

# FAMILY ISSUES ASSOCIATED WITH TICS

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# WEBINAR OUTLINE

- Journey through the lived experience of our families...
  - Initial experience for families prior to tic diagnosis
  - Once you know that it is tics, now what?
- Tics and comorbid disorders can affect family functioning
- Treatment for tics – considerations for families
- Function-based assessment and intervention approach for families
- Supporting families of children with tics
- Discussion

***Tic disorders affect families, not just the child with tics. Therefore, it is important to provide comprehensive family-based clinical care when working with a child with a tic disorder (Himle et al., 2018).***



# INITIAL EXPERIENCE FOR FAMILIES - JOURNEY OF DISCOVERY

*Median delay between onset of tics  
and diagnosis of tic disorder was  
almost 3 years in Danish study  
(Mol Debes, Hjalgrim, & Skov, 2009)*

*It is important to  
understand a family's  
journey to diagnosis, to  
guide clinical care.*





# PARENTS NOTICE CHANGE IN “BEHAVIOUR”

- What are those movements?
  - Eye movements: Seizures? Vision issues?
  - Stop doing that!
- What are those sounds?
  - Sniffing and throat clearing: Allergies?
  - Saying inappropriate things: Poor behaviour?
  - Be quiet!

*Tics are suggestible, so drawing attention to them can actually increase them.*



# PARENTS MAY BECOME OVERLY CONCERNED

- Is this something serious?
  - Alberta Children's Hospital ER Visit
  - Family physician
- Why is this happening?
  - Stress
  - Poor sleep, nutrition
  - PANS/PANDAS? (Pediatric Acute-Onset Neuropsychiatric Syndrome)
  - Starting ADHD stimulant medication
  - Genetic link

*New onset tics are a change in behaviour, and may be unusual and persistent, which causes parents to worry.*



# CHILD MAY BE REFERRED TO MULTIPLE SPECIALISTS PRIOR TO DIAGNOSIS

- Optometrist: Vision issues?
- Neurologist: Seizures?
- Immunologist: Allergies?
- Ear, nose, and throat specialist: Allergies?
- Pediatrician
- Movement disorders neurologist

*Tics can be any type of movement or sound, so often other health issues are investigated prior to receiving a tic diagnosis.*



# CAREGIVERS EXPERIENCE A RANGE OF REACTIONS TO TIC DIAGNOSIS (Himle et al., 2018)

- Relief
- Anger/resentment for taking so long to receive diagnosis
- Confusion/misunderstanding
- Fear/uncertainty about child's future
- Guilt/blame
- Denial



# DIFFERENT LABELS ARE PROVIDED WITH TIC DIAGNOSIS

- Labels depend on number/duration of tics, and include:
  - Provisional Tic Disorder
  - Chronic Motor or Vocal Tic Disorder
  - Tourette Syndrome
  - NEW: Acute Onset of Tic-Like Behaviours in Teen Females During COVID-19 Pandemic
    - May 12, 2021, 7:30 to 8:30 pm: Webinar by Tamara Pringsheim and Davide Martino for parents on acute onset of tic-like behaviours in teen females during pandemic

*Different labels, but all indicate presence of tics.  
Label may change over time.*



# CONFIRMATION OF TIC DIAGNOSIS

- Tic diagnosis typically provided by physician:
  - Family Physician
  - Pediatrician
  - Psychiatrist or Psychologist
  - General Neurologist
  - Movement Disorders Neurologist (Calgary Tourette and Pediatric Movement Disorders Clinic)
- Not always clear what movements/sounds are tics...

*It can take time to receive a tic diagnosis... One goal of the Tourette OCD Alberta Network is to educate clinicians about tics, reducing the time to receive the appropriate diagnosis.*



