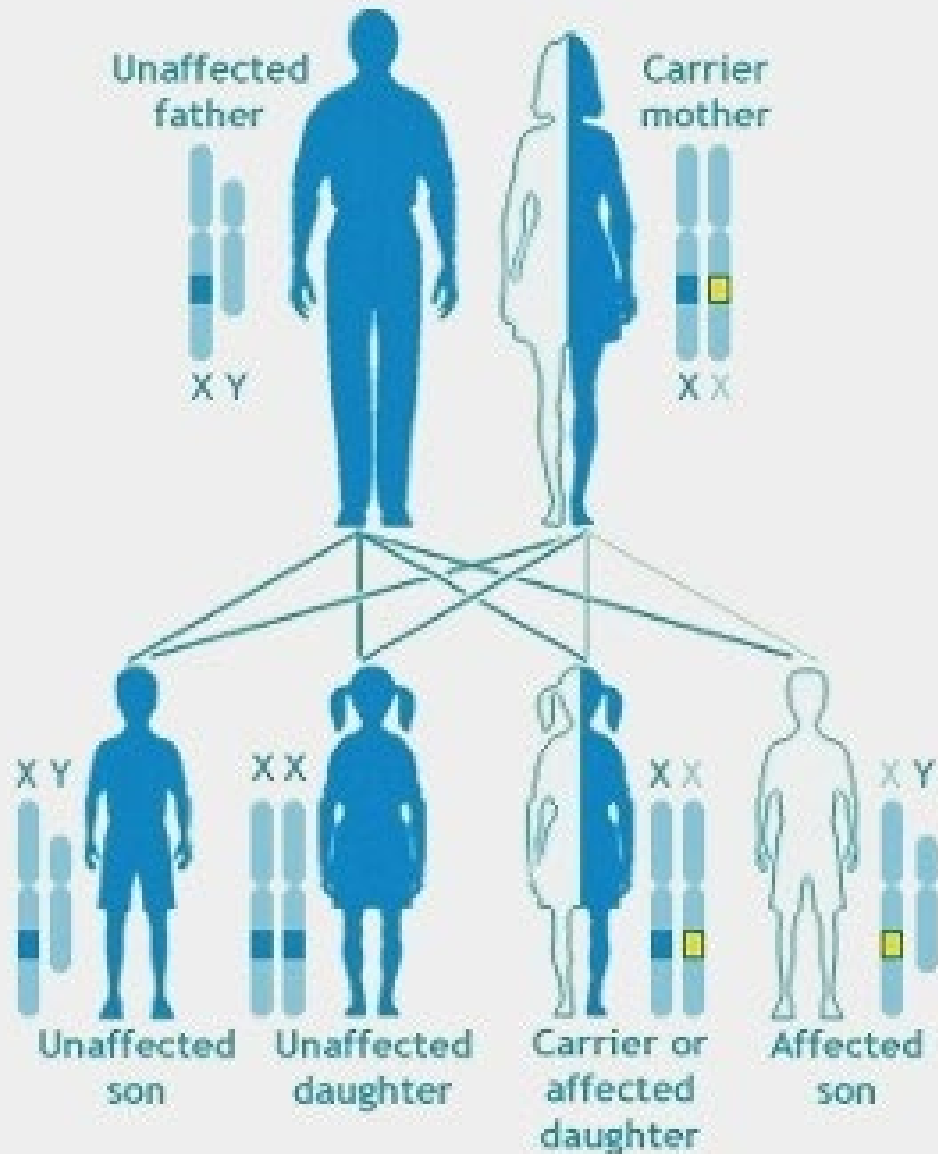
[Learn more](#)

Fragile X Affects Brain Neurons at Synapses



[Learn more](#)

X-Linked Inheritance in Fragile X Syndrome



adapted from US National Library of Medicine

Fragile X is Inherited

- Carrier mothers have 50% chance of passing mutation to sons and daughters
- Carrier fathers have carrier daughters and unaffected sons
- Fragile X premutation can be passed silently through generations

[Learn more](#)

Fragile X

- Spectrum disorder
- Repetitive behaviors
- Diagnosed by DNA test
- 50% of males also have ASD
- 20% of females also have ASD

Autism

- Spectrum disorder
- Repetitive behaviors
- Diagnosed by behavior checklist
- 1-6% of cases caused by FXS
- Other underlying causes?

[Learn more](#)

Notable Strengths and Weaknesses

- Humor
- Sociability
- Imitation skills
- Anxiety
- Nervous system timing delays
- Cluttered speech patterns

[Video: Buddies with Fragile X](#)





Learning Style

Simultaneous not Sequential

- Good sight word learners, struggle with phonetics
- Motivated by end result, impatient with the process
- Use backward chaining; use checklists to mark progress toward a goal

credit: Laurie Yankowitz, Ed.D.

Expect Inconsistency

- Engagement and performance is likely to vary greatly; it can be difficult to understand why
- Try to accept this to avoid frustration; your student will pick up on frustrated energy and that will exacerbate anxiety



Strategies - Calming

Integrate the ones that work throughout the day

- Heavy work: rearranging desks, cleaning windows, moving books
- Vestibular input: going for a walk, wall push-ups, swinging

Don't force eye contact

Eye contact will come naturally as student becomes more comfortable



Environmental Triggers

Students often have hypersensitivities to sound, light, textures, taste, smell

- Adjust environment (dim lighting, allow use of muting headphones).
- Create calm, quiet classroom with built-in breaks and predictable daily routine.
- Consider distractibility and anxiety when arranging seating.



[credit: Laurie Yankowitz, Ed.D.](#)

Think “Indirect”

Students with FXS can enjoy attention, but usually shy away from the limelight

- Give compliments in 3rd person about the student to others within earshot
- Use a triad to teach through a peer
- Encourage typical peers to model appropriate behaviors
- Avoid direct, open-ended questions: prompt “Today is ...” vs. “What day is today?”



credit: Laurie Yankowitz, Ed.D.

Strategies - Attention



- Incorporate high interest materials into all areas of the curriculum
- Provide social skills lessons and social stories
- Introduce novel tasks interspersed with familiar tasks to hold attention and reduce anxiety
- Reward with “high fives” rather than hugs or pats (close physical contact can over-stimulate).

credit: Laurie Yankowitz, Ed.D.

Educational Strategies

- **Verbal expression is cognitively taxing**
Offer non-verbal ways for students to show what they know, such as following directions and pointing to visual representations.
- **Math is hard**
Use visual and tactile strategies. Include real object counters, size and shape manipulatives, and concrete examples.
- **Provide visual cues**
Icons, logos, color coding, numbering, arrows



Easing Transitions

Transitions are hard

Transitional objects or a job/role can offer a purpose and shift attention from the change (e.g.: deliver a letter to another teacher).

- Give 10 and 5 minute prompts
- Allow to be at the head or back of the line

credit: Laurie Yankowitz, Ed.D.



- Fragile X research is drastically underfunded, considering the promise it holds for advancing understanding of other disorders from autism to Alzheimer's.
- FRAXA has funded over \$30 Million in research grants. [See them](#)
- FRAXA runs scientific meetings, advises biotech and pharmaceutical companies, provides consulting, and supports families around the world. [Contact Us](#)