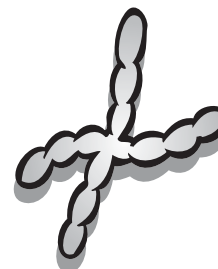


Understanding Fragile X Syndrome

By Dale Ducworth, CCC-SLP

What is Fragile X Syndrome?

Fragile X Syndrome is a condition caused by a genetic mutation of the X chromosome. It is the most common cause of inherited form of intellectual disability. This syndrome occurs in the general population in approximately 1 in 4000 males and 1 in 6000 females. The symptoms of Fragile X vary greatly among individuals. Some may experience significant challenges, while for others, the effects are so minimal that they are never diagnosed.



How is Fragile X passed on to a child?

Either parent may carry the gene and pass it on to his or her children. Most of the time the parent has no apparent signs of the condition. The child who inherits the gene is either a carrier with no symptoms or fully-affected to varying degrees. It is not unusual for several members of the same family to have Fragile X. Simple DNA tests can accurately detect both carriers and fully-affected individuals.

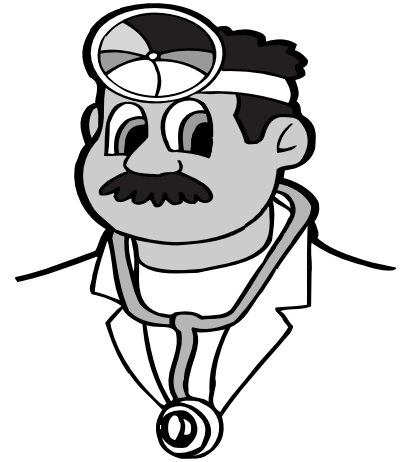
What are the effects of Fragile X?

Typical physical characteristics of Fragile X include a long face with a prominent chin, large ears, flat feet, and hyperextensible joints, especially in the fingers. Cognitive impairments may be present, ranging from mild learning disabilities to severe intellectual disability. Other common symptoms include attention deficit disorder and hyperactivity, mitral valve prolapse (a heart condition), hand flapping, and difficulty with social interaction. Males usually have more severe symptoms of Fragile X than females. The basic physical and behavioral characteristics are the same in males and females, but females exhibit these symptoms to a lesser degree. The majority of males with Fragile X have significant cognitive disabilities which affect their ability to think, reason, and learn; only one-third of females show significant disabilities. Approximately one-third of all children with Fragile X also have some degree of autism.

Education for Children with Fragile X

Since the severity of the symptoms of Fragile X varies greatly among individuals, the education of these children also varies according to their specific abilities and needs. All children with Fragile X do not have disabilities, but for those that do, the Individuals with Disabilities Education Act (IDEA) ensures that children ages 3 through 21 (or until high school graduation) receive free, appropriate public education. For school-age children, the educational options range from inclusion in the regular classroom with special provisions

(special education services, speech, occupational, physical, or behavioral therapy) to placement in a full-time special education classroom. The Early Intervention for Infants and Toddlers with Disabilities and Their Families program, which is an amendment to IDEA, provides early intervention for children with disabilities from birth to three. Services for children through this program may take place in the child's home, school, hospital, or clinic.



What is the treatment for children with Fragile X?

There is no cure for Fragile X; however, it is important that a child with Fragile X be under the care of a physician familiar with the associated physical and behavioral problems. A multidisciplinary approach that includes special education, speech and language therapy, occupational therapy, and behavioral therapies, (depending on the needs of the child) may help minimize the symptoms of this condition. Medications may also be helpful for treating anxiety, hyperactivity, and poor attention. Since the severity of the symptoms varies widely, treatment plans should be individualized. Early intervention is key to ensuring that a child with Fragile X develops to his or her maximum potential. Even those with severe impairments can eventually master many self-help skills.

For more information or answers to questions regarding Fragile X Syndrome, consult your physician or contact with one or more of the organizations below.

Resources

Fragile X Research Foundation— <http://www.fraxa.org/>

The National Fragile X Foundation— <http://www.fragilex.org/html/what.htm>

National Institute for Child Health and Human Development— http://www.nichd.nih.gov/health/topics/fragile_x_syndrome.cfm