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## ***Ask the Expert***

# Tourette Syndrome and ADHD

Starting a New Year with Health, School and Home supports



Barbara Coffey, MD



Pamela Malley, MA, CCC-SLP



Kathy Giordano, BA

The National Resource Center on ADHD: A Program of CHADD is the nation's clearinghouse for evidence-based information on ADHD. This *Ask the Expert* webcast is supported by Cooperative Agreement Number NU38DD005376 from the Centers for Disease Control and Prevention (CDC) and does not necessarily represent the official views of the CDC. The National Resource Center on ADHD, CHADD and the CDC do not endorse, support, represent or guarantee the accuracy of any content presented or endorse any opinions expressed in this webcast.

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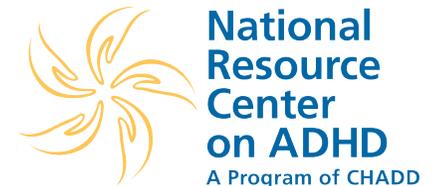
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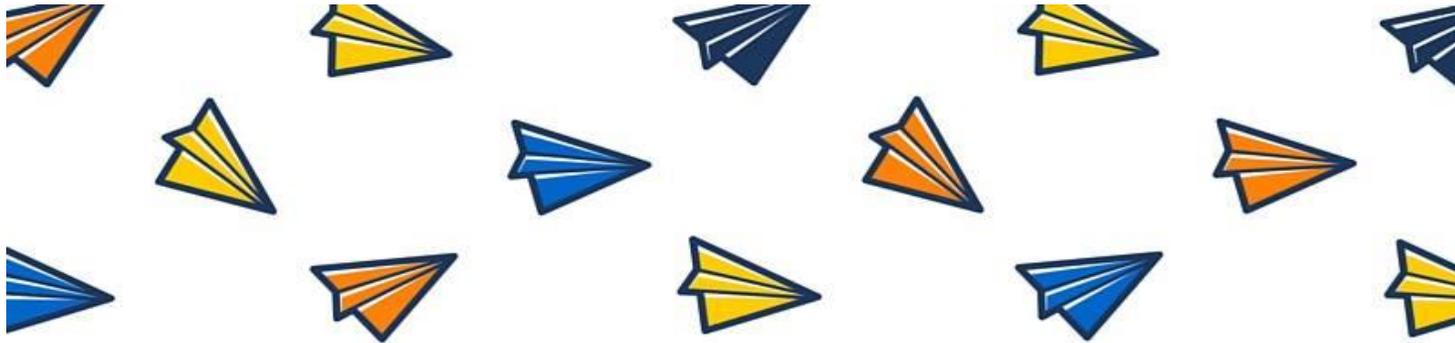
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For more information:

<http://www.chadd.org/About-CHADD/National-Resource-Center.aspx>





**Do you need help with choosing  
what direction to go ?**

Call and speak to an  
ADHD Information and  
Resource Specialist



1-800-233-4050,  
Mon-Fri, 1-5pm ET



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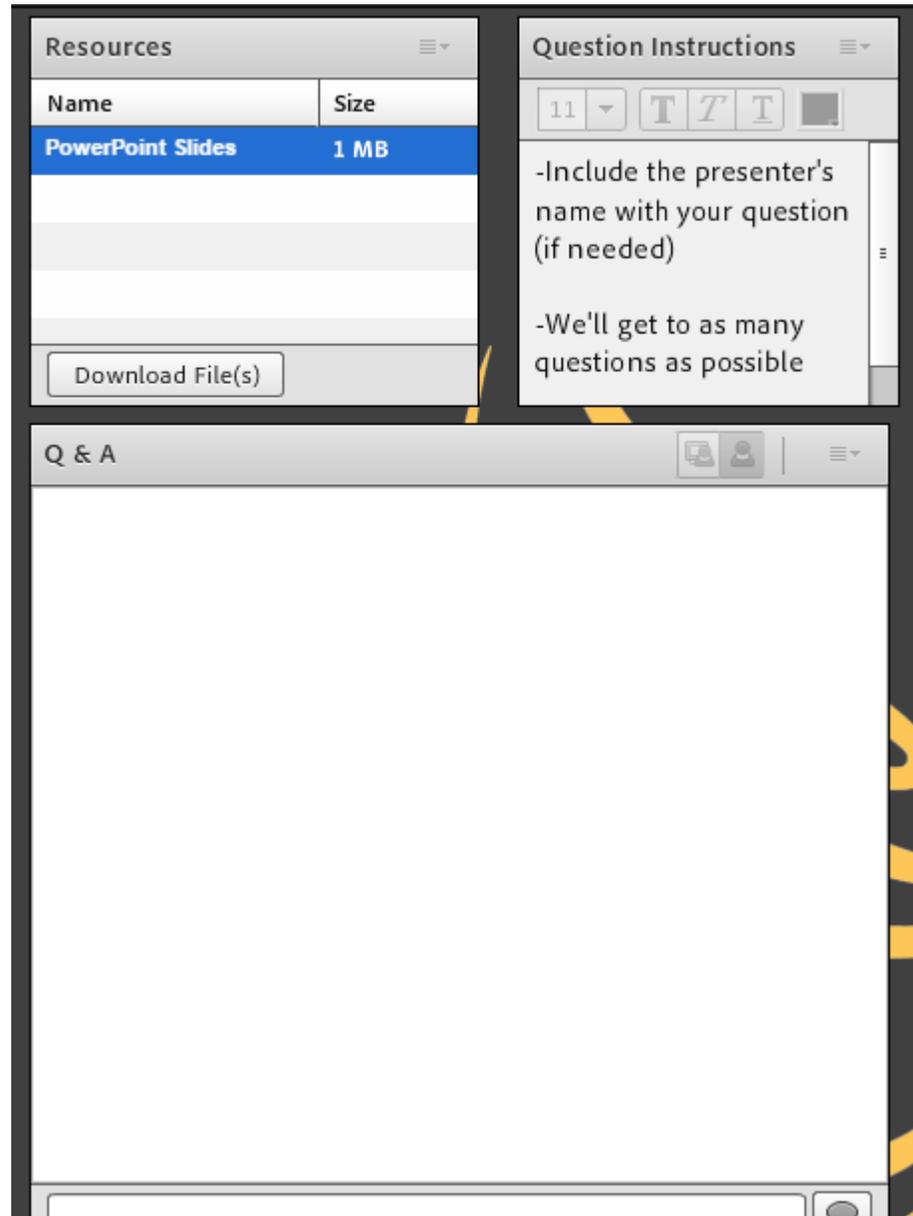
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# Tourette Association of America

The Tourette Association is dedicated to making life better for all people affected by Tourette and Tic Disorders.

- The only nationwide organization serving this community, the Association works to raise **awareness**, fund **research** and provide on-going **support**.
- Partnership with the US Centers for Disease Control and Prevention (CDC) to provide education and resources on Tourette Syndrome and Tic Disorders.
- Directs a network of 32 chapters and over 80 support groups across the country.
- For more information on Tourette and Tic Disorders, call **1-888-4-TOURET**, visit **www.tourette.org**, and follow us on Facebook, Twitter, Instagram and YouTube.



# Tics, Tourette Syndrome and ADHD: How To Disentangle Symptoms and What To Do?

**Barbara J. Coffey, MD, MS**

Professor, Department of Psychiatry

Chief, Tics and Tourette's Clinical and Research Program

Tourette Association of America Center of Excellence

Icahn School of Medicine at Mount Sinai

Research Psychiatrist

Nathan Kline Institute for Psychiatric Research



# Disclosures (Past 12 Months)

- American Academy of Child and Adolescent Psychiatry: Honoraria
- Auspex/Teva: Research Support
- Catalyst: Research Support
- Genco Sciences: Advisory Board
- NIMH: Research Support
- Neurocrine: Research Support
- Shire: Research Support
- Tourette Association of America: Research Support, Medical Advisory Board, TAA-CDC Partnership



# Tics: Definition

**Tics:** are sudden, rapid, repetitive, non-rhythmic, **movements or vocalizations** which occur in the context of otherwise normal motor activity

- Tics change in type, intensity, and location
- They are Increased by stress, excitement or anxiety
- They can be suppressed temporarily
- They are reduced by focused activities
- They are often preceded by a specific or generalized urge or sensation



## **Motor Tics:**

**Simple (one muscle group):** eye blinking, head shaking, shoulder shrugging, abdominal tensing

**Complex (coordinated, more purposeful movements):** touching, tapping, walking in patterns, skipping, jumping

## **Phonic (Vocal) Tics:**

**Simple (single sound):** sniffing, coughing, grunting, throat clearing, snorting, barking, squeaking

**Complex (multiple sounds together):** repeating short phrases (such as Oh, OK, I love you, Mom), repeating others' words, repeating own words, rarely coprolalia (involuntary uttering of obscenities)

## **Tourette's Disorder (Tourette Syndrome)**

Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently.