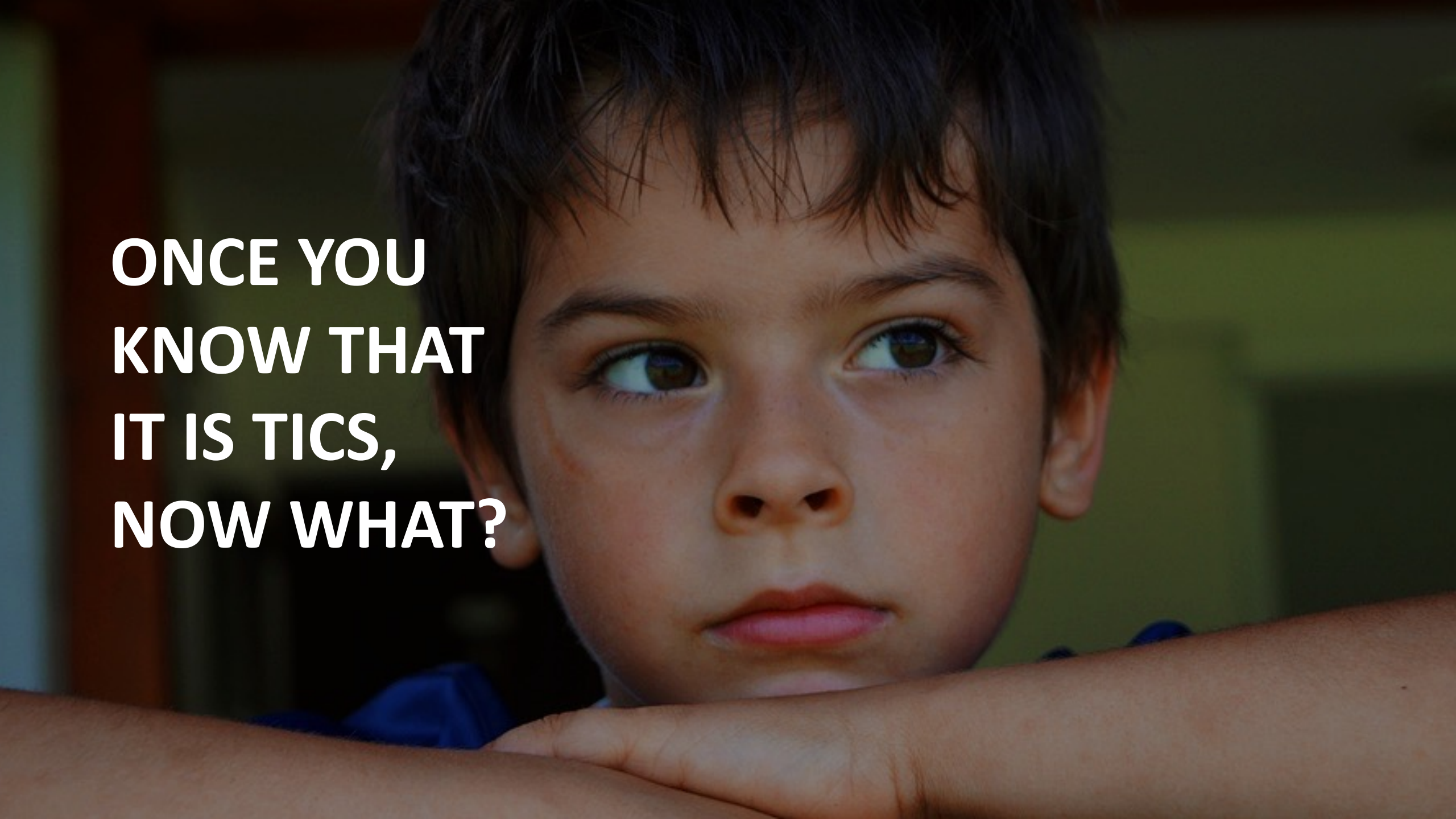
# HELPING FAMILIES IDENTIFY TICS

- Teaching families how to differentiate between tics, comorbid symptoms, and developmentally normal behaviour:
  - Need to know it is a tic to be able to respond (or not respond) appropriately...
  - Simple motor/vocal tics: usually easier to identify simple tics
  - Complex motor/vocal tics: more challenging – appears to have more intent (“purposeful”), and can be more challenging to identify as tics
- Common characteristics of tics:
  - Timing: usually have simple tics prior to complex tics
  - Premonitory urge: may have with tics (particularly complex tics)
    - Compulsions in response to obsessive thought
  - Setting: tics not usually constrained to particular settings, activities, or mood states
- Refer to Tamara Pringsheim’s psychoeducation webinar on Tourette OCD Alberta Network website

***Most children are able to differentiate between tics and purposeful behaviour.***



**ONCE YOU  
KNOW THAT  
IT IS TICS,  
NOW WHAT?**





# PSYCHOEDUCATION IS KEY EARLY INTERVENTION

- Psychoeducation has many benefits (Himle et al., 2018):
  - Reassures caregivers/child
  - Promote positive attitudes and healthy interactions toward child with tic disorder
  - Informs treatment decisions
  - Increase treatment engagement/adherence
  - Reduce guilt/stigma surrounding tic diagnosis
  - Restore trust in health care providers
  - Create optimism for future – tic disorders are a manageable condition
- Refer to Tamara Pringsheim's psychoeducation webinar on Tourette OCD Alberta Network website

