

We ALL Belong: Helping Kids with Tourette Syndrome, OCD and ADD Succeed in the Classroom and the Community

Ellie Jarvie, LCSW, WTSA board member and person with TS;

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Bryan Shelby, Parent of a child with TS and WTSA Board Member

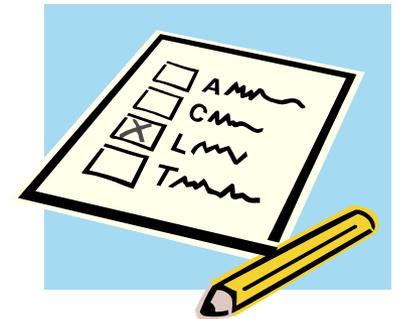
Learning Objectives

- ▶ Participants will be able to better understand the complexity of Tourette Syndrome and the interrelationship between TS and most common associated disorders
- ▶ Participants will understand the lived experience of Tourette Syndrome and its impact on family members through the examples provided by a youth and adult with TS, and a father of a child with TS.
- ▶ Participants will improve their knowledge of classroom and community accommodations and survival strategies for supporting youth with TS, and gain insight related to collaboration with parents, teachers and professionals and youth.
- ▶ Participants will gain knowledge of national and local support options and get the perspective of youth and family members who participate in these events.

Reflection:

What do you think of when you hear the words Tourette Syndrome?

What expectations do you have for today?



What is Tourette Syndrome?

Your thoughts

Neuro-Biological disorder

Involuntary

More common than originally thought

Affects boys more often than girls

More than coprolalia

Symptoms vary between individuals

Waxing and Waning are a hallmark of the disorder

Tics are the “tip of the iceberg”

Tourette Syndrome DSM-5 diagnostic criteria

Both multiple motor tics (for example, blinking or shrugging the shoulders) *and* vocal tics (for example, humming, clearing the throat, or yelling out a word or phrase), although they might not always happen at the same time.

Have had tics for at least a year. The tics can occur many times a day (usually in bouts) nearly every day, or off and on.

Have tics that begin before he or she is 18 years of age.

Have symptoms that are not due to taking medicine or other drugs or due to having another medical condition (for example, seizures, Huntington disease, or postviral encephalitis).

Motor Tics

Simple Motor Tics

Eye blinking, grimacing, nose twitching,
Leg movements, shoulder shrugs,
Arm and head jerks

Complex Motor Tics

Hopping, clapping, throwing,
Touching (self, others, objects)
Holding funny expressions,
Sticking out the tongue, kissing,
Pinching, tearing paper or books

Vocal Tics

Simple Vocal Tics

Whistling, coughing, sniffing,
screeching, animal noises, grunting, throat clearing

Complex Vocal Tics

Linguistically meaningful utterances

Coprolalia– racial slurs, inappropriate language

Echolalia– repeating words/phrases

Speech Atypicalities Unusual rhythms, tone accents,

Intensity of speech, stutter-like,

Immature voice, imitating others

<http://www.youtube.com/watch?v=XjgIfoSIFqQ>

▶ 6:11 start

Tics: When you have seen one, you have NOT seen them all”

Naturally wax and wane

Change in appearance and frequency

Change in severity and intensity

May be influenced by environmental triggers

Coprolalia is NOT required for diagnosis

Think “SNOWFLAKES”



But sometimes, it seems like they can stop it...

Suppression may cause undesirable consequences such as tic rebound, difficulty focusing and concentration and learning

Experiential Exercise



Unvoluntary vs. Involuntary AKA
“Premonitory sensations” experienced by
many

Environmental Factors that May Impact TS Symptoms

- ▶ Stress
- ▶ Anxiety
- ▶ Excitement
- ▶ Fatigue
- ▶ Holidays
- ▶ Changes in routine
- ▶ Hunger
- ▶ Over/ under stimulation
- ▶ Transitions



Prevalence of Tourette Syndrome

1 of every 360 of age and living in the United States have been diagnosed with TS (CDC Data)

Other studies using different methods have estimated the rate of TS at 1 per 162 children.