The tics may wax and wane in frequency but have persisted for more than 1 year since first tic onset.

\* Onset before age 18 years.

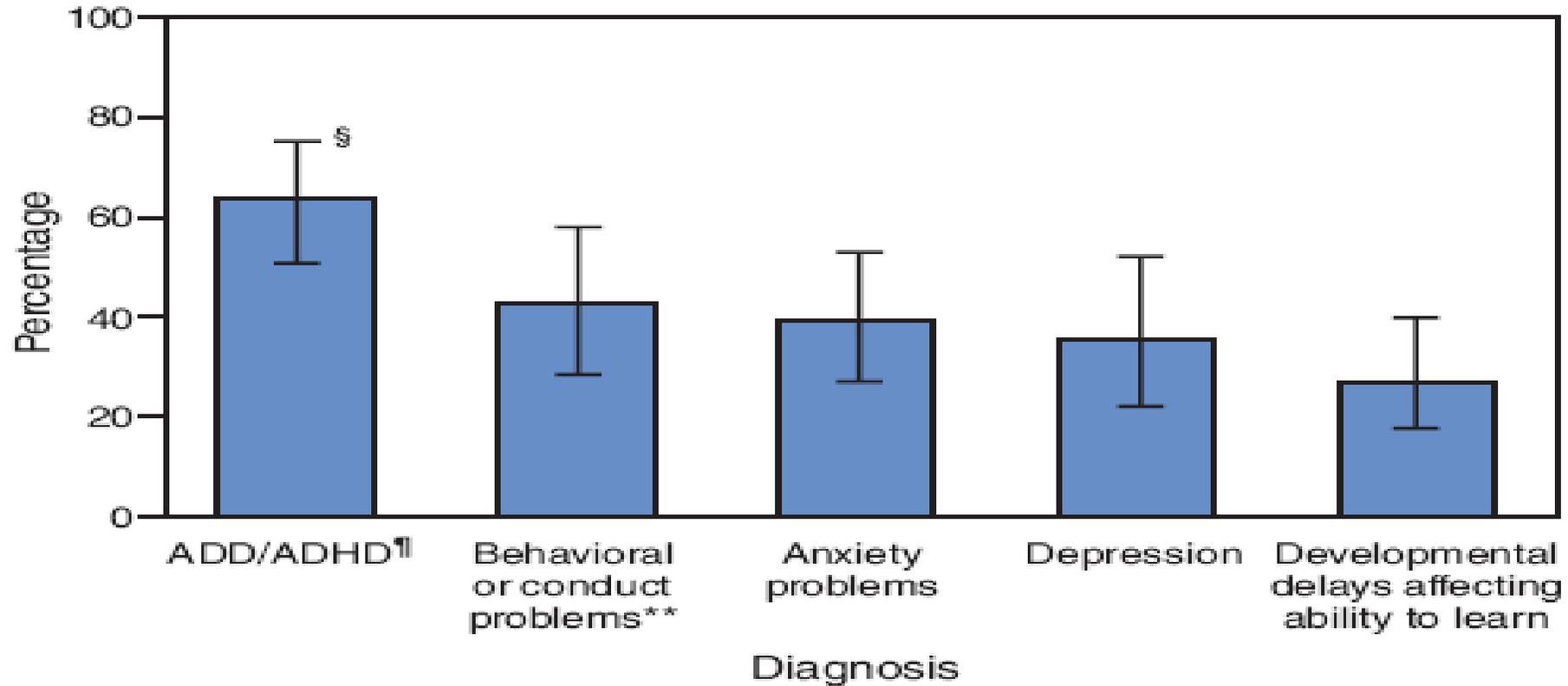


# Overlap of ADHD and Tic Disorders/Tourette Syndrome

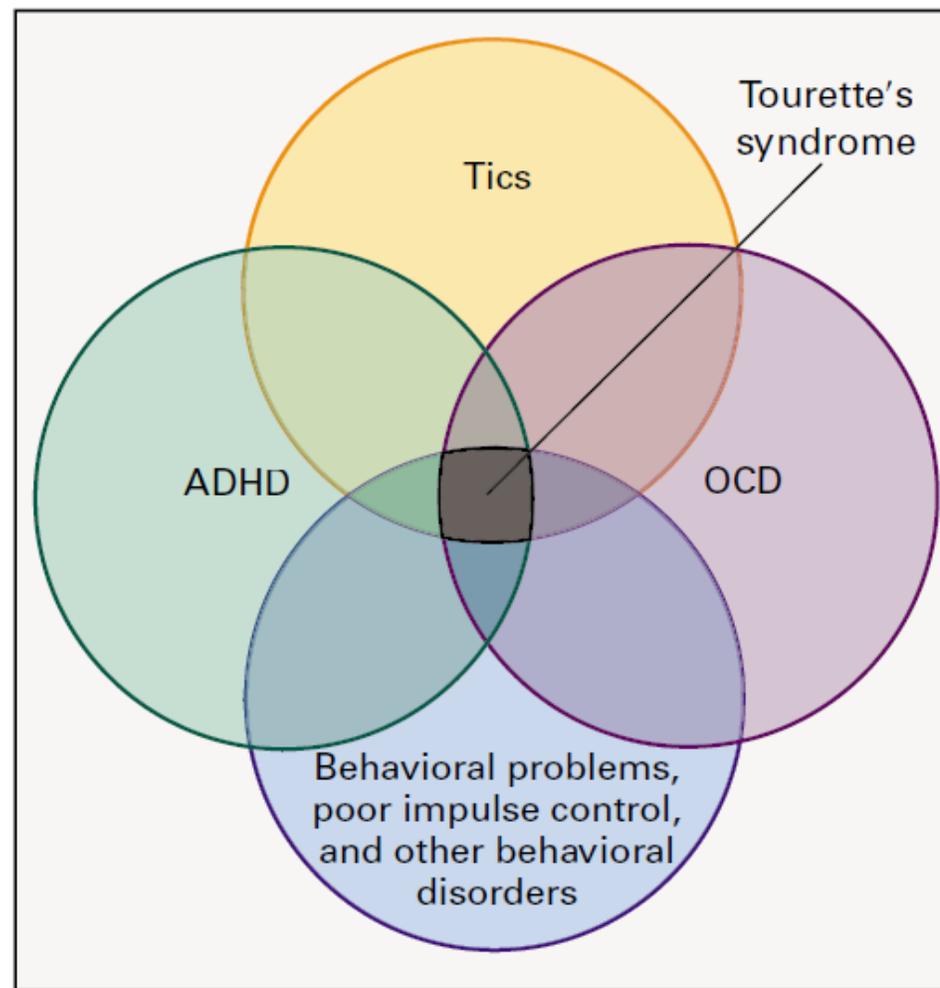
- 1) Rates of tic disorders are higher (10-30%) in children with Attention Deficit Hyperactivity Disorder (ADHD) than in children without ADHD (1-10%)
- 2) Rates of ADHD are high (50-75%) in children with Tourette's Disorder (TD).
- *(Spencer, Biederman, Coffey et al., Arch Gen Psych; 1999, 56: 842-84); Coffey, Biederman, Spencer et al. J Nerv Ment Dis; 2000;188:583-588; Freeman, Tourette Syndrome International Data base Consortium; Eur Child Adolesc Psych 2007; 16 [suppl; 1];1/15-1/23)*



## Prevalence of Selected Diagnoses Age 6-17 years: Lifetime diagnosis of Tourette Syndrome, by Parent Report (National Survey of Children's Health, United States, 2007)



- † Among children ever diagnosed with TS, 79% also had been diagnosed with at least one other selected diagnosis.