*Parents are often worried when their child starts having tics.  
Learning about the nature of tics is a positive initial approach.*



# KEY POINTS FOR FAMILIES

- Tics themselves will not damage your child's brain
- Character and frequency of tics changes a lot over time ("waxing and waning"):
  - Age 6: mean onset of motor tics
  - Pre-adolescence: peak severity
  - Late adolescence: severity declines
  - Age 14 to 17: high rate of natural remission
  - Adulthood: may dissipate, persist, or only come out at times
- Tics may increase with:
  - Unsettling situations ("stress")
  - Anxiety
  - Excitement
  - Thinking about tics (suggestible nature)
- More common in boys than girls
- Premonitory urge

*Unfortunately, tics typically peak during the pre-teen and early teen years, which are a socially challenging time to be "different." These years can pose challenges for parents as well...*



# POTENTIAL CHALLENGES OF TICS

- Pain – repetitive movements, self-injurious behaviour (Ganos et al., 2014)
- Embarrassment (depends on personality)
- Social challenges → bullying
- Difficulties with schoolwork and activities → disruptive and distracting
- Comorbid disorders are common with tics (Hirschtritt et al., 2015):
  - 86%: 1 or more comorbid disorder
  - 58%: 2 or more comorbid disorders

*Often the comorbidities that are common with tics may pose more challenges for children and families than the tics themselves.*



# PREVALENCE OF COMMON COMORBID DISORDERS IN TOURETTE SYNDROME

- ADHD: 54%
- OCD: 50%
- ADHD & OCD: 30%
- Anxiety disorders: 36%
- Mood disorders: 30%
- Disruptive behaviour disorders (ODD, CD): 30%
- Others: Autism Spectrum Disorder, learning challenges, substance use, eating disorders



# **TICS AND COMORBID DISORDERS CAN AFFECT FAMILY FUNCTIONING**





# TICS DO NOT JUST AFFECT THE CHILD WITH TICS – TICS IMPACT FAMILIES

- For affected child, tics can (Himle et al., 2018):
  - Distract child and interfere with tasks at home and at school (ADLs, schoolwork, leisure activities)
  - Disrupt routines at home (ex. morning/bedtime)
  - Disrupt sleep
  - Limit child's activities due to pain/injury
  - Cause avoidance of social activities (ex. vacations, church, going to the movies)
  - Cause avoidance of in-person school
  - Lead to being excluded from family activities
  - Cause embarrassment



- For caregivers, tics can:
  - Lead to providing more attention/time on child with tics – may cause conflict with other children
  - Cause worry, confusion, frustration, and tension
  - Be difficult to determine what is tics vs. comorbid disorder vs. developmentally normal behaviour
  - Demand extra time for clinic visits, school interactions, etc.
  - Lead to reduced expectations for their child
  - Cause embarrassment
  - Cause feelings of guilt/blame due to potential genetic link
- For siblings, tics can:
  - Be very annoying and difficult to ignore
  - Lead to teasing child with tics
- Potential impacts with external community:
  - Cause conflict with extended family
  - Cause conflict with school