Most people have mild symptoms: Among children with TS, 37% have been reported as having moderate or severe forms of the condition.

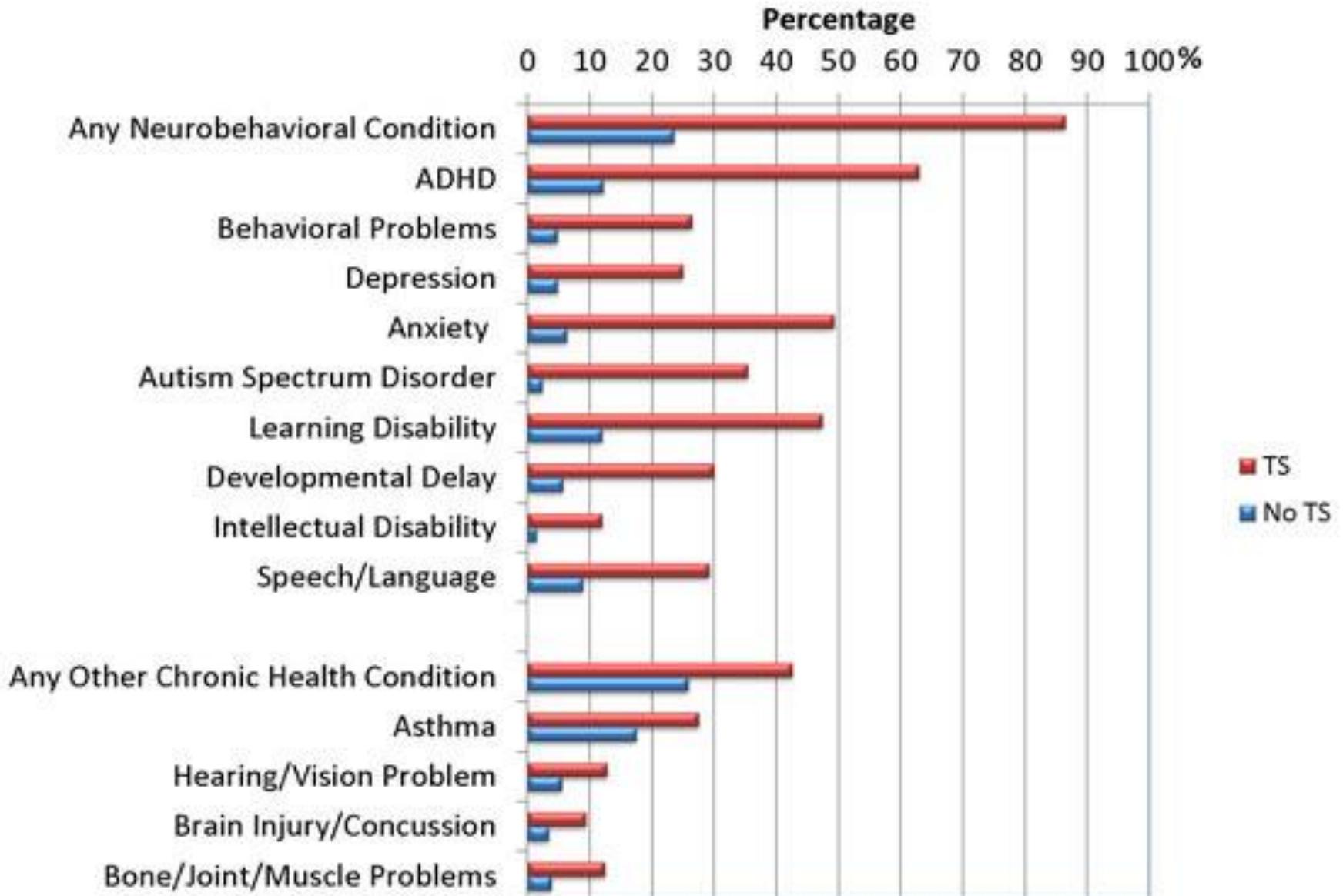
TS affects people of all racial and ethnic groups.