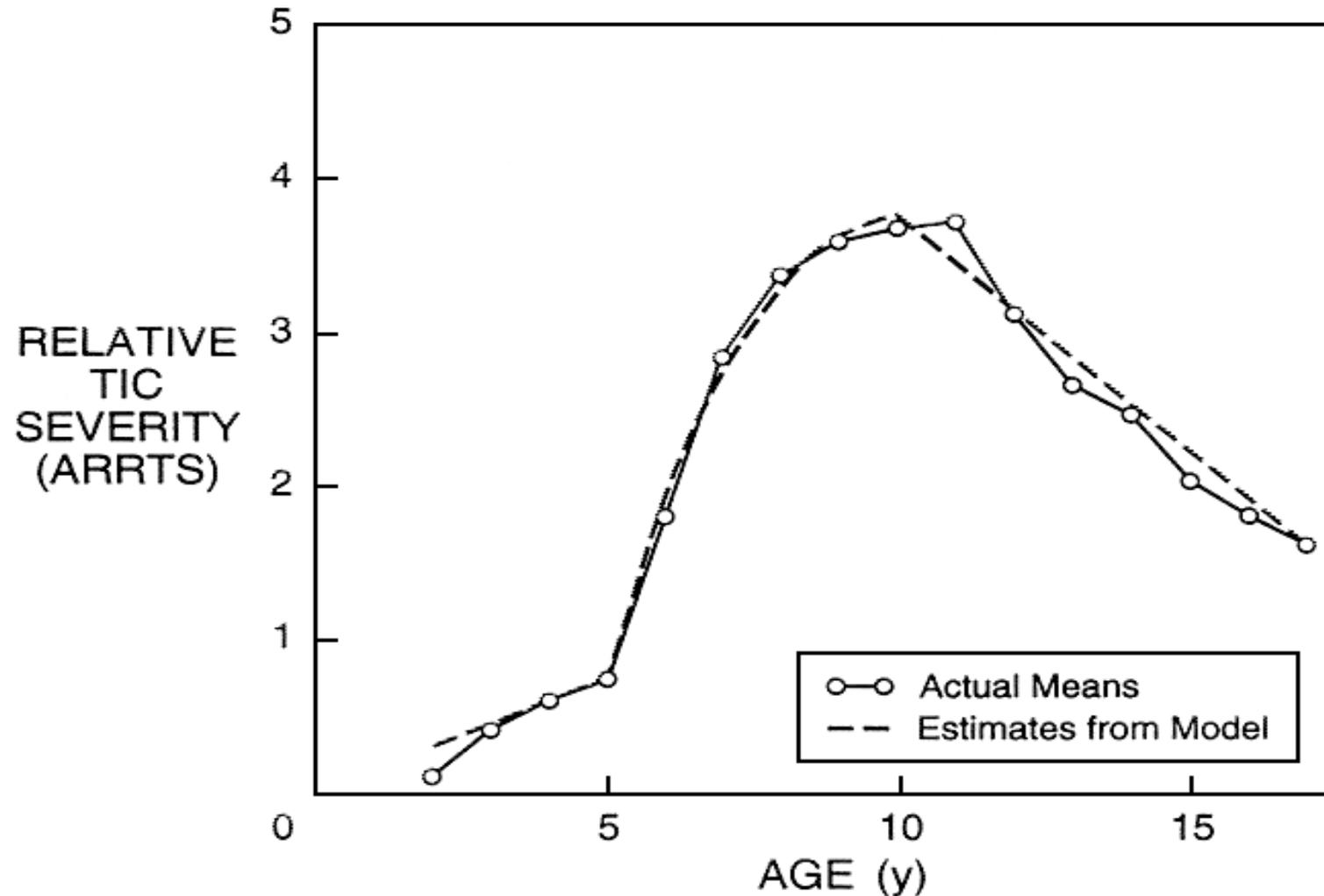
**Figure 1.** Clinical Hallmarks of Tourette's Syndrome.

The diagnosis is based on the occurrence of tics along with behavioral disorders, including attention-deficit-hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD). Other behavioral disorders include anxiety and mood disorders, learning disorders, sleep disorders, conduct and oppositional behavior, and self-injurious behavior.



# Time Course of Tic Severity Ratings

(Leckman, Zhang, et al. *Pediatrics*. 1998;102:14-19)





# Stimulants and Tics: Longstanding Controversy That Stimulants Increase Tics

One old study in 1980 reported this association

Many, many studies of children with ADHD and tic disorders/Tourette Syndrome have been published since then.

The most recent: *Cohen, S et al. JAACAP; 2015; 54(9); 728-736*

Review of 22 studies with 2385 children with ADHD.

New onset or worsening of tics were commonly reported with stimulants (5.7%) and placebo groups (6.5%).

**Risk of new onset or tic worsening associated with stimulants was similar to that of placebo (risk ratio=0.99, p=.962).**

**Conclusion:** There is no evidence for support of an association between new onset or worsening of tics with stimulant use in patients with ADHD.