***Parenting a child with tics  
may be a different  
parenting experience...***

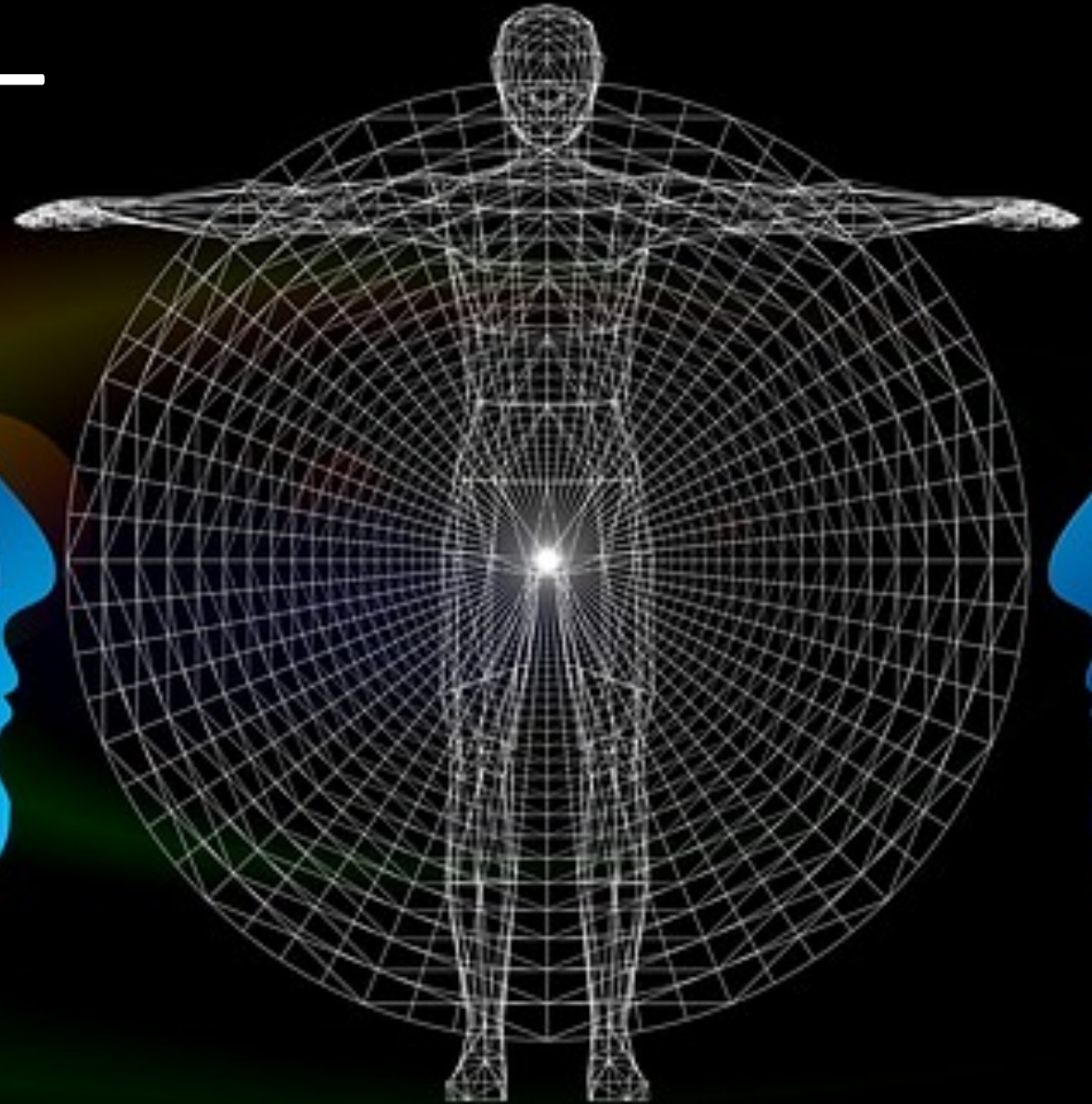


# COMORBID DISORDERS CAN IMPACT FAMILY FUNCTIONING

- ADHD:
  - Need monitoring/reminders to complete simple tasks
  - Take longer to complete homework
  - Act impulsively
  - Defy requests
  - Misplace items
- OCD:
  - Get stuck on tasks
  - Get upset when rituals interrupted
  - Seek constant reassurance
  - Involve family members in rituals
  - Require caregivers to accommodate their symptoms
- Other health challenges :
  - Rage attacks
  - Sleep disruption (particularly common with ADHD)
  - Sensory challenges
  - Fine motor delays



# TREATMENT FOR TICS – CONSIDERATIONS FOR FAMILIES





# MAKING TREATMENT DECISIONS

- Help families to prioritize treatment goals (Himle et al., 2018):
  - Explore which symptoms are impacting whom and why
  - Determine which symptoms are causing greatest burden on family/child
  - Ask family/child to list/rank most important treatment outcomes
- Ensure that families are aware that treatment does not usually eliminate tics
- Provide families with appropriate options for treatment
- Support families in obtaining appropriate treatment for their tics
- Consider treatment for your child if tics causing **functional impairment**

*“Watchful waiting is an acceptable treatment approach in individuals who do not experience functional impairment from their tics” (Pringsheim, 2021)*



# NON-MEDICATION OPTIONS

- Comprehensive Behavioural Intervention for Tics (CBIT)
  - Requires premonitory urge
  - In-Person vs. internet-delivered: [tichelper.com](https://tichelper.com)
  - Refer to Gabrielle Wilcox's CBIT webinars on Tourette OCD Alberta Network website
- Exposure and Response Prevention (ERP)
- Other options:
  - Exercise can possibly reduce tic severity, anxiety, depression, and OCBs (Pringsheim et al., 2020)
  - Alternative therapies
  - June 16, 2021, 7:30 to 8:30 pm: Webinar by Tamara Pringsheim on physical activity, diets, and supplements for tics