Boys are affected three to five times more often than girls.

Access for racial minorities is an issue: A TS diagnosis is twice as likely among non-Hispanic White people than among Hispanic and non-Hispanic Black people.

While improving, there is still a lag between onset of symptoms and diagnosis: A diagnosis of TS is twice as common among children 12 through 17 years of age as among those 6 through 11 years of age.

Data from the 2011–2012 National Survey of Children's Health

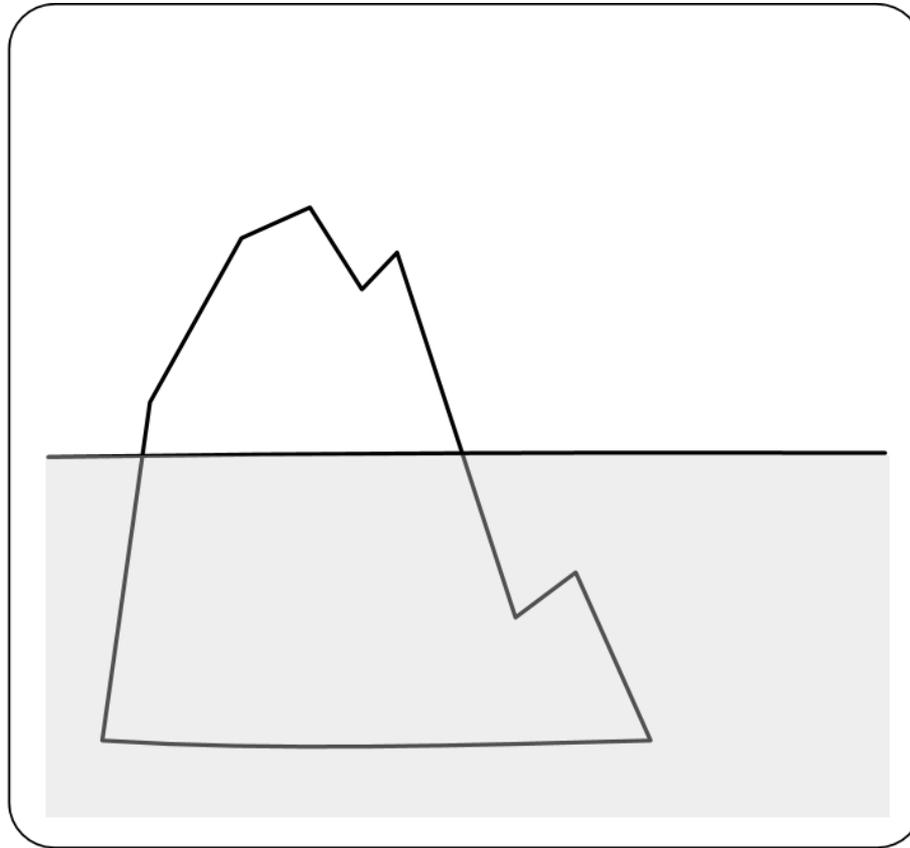


Key Points from the CDC data

- ▶ It is common for children with TS to have other mental health and chronic health conditions.
- ▶ TS and co-occurring conditions mean greater healthcare needs, more school problems, and higher parents' level of stress and frustration.
- ▶ The findings support previous recommendations that it is important to consider co-occurring conditions when diagnosing and treating children with TS.