## **Management Guidelines: ADHD and Tics/Tourette Syndrome**

Most children with Tourette's and ADHD will experience improvement in tics in late adolescence

Tics should only be treated if they cause significant distress to the individual or impair functioning

ADHD is usually persistent

ADHD symptoms are generally more problematic, and are typically associated with more impairment than tics

Thus, ADHD usually needs treatment

Cognitive behavioral therapy and medications are used to treat both tics and ADHD and can be used in combination



# Tics, Tourette Syndrome and ADHD: Supporting Your Child's Educational Needs

**Pamela Malley, MA, CCC-SLP**

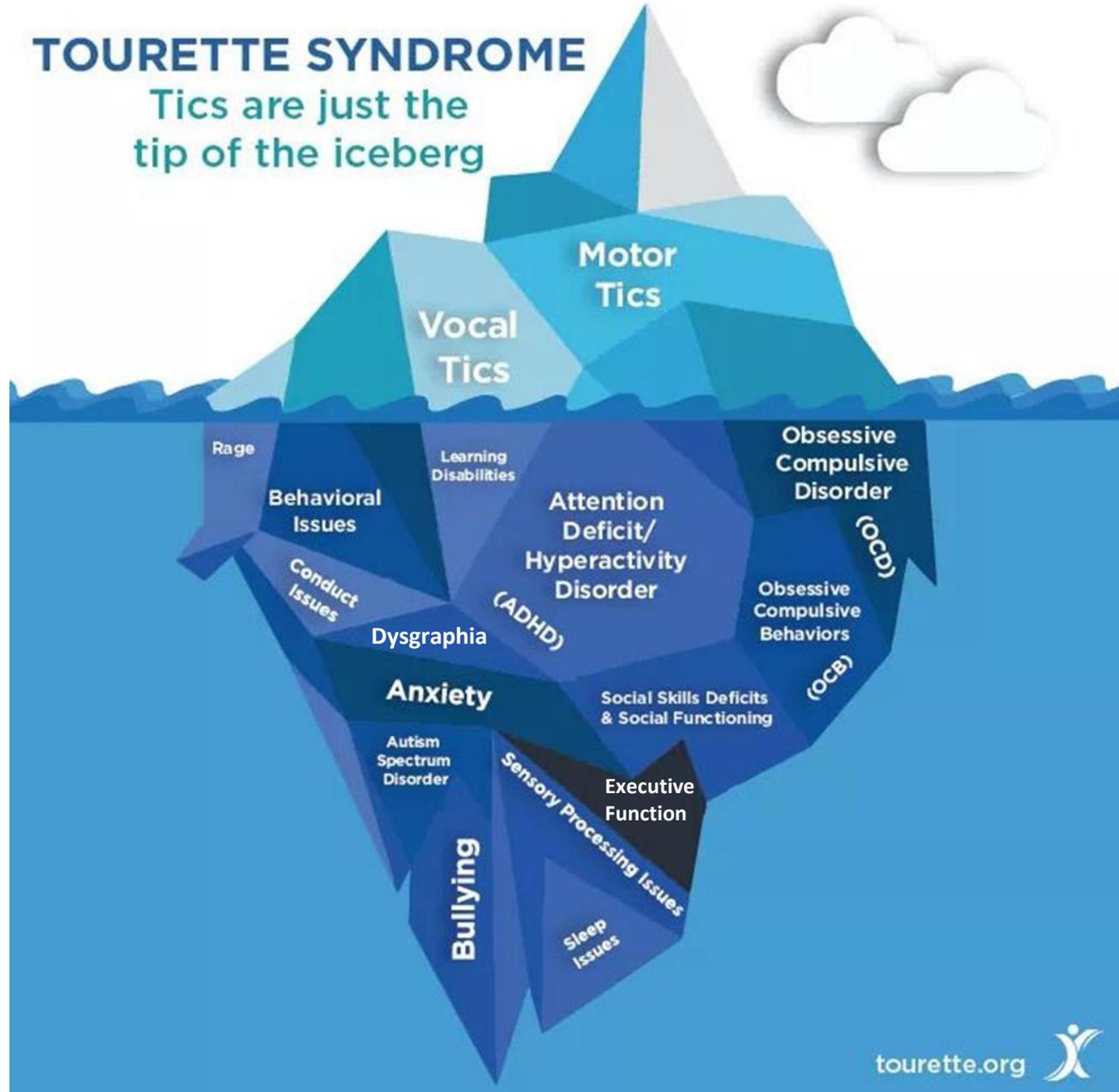
Speech-Language Pathologist

Tourette Association Education Advisory Board Member



# TOURETTE SYNDROME

Tics are just the tip of the iceberg





# New Year=New Start

## New Year's To Do List:

### 1. Identify all of the areas where your child is successful:

- Arts/Music
- Athletics
- Specific topic of interest
- Work Ethic/Attitude
- Technology

### 2. Identify areas of need:

- Executive Function Skills
- Academics
- Anxiety
- OCD/ADHD/Other co-occurring condition
- Social Skills/"Behaviors"
- Other?