# MEDICATION OPTIONS

- Goal of medication to reduce tics and improve functioning
- Requires monitoring/in person clinic visits:
  - Antipsychotics:
    - Monitor for neurologic and metabolic side effects
    - CAMESA Guidelines: [comesguideline.org](http://comesguideline.org)
  - Alpha agonists:
    - Monitor postural vitals
    - May require ECG
  - Botox injections: q 12 weeks

***Deciding whether or not a child should take a medication is a big decision for parents /children. It is important for families to learn about the potential benefits and side effects.***

***Only about 20% of children at the Calgary Tourette Clinic are prescribed medication to treat their tics (i.e. when tics causing functional impairment). If prescribed, close monitoring is done.***



# POTENTIAL TREATMENT CHALLENGES

- Parents may be reluctant to consider prescription medications
  - Some parents more open to alternative therapies only
- Parents may not agree with each other on treatment options
- Children may not agree with parents on treatment options
- Children may not be able/willing to participate in non-medication options (ex. young/defiant child or child with severe ADHD)
- Limits of CBIT and ERP (ex. need for premonitory urge with CBIT, etc.)
- Access to appropriate treatments:
  - Cost and availability of medications
  - Cost and availability of non-medication options
  - Tourette OCD Network to improve accessibility of treatment options...



# TREATMENT FOR COMORBID DISORDERS

- Prioritize overall treatment plan for child:
  - Non-medication treatment options may not be possible if child's ADHD untreated
  - Other challenges may be more pressing than tics (ex. severe anxiety, low mood, OCD)
- Support families in obtaining appropriate treatment for comorbid disorders
- Treatment is not just about reducing child's tics...

*Successfully reducing a child's tics only results in modest improvements in caregiver strain, family functioning, and comorbid symptoms (Woods et al., 2011)*



# **FUNCTION-BASED ASSESSMENT AND INTERVENTION (FBAI) APPROACH FOR FAMILIES**





# TEACH FAMILIES HOW TO EFFECTIVELY RESPOND TO TICS USING FUNCTION-BASED APPROACH

- Function-Based approach can (Himle et al., 2018; Woods et al., 2008):
  - Decrease tic-related functional impairment
  - Decrease situational exacerbations
- Tic severity is influenced by:
  - Internal factors: mood states (ex. anxious, excited, bored, tired)
  - External factors:
    - In Specific settings – ex. home vs. school
    - During Certain activities – ex. in the car, during homework
    - With certain people – ex. one parent vs. the other
  - Tic-contingent reactions:
    - Suggestible nature – ex. talking about tics, asking a child to stop ticcing
    - Teasing/mimicking child
    - Avoiding non-preferred tasks – ex. homework, chores



# IDENTIFY AND MODIFY FACTORS/REACTIONS TO DECREASE TIC SEVERITY

## ASSESSMENT:

- Identify internal/external factors and reactions that are associated with **problematic tic exacerbations**:
  - During what specific situations are the child's tics worse?

## INTERVENTION:

- Modify the setting and change the reaction to tics to:
  - Reduce the impact of tics on affected child/family
  - Help families to respond to tics in a healthier way
  - Improve overall family functioning



# EXAMPLES OF FUNCTION-BASED ANTECEDENT INTERVENTIONS (Himle et al., 2018)

Tic-Exacerbating Antecedent	Function-Based Antecedent Intervention
Stress/Anxiety	Teach relaxation/coping strategies Minimize unnecessary stressors
Fatigue	Teach good sleep hygiene Schedule breaks and break tasks down into manageable components
Transitions	Schedule activities Provide countdown alerts
Boredom	Assign pleasurable activities & easily mastered tasks
After school	Provide short break prior to demanding tasks Have planned after-school routine Complete essential tasks when less likely to tic
TV/Video Games	Minimize screen time Adjust timing of screen time to after important tasks
In Public	Practice how to respond to others & disclose tics Increase/substitute for activities that are less likely to be impacted by tics