Motor and Vocal Tics

ADHD
OCD
Anxiety
Speech
Dysfluency
Sensory
Defensiveness
Sleep Issues
Dysgraphia



Rage Attacks
Emotional
Dysregulation
Working
Memory
Deficits
Executive
Dysfunction
Depression
Learning
Disability

Obsessive–Compulsive Disorder (OCD) and TS

Obsessions

Intrusive and recurring thoughts and images or impulses that your mind gets stuck on which are unpleasant and disrupt functioning

Compulsions

Behaviors that are used to reduce the anxiety accompanying the obsessions
OCD and TS share chronic waxing and waning
Can be stigmatizing and isolating

<http://rogersinhealth.org/resources/alex-ocd-recovery>

Executive Dysfunction and TS

- ▶ Goal directed thinking skills
 - Plan
 - Organize
 - Time management
 - Working memory
 - Metacognitive
 - Knowledge about your own thoughts and the factors that influence your thinking
- ▶ Behavior skills to reach goals
 - Response inhibition
 - Self regulation
 - Task initiation
 - Flexibility
 - Goal directed persistence



Sensory Processing Dysfunction

Under/over reaction

Easily distracted

Activity level

Social/emotional problems—poor self concept

Transition difficulty

Delays in academic performance

Problems with motor coordination



Dysgraphia

Difficulty writing

Executive Function Skills

Grasp

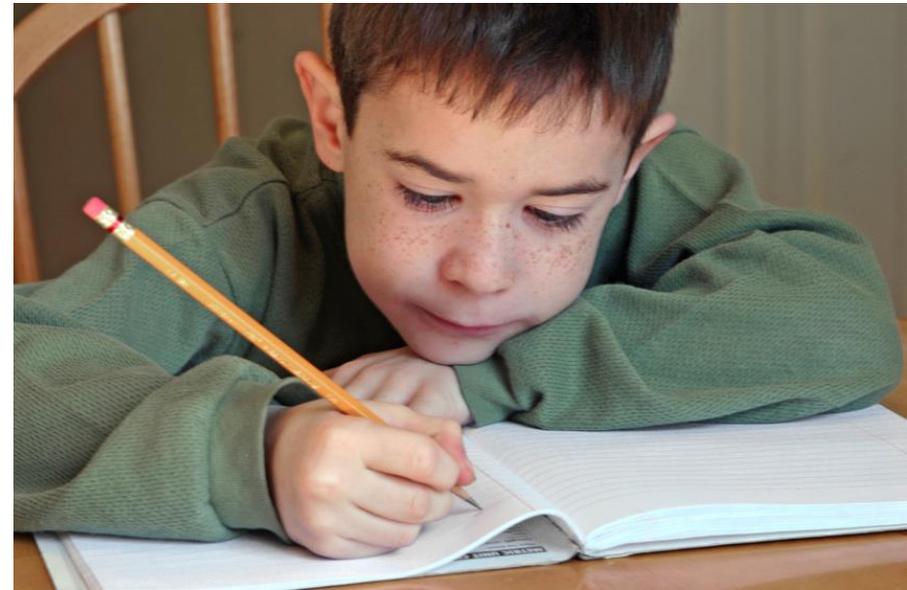
Tics

OCD

Eye/hand coordination

Visual perception/Spatial

Assistive Technology



Medical treatment for TS and associated disorders

Most medications are 'off label' uses. There is currently no medication designed to exclusively treat TS

Always balancing symptoms versus side effects

Most significant symptoms targeted – ADHD or OCD may be a bigger issue than the tics.

Medications may cause sedation, making learning difficult

Medications used to treat TS and associated conditions

Antidepressants: also used for OCD
Zoloft, Paxil, Prozac, Anafranil,

Antihypertensives: also used to treat
impulsiveness

Catapres/ Clonidine

Tenex/ Guanfacine

Antipsychotics: Neuroleptics: Haldol, Orap,
Abilify



Non Medical Treatments

- ▶ CBIT – Comprehensive Behavioral Intervention for Tics
Evidenced based approach for reducing tics, consists of awareness training competing response and social support
- ▶ Needs to be done by a trained professional
<http://www.tsa-usa.org/Medical/CBIT.html>
- ▶ Many pathways– exercise, diet, underlying issues can play a part
- ▶ TS as a part of who one is rather than disorder

