



Family Engagement Newsletter

Understanding Tourette Syndrome

By Wendy Overturf

Tourette Syndrome (TS) is a genetic condition of the nervous system. TS causes people to have “tics”. Tics are sudden twitches, movements, or sounds that people do repeatedly. People who have tics cannot stop their body from doing these things. For example, a person might keep blinking over and over. Or a person might make a grunting sound unwillingly. Having tics is a little bit like having hiccups. Even though a person might not want to hiccup, the body does it anyway. Sometimes people can stop themselves from doing a certain tic for a while, but it is hard. Eventually the person has to do the tic. There are two types of tics—motor and vocal. Motor tics are movements of the body. Examples of motor tics include blinking, shrugging the shoulders, or jerking an arm. Vocal tics are sounds that a person makes with his or her voice. Examples of vocal tics include humming, clearing the throat, or yelling out a word or phrase.

TS is not a learning disability, but some of the symptoms and co-occurring conditions can have a substantial impact on a child's ability to learn. Therefore, some children with TS may [qualify for special education services under the Other Health Impairment \(OHI\) category](#). The 2004 IDEA regulations that govern special education specifically added TS as an example of a disability that may qualify a student for special education. The federal regulations included this comment:



Explanation for including TS in IDEA: “We believe that Tourette Syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including TS in the definition of OHI (Other Health Impaired) may help correct the misconception of TS as a behavioral or conduct disorder and prevent the misdiagnosis of their needs.”

As in any diagnosis that would set a child apart from their classmates, having TS can unfortunately make the child a target for bullying. When families of children with TS or the children themselves are asked about the most difficult part of having TS the most frequent answer is dealing with peers. Social interactions are potentially very challenging for children with TS. Educating other students about TS can be an important first step in preventing bullying. If a child's fellow classmates are not properly educated about TS, the potential for bullying can increase and the child with TS is more likely to develop poor social skills, under-achieve academically, and suffer from low self-esteem. When other students understand TS, they generally become more comfortable with their classmate with TS and are less likely to bully or to condone the bullying.

Many kids are initially reluctant to educate their peers about TS because they are concerned it will only highlight their differences. They worry that they will be put in the spotlight and will become even more self-conscious. This worry is legitimate, but in fact, the opposite often occurs. Many children with TS report that after a peer education program, they are less self-conscious. They become more comfortable because once their peers know they have TS and what it is, there is less explaining to do. Many children with TS report that their tics actually decrease as a result, because they are less socially anxious. Peer education can take many forms, and a child's level of participation may vary depending upon the child's comfort level. Some children want to actively participate by going up to the front of the room and personally conducting the peer education program. Others may prefer to let a parent or teacher take the lead but are willing to participate in a Q&A session. Still others may feel strongly that they do not want to be identified or participate in any way. It is important to respect a child's desires.

The Tourette Association of America has a great website that might be helpful and provide resources for children who have TS, their parents, and school personnel. Additionally, this website has a section on [“Educating Classmates About Tourette Syndrome.”](#) This site has a script that can be used with younger children, has interactive exercises, and several videos. Another resource is the [Tourette Association of America Wisconsin Chapter](#). This is a volunteer led, nonprofit organization supporting the needs of individuals and families affected by Tourette Syndrome and Tic Disorders.

Statewide Events

[Endless Possibilities 2021: Successful Transitions](#)

This virtual conference, coordinated by WI FACETS, and other family support/disability organizations allows parents and professionals affordable access to gain knowledge to enhance their ability to better support students with disabilities.

Keynote & Presenter: Creating a Roadmap for Inclusive IEPs and Transition, [Dan Habib](#), award-winning filmmaker and parent of an adult son with a disability.

Sessions include: ACTION! Effective Practices in Transition * DVR: Possibilities During Times of Change and Transition * College & Career Ready IEPs and Transition Back to In-person Learning * Completing a Successful PTP * Including Health Care Transition into the PTP & IEP * Self-Care Sessions: How to Forgive in an Unforgiving World and *Fall* into Gratitude and Joy-It's that Easy!