# Strategize

1. If necessary, have a team meeting to strategize: what information can be learned from observing your child's areas of strength to improve areas of need?
  - If child is artistic, incorporate art with smart pen
  - If child is musical, teach study strategies using rhythm or beats
2. Include the child in strategizing, when possible.
3. If needed, request a functional behavior assessment, but *be sure to include observations in successful environments.*
4. *Put your plan in writing and include the details!*





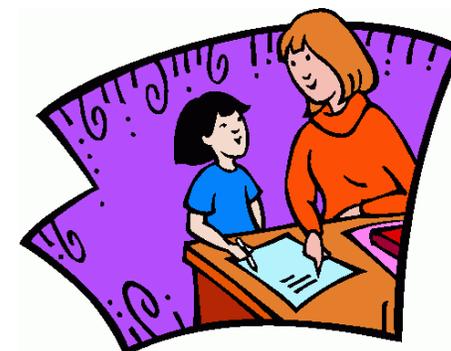
# Implementing Strategies

1. In order to be successful, everyone must be on board.
2. Implementation must be *consistent*: assign a go-to person who will oversee the plan, make sure everyone is on the same page.
3. Designate a teacher to hold a regular meeting time with the child to review and evaluate your plan; may need to meet daily at first, then weekly, then monthly, etc.



# Implementing Strategies

4. Success will not occur overnight, so don't give up too soon.
5. Skills must be taught one step at a time and the child may need extensive support at the beginning.
6. If there is little or no improvement after a few weeks, evaluate what adjustments might be made.
7. Discuss progress/issues with child to gain his/her insight.





# Implementing Strategies

8. Follow through is critical: if nobody is overseeing the plan, something will fall through the cracks.
  
9. When things get frustrating, do a “perspective check”
  - Is the child a problem or does the child *have* a problem?
  - Who is getting frustrated and what is really the cause of the frustration?
  
10. Focus on positive supports, not punishment/reward systems.



# Resources

We're here to help!

<https://www.tourette.org/resources/overview/>

[http://taoa.convio.net/site/Survey?ACTION\\_REQUIRED=URI  
ACTION\\_USER\\_REQUESTS&SURVEY\\_ID=1760](http://taoa.convio.net/site/Survey?ACTION_REQUIRED=URI ACTION_USER_REQUESTS&SURVEY_ID=1760)



# Tics, Tourette Syndrome and ADHD: A Parent View

**Kathy Giordano**

Tourette Association Education Specialist

Mother of 3 adult children – 2 with Tourette and ADD



# A Good Time for Resolutions

- Remind yourself daily that your child:
  - does not want to make you angry
  - would like to do well in school
  - wants to be “good”
  - has symptoms that appear to be purposefully bad, disrespectful
  - punishment, threats or rewards do not change or cure their symptoms
  - does not like needing to ask you questions and would like to ‘get it’ the first time
  - recognizes when he/she is upsetting someone
  
- Our job as parents is to attempt to determine WHY they struggle so we can help develop strategies to *Manage* symptoms.



# Know Different Between Impulsive and Disinhibition

- **Impulsive** – Acts before thinking
  
- **Disinhibition** – The inability to inhibit actions, *in the moment*, in spite of an awareness that it is inappropriate
  - Verbal – name calling, rude comments, disrespectful
  - Physical – breaking items, holes in walls
  
- Punishment and Rewards not effective because not something that child can control ‘in the moment’. Strategies to help them *manage* difficulties in order to respond in a more positive way – Do Work



## Remind Yourself - Talents and Skills

- Many children who have difficulties with impulsivity and disinhibition also have talents and abilities in art, music, creativity, science, technology, sports, etc.



