



INCLUSIVE 4-H



96016

Youth and Tourette Syndrome

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What is Tourette Syndrome?

Tourette Syndrome is a neurological disorder causing “tics” usually beginning at ages 6 to 9 years. But it can begin as late as 18 years. The tics usually present themselves as facial or body tics. Verbal tics are much less common but are the most widely identified by the general public. A tic can appear from a few times a day to several times a minute. However, tics can disappear for weeks or months at a time. For some people, Tourette Syndrome seems to vanish in their early 20s; for others it continues on throughout life.

What Causes Tourette Syndrome?

Tourette Syndrome is inherited by a dominant gene, but having the gene does not mean the individual will develop Tourette Syndrome. It is thought that this gene creates an abnormal metabolism of the brain chemical dopamine. It may also be related to serotonin, another brain chemical.

What are the Symptoms of Tourette Syndrome?

Some sort of tic is usually the presenting symptom of Tourette Syndrome. If tics are postponed or held in by the individual, they will be more severe when they do occur. Tics can escalate during puberty and during times of stress. Tics usually decrease in amount and severity when an individual is absorbed in a task or is relaxing.

Motor tics include:

- Shoulder shrugging,
- Eye blinking,
- Head jerking,
- Hand movements,
- Lip-licking,
- Facial grimacing,
- Jumping,
- Kicking.

Verbal tics include:

- Sniffing,
- Throat clearing,
- Grunting,
- Saying words.

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Additionally, people with Tourette Syndrome may also have other associated behaviors. These include:

- Obsessions,
- Compulsions,
- Ritualistic Behaviors,
- Attention-deficit/hyperactivity disorder (AD/HD),
- Learning disabilities,
- Difficulty with impulse control,
- Sleep disorders including sleep walking or sleep talking.

What is the Treatment for Tourette Syndrome?

Tourette Syndrome can be controlled by medication. However, no one particular medication seems to work. A combination of different medications gives the best results. Because many of the medications have serious side effects, many patients decide not to be medicated. Medications for AD/HD may actually worsen the tics.

Important Issues for Extension Educators and 4-H Leaders to Consider:

1. Have contact information for parents or guardians and the member's doctor in accessible places. An example of this would be behind the child's nametag and in the medical forms box which should be stored in the main office at 4-H events. This form should include information such as what kinds of medications the child is taking, allergies, if any adaptive devices are used, and other health conditions.
2. Visit with the member and his or her parent(s) to find out about the member's particular case of Tourette Syndrome. Questions that can be asked include: "What type of tic do you have?" and "What particular things seem to bring on your tics?"
3. Keep in mind that in social situations such as 4-H meetings and activities, a 4-H member with Tourette Syndrome may be trying very hard to control the tics. Have a place in which the member can release these tics in private so that he or she doesn't suffer a severe attack. This saves the member from embarrassment.
4. Members with Tourette Syndrome may be on many different medications. Make sure that the person who is put in charge of these medications knows the side effects of each one and when they are supposed to be taken.
5. Do not ridicule or reprimand a member with Tourette Syndrome when he or she displays a tic. For many people, tics are like sneezes; you can hold them in but only for so long. Don't take it personally when tics are displayed.

For More Information Contact:

Tourette Syndrome Association, Inc.

42-40 Bell Blvd.

Bayside, NY 11361

Phone: (718) 224-2999

Web site: www.tsa-usa.org

(Web site active as of May 6, 2005)

Acknowledgements:

Appreciation is extended to the following reviewers: Matthew Cavedon, trustee, National 4-H Council; Terri Dawson, director, Parent Information Center, Buffalo, Wyoming; Roger Tormoehlen, head, Department of Youth Development and Agricultural Education, Purdue University; and Karen C. Williams, associate professor and head, Department of Family and Consumer Sciences, University of Wyoming.

Special thanks is also extended to David K. Carson, former professor of Family and Consumer Sciences at the University of Wyoming and Kent Becker, associate professor of Counselor Education at the University of Wyoming for comments on earlier versions of the articles in this series.

Inclusive 4-H coordinator, Randolph R. Weigel, professor and human development specialist, University of Wyoming Cooperative Extension Service.