# EXAMPLES OF FUNCTION-BASED CONSEQUENCE INTERVENTIONS (Himle et al., 2018)

Tic-Exacerbating Consequence	Function-Based Consequence Intervention
Parental/Sibling Attention	<ul style="list-style-type: none"><li>• Teach parents that child not ticcing on purpose to get attention</li><li>• Teach parents to selectively ignore tics (no teasing/mimicking)</li><li>• Talk about tics during scheduled time, when tics are milder &amp; parent/child calm</li><li>• Child to initiate tic-related discussions</li><li>• Teach parents to prompt tic-management strategies (ex. CBIT, relaxation exercises) rather than comment on tics</li></ul>
Avoidance of Task	<ul style="list-style-type: none"><li>• Teach parents that child not ticcing on purpose to get out of activities</li><li>• Mild tic exacerbations: encourage child to “push through” to complete tasks</li><li>• Severe tic exacerbations:<ul style="list-style-type: none"><li>• Allow child to have short break from task</li><li>• Ensure child completes task as soon as tics subsided</li><li>• Prompt child to use tic-management strategies (ex. CBIT, relaxation exercises) during break</li><li>• Ask child to complete task in a timely manner, to the best of their abilities</li></ul></li><li>• Set realistic expectations for &amp; encourage child to engage in activities</li><li>• Plan social outings to minimize impact of tic exacerbations</li></ul>



# FBAI EXAMPLE OF JOHNNY (Himle et al., 2018)

- Johnny has more severe vocal tics at home after school → avoids homework & goes to room to watch TV (sometimes stays in room through dinner) → falling behind at school → conflict with brother because brother still has to do homework → difficult to do family activities

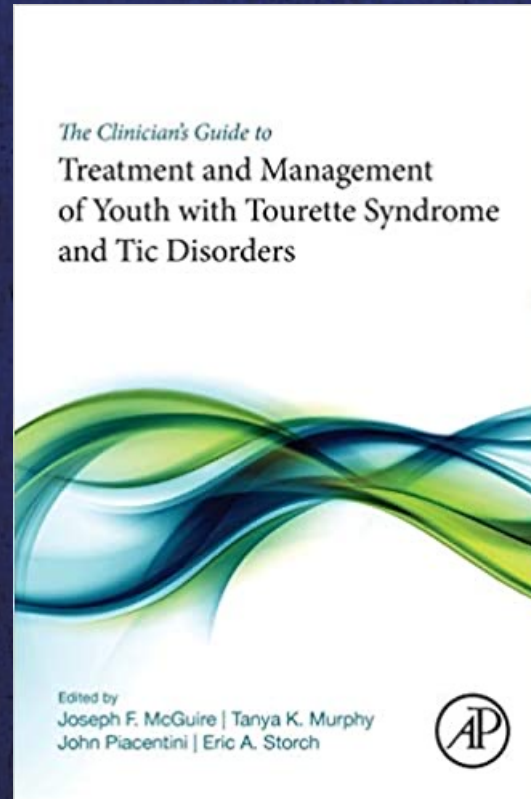
Antecedents/Consequences (What makes tics worse?)	Function-Based Intervention
<ul style="list-style-type: none"><li>Peer on school bus teasing Johnny about tics</li></ul>	<ul style="list-style-type: none"><li>Notify bus driver of teasing</li><li>Johnny &amp; friend sit near driver at front of bus</li></ul>
<ul style="list-style-type: none"><li>Johnny's mother giving him a lot of attention when he arrives home from school (ex. express frustration about his tics)</li></ul>	<ul style="list-style-type: none"><li>Johnny's mother to plan to ignore tics after school</li></ul>
<ul style="list-style-type: none"><li>Johnny avoiding homework because of his tics &amp; gaining access to preferred activity (TV)</li><li>Johnny's mother having "yelling matches" with his brother after school (power struggle due to inequity)</li></ul>	<ul style="list-style-type: none"><li>Implement reward program for Johnny &amp; his brother to earn TV time for completing homework</li><li>Schedule Johnny's homework time to morning when tics less severe</li><li>Family to regularly engage in family activities, regardless of the severity of Johnny's tics after school</li></ul>

*Also participate in other activities to reduce tics (CBIT, anxiety management, etc.)*