False Assumptions about CBIT

- ▶ That All Children with tics need or could benefit from behavior therapy
- ▶ That because behavior therapy works, TS is a learned problem or something done intentionally
- ▶ That Behavior therapy works for everyone
- ▶ That rewarding a child for not having tics is behavior therapy
- ▶ That the child is doing the tics for attention or to purposely annoy you
- ▶ Dr Doug Woods



Occupational Therapy Intervention for Individuals With TS

- ▶ ADD/ADHD
- ▶ OCD
- ▶ Anxiety Disorder
- ▶ Stress Management
- ▶ Depression
- ▶ Aggressive/Explosive Behavior
- ▶ Dysgraphia
- ▶ Transition Planning
- ▶ Job Training
- ▶ Job Coach
- ▶ Independent Living Skills
- ▶ Sleep Problems



Assistive Technology

- ▶ Anything that aids in performing task
Pencil grip, seating, computers, electronics
- ▶ Written work
 - Keyboard skills
 - Word processing skills
 - Word prediction, spell check
 - Voice activated
- ▶ Reading
 - Books on tapes
 - Computer programs



A Family Perspective

Families often experience isolation and fear

- Often they don't know others with TS
- Symptoms are often worse at home than at school
- Lag between age of onset and diagnosis
- Misinformation/ Stigma
- Waxing and waning of symptoms is stressful for the whole family

Helpful Approaches

- ▶ Listen Attentively
- ▶ Empathize
- ▶ Believe parents when they identify issues
- ▶ Encourage a problem solving focus
- ▶ Refer to WTSA for connection and ongoing support
- ▶ Remember the siblings
- ▶ “I consider the TS group a second family. They GET what we live with everyday”



