

TURNER SYNDROME

SYMPTOMS OR BEHAVIORS

- Short Stature
- Lack of sexual maturation
- Associated medical conditions: heart, thyroid, kidney, and Type 2 diabetes
- Learning Disabilities
- Physical features
 - Short webbed neck
 - Low hairline

ABOUT THE DISORDER

Turner Syndrome is a chromosomal condition that exclusively affects females. It occurs when one of two X chromosomes normally found in females is missing or incomplete (45 chromosomes instead of the usual complement of 46). The syndrome was named in 1938 after Dr. Henry Turner who was among the first to describe its features. Turner Syndrome is among the most common chromosomal abnormality, occurring in about one out of 5,000 live female births. Approximately 60,000 girls and women are affected in the United States; approximately 800 new cases being diagnosed each year.

There are many features that may be associated with Turner Syndrome. It is unusual for one female to exhibit all known features; in fact, most have few features and do not typically exhibit the associated medical conditions. The common features include:

Growth: Short stature is the most common feature of Turner Syndrome. The average height of an adult woman is between four feet eight inches (142 cm) and five feet (152 cm). Although the condition of short stature is not fully understood, one important contributing factor is the impaired ability of bones to grow. Growth hormone treatments, either alone or coupled with a low dose of androgen, can improve growth velocity and increase final adult height.

Sexual development/fertility: Lack of sexual maturation (breast development, feminine body contours, ovary development/menstruation) during adolescence is another common feature. Estrogen replacement therapy is used to help in the development of secondary sexual characteristics. With hormone replacement therapy, a woman with Turner Syndrome can lead a full, satisfying sexual life. Modern technologies have also been used to help women become pregnant.

Associated medical conditions: It is important that females with Turner Syndrome receive proper medical care from a doctor specializing in endocrinology. The most common medical conditions associated with Turner Syndrome include: heart, thyroid, kidney conditions, and Type 2 diabetes. Some females also have a tendency to become overweight. Since obesity is a contributing factor in Type 2 diabetes, it is important for young women with Turner Syndrome to develop healthy eating and exercise habits at an early age.

Other features: Arms that turn out slightly at the elbow, webbed neck, low hairline at back of the neck, prominent ears, soft fingernails that turn up at the ends and short fingers.

It is critical to remember that Turner Syndrome and related conditions affect each individual differently. Features, conditions, and treatments can and will greatly vary from student to student. With proper medical care, women with Turner Syndrome can lead full and productive lives.



TURNER SYNDROME

EDUCATIONAL IMPLICATIONS

1. Student may exhibit associated heart, thyroid, kidney or diabetic conditions that may require school health plans; also student may be absent from school due to on-going medical care and appointments.
2. Because of short stature, student may not be able to access all parts of the educational environments (classroom fixtures, lunchroom, bathroom, bus, playground, etc.)
3. Delays in sexual development and physical growth may lead to struggles in social development and self-esteem.
4. Some girls may exhibit learning difficulties that may be attributed to Turner Syndrome. Concerns may include: inability to imagine objects in relation to each other, math related spatial concerns, sense of direction and manual dexterity.
5. Some students may exhibit specific difficulties with large movement activities such as throwing, catching and kicking balls.
6. Most girls with Turner Syndrome have IQ scores in the average range.

INSTRUCTIONAL STRATEGIES AND CLASSROOM ACCOMMODATIONS

1. Assistance from the school nurse, occupational therapist, physical therapist or adapted physical education teacher may be required to address medical, motor, dexterity and educational access issues.
2. To increase student comfort, a school meeting with parents may be requested at the beginning of each school year to explain disability and child's needs. Also, a classroom disability in-service may be appropriate.
3. If a student is exhibiting social, behavioral or emotional difficulties, assistance from the school social worker or psychologist may be appropriate.
4. Encourage student to participate in a variety of school activities.
5. Resource room or specific tutoring may be required if student is exhibiting learning difficulties in areas of word comprehension, math concepts, or spatial concepts.

RESOURCES

Turner Syndrome Society of the United States
14450 TC Jester, Suite 260
Houston, TX 77014
800-365-9944
www.turner-syndrome-us.org
(resources, treatment products, and current medical research)

Minnesota Turner Syndrome Society
(Becky Mobarry)
7109 Autumn Terrace
Eden Prairie, MN 55346
952-937-9725
(state resource and support services)

The Endocrine Society
8401 Connecticut Ave, Suite 900
Chevy Chase, MD 20815
301-941-0200
www.endo-society.org
(publications, journals, physician referral and patient information)

The Magic Foundation
6645 W. North Ave.
North Oak, IL 60302
708-383-0808
www.magicfoundation.org
(non-profit organization created to support services for families of children diagnosed with chronic and/or critical disorders and syndromes that affect growth)