**Factsheet: Tourette Syndrome**

**What is it?**

Tourette Syndrome (TS) is a neurobiological disorder characterized by repetitive, involuntary and purposeless contractions that cause movements and vocalizations called tics. Early symptoms are often first seen in childhood around the ages of 3-9 years and males are 3-4 times more likely to be affected than females. Involuntary movements usually first appear in the face as a facial tic like eye blink, nose twitch or grimace.

The following criteria is needed for a person to be diagnosed with TS pursuant to DSM-5 criteria:

- begin before he or she is 18 years of age
- have symptoms that are not due to taking medication or drugs, or due to having another medical condition
- multiple motor tics and vocal tics; although they might not always happen at the same time
- tics for at least a year that can occur many times a day, nearly every day, or off and on

**What are the symptoms?**

Tics can vary in severity, frequency, type and location. However, they often worsen with excitement, stress or anxiety. They do not go away with sleep, but rather are greatly diminished. Symptoms often worsen and reach their peak throughout the teen years but can improve into adulthood.

Motor tics are tics that cause movement and can be classified as simple or complex; they often precede vocal tics. Simple motor tics are brief, sudden and usually involve a limited number of muscle groups. Simple motor tics include eye blinking, facial grimacing, jaw movements, head bobbing/jerking, shoulder shrugging, neck stretching, and arm jerking. Complex motor tics involve multiple muscle groups or a combination of movements and tend to be slower and more purposeful in appearance. Common complex motor tics can include facial grimacing combined with head positioning, hopping, twirling and jumping.

Vocal (phonic) tics are tics that produce a sound. Simple vocal tics include sniffing, throat clearing, grunting, whistling, and shouting. Complex vocal tics are words or phrases that may or may not be recognizable but that consistently occur out of context. According to the National Institute of Neurological Disorders and Stroke (2014), in 10-15% of cases the words may be inappropriate (i.e., swear words, ethnic slurs, or other socially unacceptable words or phrases).

TS commonly co-occurs with a number of other neurodevelopmental and neuropsychiatric conditions. Some may actually present before a TS diagnosis and cause more impairment than the tics themselves. Associated neurobehavioral problems may persist into early adulthood despite a significant decline in motor and vocal tics.
**Suggested school accommodations**

- Consider 504 or IEP
- Promote communication with caregivers
- Flash pass
- Seating that allows student to leave classroom if necessary
- Frequent breaks
- Consider transition time, crowded hallways, etc.

- Private area testing
- Scribe or word processor for handwriting difficulties
- Extended time for assignments
- Strategies for stress reduction
- Identify skill deficits that lead to stress
- Ignore symptoms that can be ignored

- Build schedule around student's most productive time of day
- Copies of notes if motor tics involve upper extremities
- If student has vocal tics and needs to give an oral report, allow for tapping, etc.
- If vocal tics, allow a “safe haven” area for student to go to release tics
- Training to staff and peers

**SHNIC school nurses information:**

**Specific health issues for individual health care plans**

- Diagnosis including age of onset, other co-occurring diagnosis
- Current medication list for home and school; note any potential side effects like weight gain, cardiac, tremors, cardiac abnormalities
- Baseline neurological and cardiac assessment
- Child specific characteristics of tics
- Plan to identify and communicate potential new tics
- Seizure action plan, if applicable
- Open communication plan with caregiver that includes identifying stressful life events
- Plan to monitor for bullying, depression, etc.
- Plan to monitor and keep student safe if leaving classroom for release period or “safe haven”

**Resources & Manuals**

- National Institute of Neurological Disorders and Stroke-Tourette Syndrome factsheet
  http://www.ninds.nih.gov/disorders/tourette/detail_tourette.htm

- Tourette Syndrome of America
  http://tourette.org/index.html

- Tourette Syndrome of America– Resources for educators
  http://tourette.org/Education/education_main.htm#foreducators

- Living with Tourette Syndrome– Youtube video
  https://www.youtube.com/watch?v=e8HtTb0Vk_o

- Tourette Syndrome “Plus”
  http://www.tourettesyndrome.net/