[TPIP and YIPPE TRAININGS](#)

Virtual Transition Parents in Partnership (TPIP)

TPIP trainings will take place virtually via Zoom beginning this fall. Now is a great time to take advantage of top-notch and no cost training without the stress of traveling or being away from home. TPIP will prepare families for the transition process for their youth with disabilities ages 14-21 in the areas of employment, education, living and health.

Youth in Partnership with Parents for Empowerment (YiPPE)

YiPPE will take place in person at two different locations beginning this fall (Green Bay and Milwaukee). Now is a great time to take advantage of catching up on what you need to know for transitioning your youth from school to postsecondary options while having the opportunity to connect with other families. YiPPE is an opportunity for youth with disabilities and their parents to learn about the transition process in a unique way while building real life skills in the areas of employment, education, living, and health.

Click on this [link](#) to view training options, dates, and registration information for both of these no cost events.



At Home Learning Strategies

Keeping Kids Learning During the Summer

Parent involvement during the summer months is crucial to student success. According to the National Education Association, "Parents who are actively involved in their children's learning at home help their children become more successful learners in and out of school."



- **Set aside time each day to read.** Track the books your child reads and reward him or her with a special activity or treat when he or she reaches certain milestones (for example, every 10th book). Do art projects based on favorite titles, such as drawing a favorite scene, or making paper bag puppets.
- **Visit your local library.** Many libraries have wonderful summer reading programs that reward children for the number of books they read.
- **Make every day educational.** Children learn problem-solving, math, science, and vocabulary as they help with groceries, laundry, and cooking.



[Early Literacy Activity Calendar: August 2021](#)

This calendar helps parents and kids connect while practicing reading, math, science, and more. This month's activities include writing in the sandbox, creating a homemade bowling lane, and talking science over root beer floats.

[Children's Activity Calendar: August 2021](#)

Families can use this calendar to find joy through crafts, recipes, and book suggestions. August 8th is National Happiness Happens Day. Celebrate everyday moments of joy and delight by [Helping Kids find Happiness in the World Around Them](#) (via growkidsminds.com)



Clip, paste, and write about your family adventures.

Many families are now taking more trips now that COVID has diminished. A family vacation or day trip is a perfect opportunity to create a trip scrapbook that will be a lasting souvenir of family adventures. Collect postcards, brochures, and menus from restaurants and tourist attractions. Encourage your child to write descriptions of the places you visit and tell stories about your family's adventures.

Play an outdoor memory game.



Practice words, math problems, matching, and more with this giant outdoor paper plate memory game. Gather up some paper plates and draw items on each. These can be shapes, colors, words, or numbers depending on what you want to practice with your child. Make sure you draw two of each item, so you have a pair. Spread the plates face down on the lawn and challenge your child to find the matches. To add an extra challenge for older children, play this game with numbers and ask them to add or multiply each of the numbers together.



Turn a card game into math practice.

Practice mental math, times tables, and simple math equations with a deck of Uno cards. Split the deck into two piles, placing a piece of paper with an addition, subtraction, or multiplication symbol between the two. Have your child flip over a card from each deck, solving the equation that appears. For an extra level of competition, switch between addition, subtraction, and multiplication each time your child flips new cards.

Watermelon Activities ([from Frugal Fun for Boys and Girls](#))

August 3, 2021 is National Watermelon Day and a great time for watermelon. But did you know that it can also be used to develop skills?



Watermelon Play Dough-Make [some watermelon play dough and number cards](#). Kids can count out the right number of watermelon seeds to match the number. Because most watermelons are now seedless you may have to substitute black beans or coffee beans for the seeds.

Melon Balls and Pattern Skewers-Purchase a melon baller and some wooden skewers, which are typically available at a dollar store. Have your children make watermelon balls. When finished, use some grapes and the watermelon balls and have your children make different patterns on the skewer. When they are finished they also will have a healthy treat!