Brought to you by JOSEY-BASS TEACHER

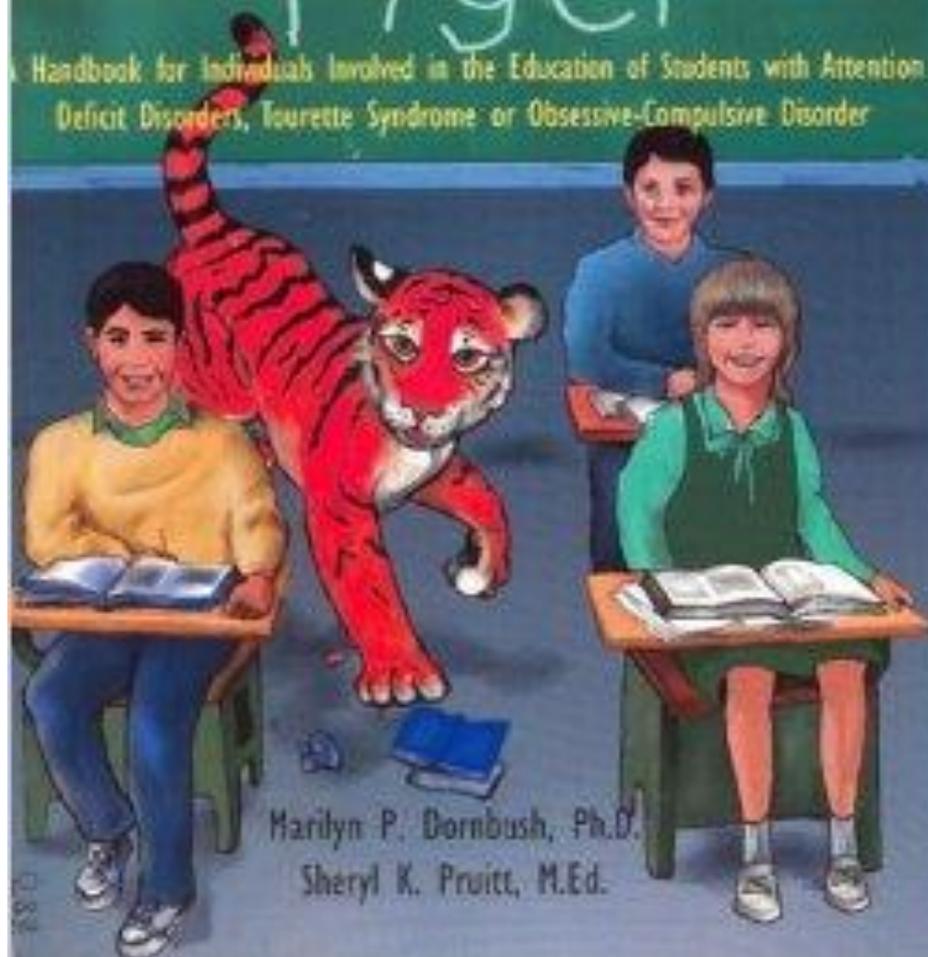
The
Tourette
Syndrome
& OCD
Checklist

**A Practical Reference for
Parents and Teachers**

SUSAN CONNERS, MEd
FOREWORD BY CATHY L. BUDMAN, MD

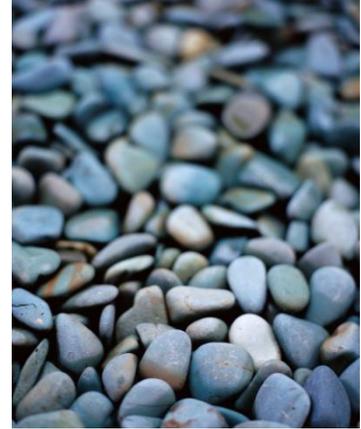
Teaching the Tiger

Handbook for Individuals Involved in the Education of Students with Attention
Deficit Disorders, Tourette Syndrome or Obsessive-Compulsive Disorder



Marilyn P. Dornbush, Ph.D.
Sheryl K. Pruitt, M.Ed.

Important!



Involve the student in their accommodation plan. Ask the student what they would like to try/ what may help. Because sensory issues are often involved, it's important to know what a student may feel comfortable with.

Symptoms will wax and wane, and often occur lifelong. Those who are successful as adults are those who have been able to implement strategies to deal with tics and associated disorders in their day to day life.

Accommodations for ADHD

Preferential seating in the classroom

Provide a quiet place to work in the classroom. A headset with instrumental music might help block out distractions.

Allow for freedom of movement.

Structured, but flexible classrooms are the best setting for the child with ADHD.

Establish a hand gesture as a reminder to refocus and get back on task.

Break down assignments. Give one paper at a time rather than several. Break down all long-range assignments and projects into shorter more manageable parts

Reduce the length of homework assignments. Quality, not quantity is the important thing.

Provide a daily assignment sheet.

Allow student to leave his last class a little early to pack up and organize their materials.

-Susan Cannors, MEd

Accommodations for Motor and Vocal Tics

Tests taken in a separate location with time limits waived or extended.

Provide a refuge where the student may go.

Give the child frequent breaks out of the classroom to release tics in a less embarrassing environment.

If tics are socially inappropriate it may be necessary to brainstorm possible solutions

Since tics tend to worsen when a child is tired, try to schedule core academics toward the beginning of the day.

Communicate with parents very frequently to report worsening of tics or new tics that have developed.

Stress aggravates tics. A supportive and accepting classroom will make the student feel safe and eliminate many feelings of anxiety and frustration

_Susan Conners, MEd

Youth Ambassador Program

Providing peer education Reduces social rejection, and decrease negative perceptions.

The Youth Ambassador Program trains teens to talk about TS to their peers.

Wisconsin has three trained youth Ambassadors who will give presentations at no cost to schools or youth serving organizations.



Wisconsin Tourette Syndrome Association

TSA-Wisconsin.org



- ▶ Peer support helps those with TS and their families with positive connections, reduces isolation and gives opportunities for growth
- ▶ Support groups in Milwaukee, Madison and Green Bay
- ▶ Check Meetup.com
- ▶ “Wisconsin Tourette” and select “any distance”

Upcoming Local Events

- ▶ Local support group, Sunday afternoon, TBD
- ▶ 5K Walk, June 4, 2016 Green Bay



Tourette Syndrome Camping Organization

- ▶ Founded in 1994, one of the longest running TS Camps in the Nation.
- ▶ Staff Include professionals with TS such as a NASA engineer, Teachers, etc.