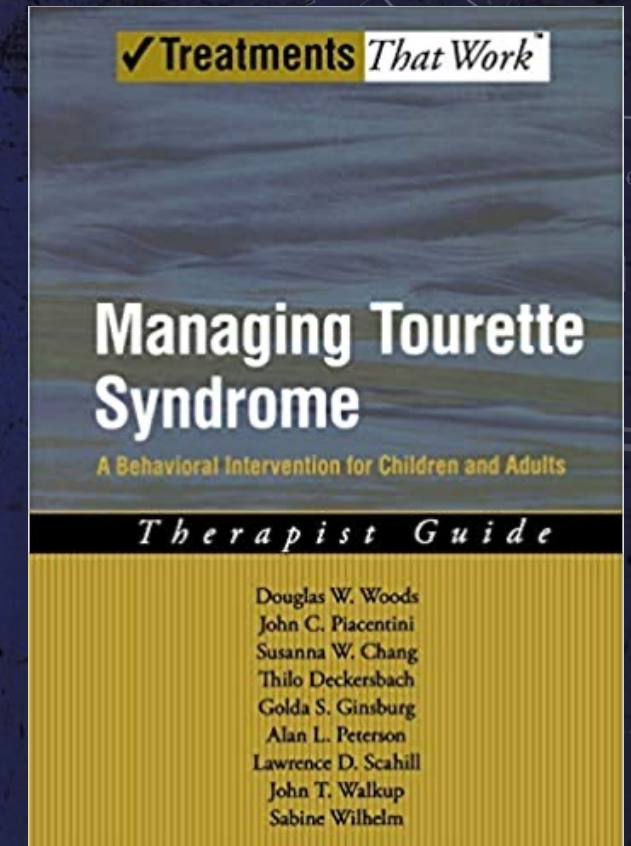


# GUIDE FOR HOW TO IMPLEMENT FBAI

- Family Issues Associated with Tics, from the Clinician's guide to treatment and management of youth with Tourette Syndrome and tic disorders (Himle et al., 2018):



- Provided in CBIT treatment manual (Woods et al., 2008):



- June 3, 2021, 7:30 to 8:30 pm: Webinar by Jennifer Ference-Belhomme for parents on managing avoidance and accommodation of complex tic-like behaviours



# SUPPORTING FAMILIES OF CHILDREN WITH TICS





# FOSTER CHILD'S STRENGTHS

- Purpose (Himle et al., 2018):
  - Creates sense of accomplishment for child
  - Improves parent-child relationship
  - Decreases parental distress
- Support family in identifying child's strengths
- Encourage children/families to increase time spent on preferred activities, focusing on activities that:
  - Child and family enjoy together
  - Avoiding due to tics



# TEACH FAMILIES HEALTHY WAYS OF TALKING ABOUT TICS/COMORBIDITIES WITH OTHERS (Himle et al., 2018)

- Learn how to talk effectively about tics and comorbid conditions at home
- Provide supportive environment for child to freely express self
- Parents should model behaviours want to see in their child – assertively provide brief nonjudgmental education about tics to others
- Child to have an explanation prepared for others – only share what they are comfortable sharing
- Tourette Association of America has resources for helping families to educate others about tic disorders:
  - [tourette.org/resources/overview/](https://tourette.org/resources/overview/)

## Why do I act this way? Because I can't control it.

I have **Tourette Syndrome or a Tic Disorder** – a medical condition. It causes me to cough, sniffle, or clear my throat even though I am not sick. Please understand that this is a medical condition and I cannot control my tics. Treatment for Tourette and tics is limited and there is no cure. I am grateful for your understanding and empathy.

My condition is covered by the American Disabilities Act.  
Visit [Tourette.org](https://Tourette.org) to learn more.



## Medical Information Card

(name optional)

**Tourette Syndrome (TS)** is part of a spectrum of hereditary, childhood-onset, neurodevelopmental conditions referred to as Tic Disorders. These conditions affect both children and adults, causing them to make sudden, uncontrollable movements and/or sounds called tics. More than annoying, TS and tics can be emotionally, physically, and socially debilitating.

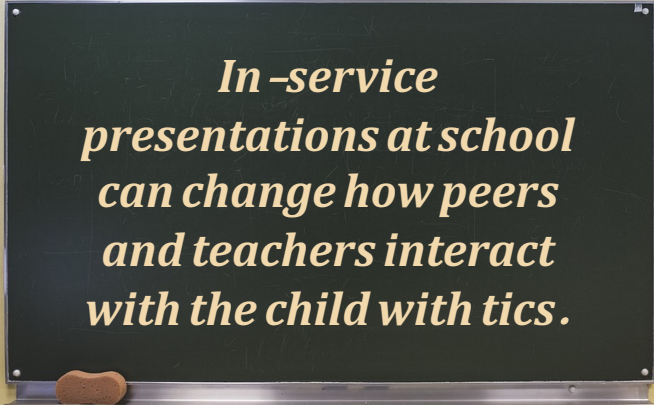
[tourette.org](https://tourette.org) • 888-4TOURET





# ASSIST FAMILIES WITH OBTAINING APPROPRIATE SUPPORTS AT SCHOOL

- Provide diagnosis letter with recommended accommodations in support of Individualized Program Plan (IPP) to provide teachers with guidance
- Consider having in-service presentation done for students/teacher:
  - Formerly done by Tourette Canada
  - Now provided by Tourette OCD Alberta Network