Online Resources: Other Health Impairment

[Center for Parent Information and Resources \(CPIR\)](#)

This website has links to information related to incidence, characteristics, diagnosis and treatment, and school services related to children who have other health impairments (OHI). The website also includes links to many other resources related to specific disorders that may be included under the OHI category.

[Wisconsin Department of Public Instruction](#)

The website has information related to eligibility criteria for Other Health Impairment and links to additional medical and health information that may be of interest.

[FINDING YOUR WAY— A Navigation Guide for Wisconsin Families Who Have Children and Youth with Special Health Care Needs and Disabilities](#)

The Wisconsin Children and Youth with Special Health Care Needs Program developed this guide in partnership with the Community of Practice on Autism Spectrum Disorders and other Developmental Disabilities to assist families who may have concerns or questions about their child’s development or have recently received a diagnosis of a special health care need or disability. It provides brief descriptions of programs, services, and systems of support and gives contact information to learn more about these and other resources.

[Children and Youth with Special Health Care Needs \(CYSHCN\)](#)

CYSHCN collaborates with national, state and community-based partners to link children to appropriate services, close service gaps, reduce duplication, and develop policies to better serve families.

[Epilepsy Foundation](#)

This website has information for parents and professionals related to epilepsy disorders. It also has a link to a [“toolbox”](#) and provides information on forms and information parents may want to have available in case of an emergency. Information about other support groups and services is also on this site.

[Living with Spina Bifida](#)

The Centers for Disease Control and Prevention (CDC) has programs and research which may help improve the quality of life and encourage full participation at every age for those living with spina bifida.

[Children and Adults with Attention-Deficit/Hyperactivity Disorder \(CHADD\)](#)

CHADD is a national nonprofit organization that improves the lives of people affected by ADHD through education, advocacy, and support. CHADD is in the forefront in creating and implementing programs and services in response to the needs of adults and families affected by ADHD through collaborative partnerships and advocacy. This includes training for parents and K-12 teachers, hosting educational webinars and workshops, being an informative clearinghouse for the latest evidence-based ADHD information, and providing information specialists to support the ADHD community.

[Family Voices](#)

Family Voices is a national organization and grassroots network of families and friends of children and youth with special health care needs and disabilities that promotes partnership with families—including those of cultural, linguistic, and geographic diversity—in order to improve healthcare services and policies for children.

[Wisconsin Birth to 3 Program](#) (Wisconsin Department of Health Services)

The first three years are the most important building blocks of a child’s future. The Birth to 3 Program is a federally mandated early Intervention program to support families of children with developmental delays or disabilities under the age of three.



WI FACETS



Event title links to information & registration for WI FACETS FREE workshops & webinars:

To register by phone: 877-374-0511
All webinars 12:00—1:00 PM
(unless otherwise noted)

[Compassion Resilience – Self Care Snapshot Series: Connecting to Our Purpose](#)

Presenter: Emily Jonesburg,
Rogers InHealth
Date: August 9, 2021, 12pm-12:30pm

[IEP 1: Special Education Basics](#)

Presenter: Bonnie Vander Meulen,
WI FACETS
Date: August 10, 2021, 12pm-12:30pm

[Friendly and Productive IEP Meetings \(Spanish\)](#)

Date: August 12, 2021
Training in Spanish - To register, contact Nelsinia Ramos, nramos@wifacets.org

[Section 504 - What Parents Need to Know](#)

Presenter: Matthew Zellmer, WI FACETS
Date: August 17, 2021

[Communicating in a Supportive Role](#)

Date: August 18, 2021
Presenter: Lori Albers, Parent

[IEP 2: Special Education Referral Process](#)

Presenter: Bonnie Vander Meulen,
WI FACETS
Date: August 24, 2021, 12pm-12:30pm

[Supporting your Preschool Child's IEP at Home](#)

Presenter: Jessica Nichols, WI DPI
Date: August 25, 2021

[IEP Checklist](#)

Presenter: Matthew Zellmer, WI FACETS
Date: August 31, 2021

Learning
Opportunities



Resources to Support English Language Learners From the U.S. Department of Education

[Multi-Tiered/Leveled Systems of Supports for English Language Learners](#)

Briefs highlight research to support students with or at risk of a disability. Research based strategies for reading, culturally responsive practices, professional learning and coaching, and data-based decision making are features considered to support English language learners within strong universal supports and inclusive environments.