Family Day at YMCA Camp Duncan
April 3, 2016

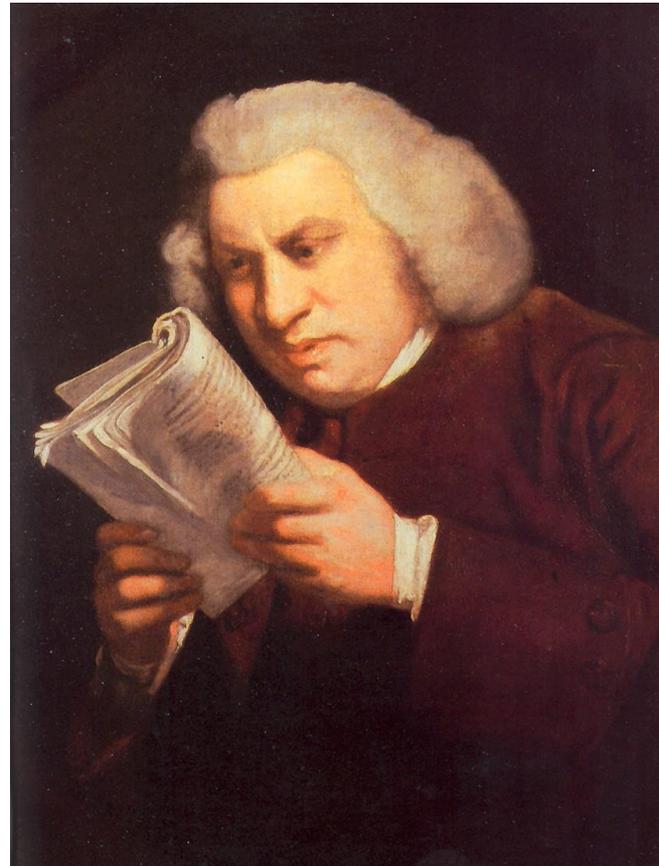
- ▶ Summer Camp for Youth 7-16

<http://www.youtube.com/watch?v=NUxnJzCXdLE>

Famous People with Tourette Syndrome

Dr. Samuel Johnson (1709 – 1784)

- ▶ Author of the first English Dictionary
- ▶ Symptoms described by biographer James Boswell
- ▶ Also suffered from depression



Jim Eisenreich

Played with the 1993 National League Pennant Philadelphia Phillies

Played with 1997 World Series champions, the Florida Marlins.

Although Jim had had Tourette's since childhood, he wasn't diagnosed until he was a baseball player with The Minnesota Twins



Michael Wolff

- ▶ <https://www.youtube.com/watch?v=2xjtmENtmog>
- ▶ Famous Jazz producer, composer and musician.
- ▶ Was not diagnosed until his 30's
- ▶ Wolff and his wife Polly Draper sit on the Tourette Syndrome Association's Board of Directors.
- ▶ His sons Matt and Alex Wolf form the Naked Brothers Band



Tim Howard

- ▶ Tim is the goalkeeper for Everton of England and the United States national team.
- ▶
- ▶ Played in the 2000 Olympics.
- ▶ 16 saves in the World Cup in 2014
- ▶ His teachers viewed him as a discipline problem, and he was teased for his tics and compulsions
- ▶ http://www.youtube.com/watch?v=DuXrxMrk_dQ



Marleen Martinez



- ▶ http://www.denverpost.com/business/ci_26721850/scientist-beats-odds-her-upbringing-help-guide
- ▶ Grew up helping her family as a Migrant Farm Laborer
- ▶ Is an Engineer designing the Orion Space Probe
- ▶ Featured in the PBS Show Makers: Women in Space
- ▶ Assistant Director Tourette Syndrome Camp, USA

Tourette Association of America

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