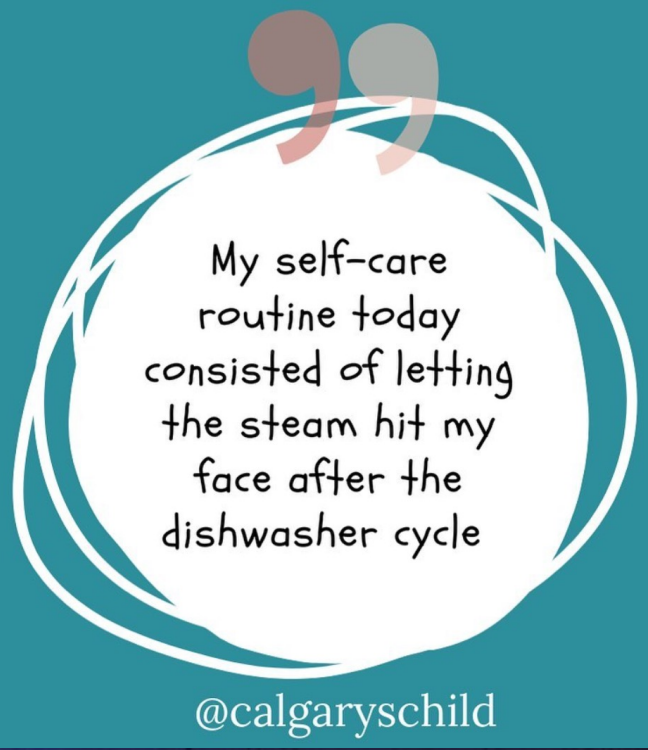
***In-service  
presentations at school  
can change how peers  
and teachers interact  
with the child with tics.***

A chalkboard with a silver frame and a small orange eraser on the ledge. The text is written in a bold, italicized, yellow font.



# ENCOURAGE CAREGIVERS TO PRACTICE SELF-CARE

- Schedule regular time to attend to own needs
- Engage in social activities not related to tics/caregiving
- Address own mental health challenges
- Work as a team:
  - Share responsibilities of caring for child with tics
  - Ensure time spent with other children as well



My self-care  
routine today  
consisted of letting  
the steam hit my  
face after the  
dishwasher cycle

@calgaryschild





*It Takes a Village*



# INCREASE SOCIAL SUPPORT FOR FAMILIES

- Increase social support for families:
  - Link families together
  - Support groups
- Implications of the COVID-19 pandemic:
  - Stress and negative life events associated with increased tic severity and worsening comorbidities
  - Major stressful life events associated with increased family strain and poorer family functioning
  - Some children with tics OK with spending more time at home, and homeschooling
  - Significant mental health impact
  - For children with comorbid conditions may face more challenges



# PROVIDE RESOURCES FOR FAMILIES

- Ensure that families are directed towards appropriate resources in the community:
  - Tic disorder-specific resources
  - Resources for comorbid disorders
  - Resources for other childhood health issues (ex. sensory processing disorders, learning disorders, sleep, etc.)
  - Family-based community resources
  - Mental health resources (urgent and non-urgent)
- Tourette OCD Alberta Network website provides great resources



# REFER TO APPROPRIATE SPECIALISTS

- Refer as appropriate to other specialists, including for comorbid disorders:
  - Mental health: MAPS OCD Program, Psychiatry, Access Mental Health, Complex ADHD Treatment Team
  - Tourette and Pediatric Movement Disorders Clinic at ACH: limited psychology, PT, OT from ACH Neuroscience Clinics
  - Others: Child Development Services (ex. Autism Spectrum Disorder Diagnostic Clinic)

*Directory of Health Care Professionals who have training /interest in Tourette Syndrome and OCD provided on Tourette OCD Alberta Network website*



**THERE IS HOPE...**





# REINFORCE HOPEFUL MESSAGES WITH FAMILIES

- Tics are common in childhood – families are not alone
- Tics will likely improve into adulthood, and have a high rate of natural remission by the late teen years
- Behavioural and medical therapies can decrease tic severity
- Families can effectively support their child with tics with a function-based approach
- Excellent resources are available in the community to support families
- As health care professionals, we can meaningfully impact our families
- Tourette OCD Alberta Network available to provide education, support, and resources for families affected by tics: [touretteocdalbertanetwork.ca](http://touretteocdalbertanetwork.ca)



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