[Tools And Resources for Addressing English Learners with Disabilities](#)

The Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973 address the rights of students with disabilities in school and other educational settings. This toolkit has information on evaluations, writing the IEP, and potential appropriate accommodations.

The Wisconsin Department of Public Instruction also has a [webpage](#) pertaining to English Language Learners. On that webpage an article is referenced, "[Best Practices for Serving English Language Learners and Their Families](#)," that has an excellent section on promoting family engagement with families of English Language Learners.

Research to Read

Social stigma and self-perception in adolescents with Tourette Syndrome

Cox, J. H., Nahar, A., Termine, C., Agosti, M., Balottin, U., Seri, S., & Cavanna, A. E. (2019). Social stigma and self-perception in adolescents with tourette syndrome. *Adolescent health, medicine and therapeutics*, 10, 75–82. <https://doi.org/10.2147/AHMT.S175765>

[Article Link](#)

Tourette Syndrome (TS) is a complex neurodevelopmental disorder characterized by multiple motor and vocal tics, which commonly presents with multiple behavioral problems, including co-morbid attention-deficit and hyperactivity disorder and obsessive-compulsive disorder. Both tics and co-morbid conditions have been shown to potentially affect patients' health-related quality of life. While TS typically presents in childhood, its manifestations peak in severity during adolescence, a critical period in which affected individuals are exposed to potential stigma from peers. Physical and behavioral manifestations can also contribute to stigma, which subsequently leads to poorer health outcomes, discrimination, and a reduced willingness to seek help. The available evidence suggests that young patients with TS can experience reduced social acceptance from peers and difficulties establishing relationships. There is also evidence that some health care professionals share the unhelpful belief that young patients with TS should be disciplined to correct their disruptive behavior, based on the erroneous assumption that tics can be consciously controlled. Studies focused on self-perception in patients with TS have yielded inconsistent results, with some studies showing problems in the domains of self-concept and self-esteem. Feelings of isolation, loneliness, and experiences of bullying have been reported more consistently. Interventions are required to reduce misconceptions about the condition and thus reduce stigma through targeted education and behavioral interventions. A multi-faceted approach that focuses on educating children, adults, and educators about TS would be beneficial to help alleviate stigma. This can be combined with self-advocacy and tailored psychological therapies for young patients with TS. The present paper reviews the current literature on stigma and self-perception in adolescents with TS to inform clinical decisions about management strategies and possible interventions to improve health-related quality of life.

This monthly update is provided by the Wisconsin Family Assistance Center for Education, Training & Support (WI FACETS) to share statewide information regarding parent leadership and family involvement. *If you would like to receive this monthly update or if you would like to have your name removed from the distribution list, contact: Wendy Overturf at woverturf@wifacets.org.*



Contributions to the Newsletter

Upcoming newsletter topics: September: Assistive Technology
October: Learning Disabilities
November: Emotional Behavioral Disabilities

To submit contributions of articles, events, or resources, you may use the attached word document. Send submissions to woverturf@wifacets.org. If you are unable to access the form, you may send the information in an email.

Material appropriate for the monthly newsletter include web links to sources of family involvement/parent leadership resources, advertisements for statewide trainings for parents, youth or parent/educator audiences, information about statewide parent agencies, recent research pertaining to family engagement, and family engagement success articles.

**The WI FACETS Family Engagement E-Newsletter
can be found online at:**

<https://servingongroups.org/resources>



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