- By encouraging and supporting areas of strength/interest:
  - provides a positive image
  - positive self-esteem
  - increased social interactions/skills
  - possible careers



## Acceptance and Positive Focus

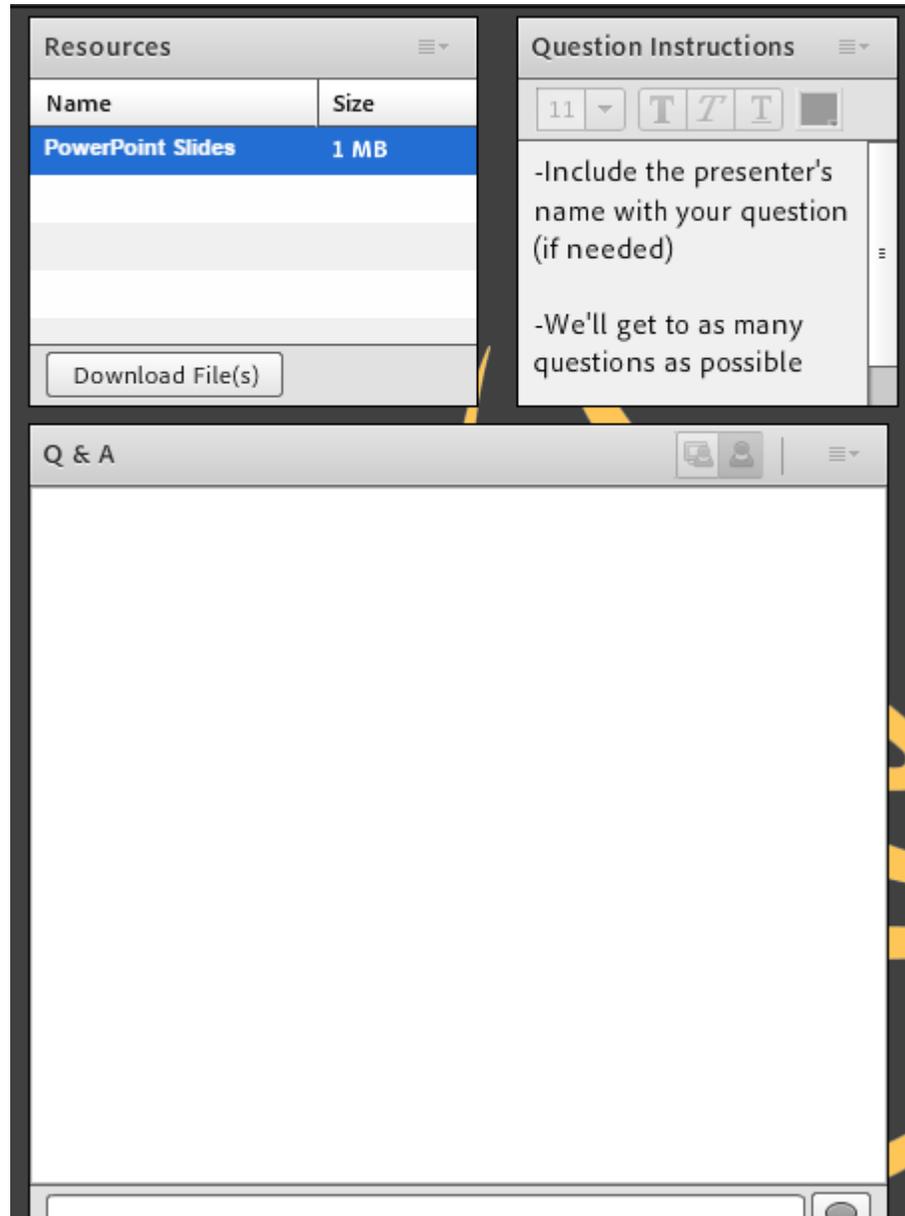
- Accept their apologies
- When child is calm, discuss strategies that will help
  - Exercise; calm time; soft/loud music; sleep, healthy food
  - Key words for you and them may help to indicate a strategy is needed.
- Find people with similar difficulties *but* with positive outlook
- Tourette and ADHD are typically misunderstood
- Family, friends, professionals, strangers will offer many suggestions
- Listen to your 'Parent Gut Feelings'
- Love your child even when you are exhausted
- Take Care of You



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# Upcoming Webinars

## How to Survive Mornings with ADHD

Tuesday, January 31, 2017 at 2pm ET

Guest expert: Michele Novotni, Ph.D.

## Is My High School Student Ready for College?

(And is my college student ready to go back?)

Wednesday, February 8, 2017 at 2pm ET

Guest expert: Ari Tuckman, PsyD, MBA

[www.chadd.org/asktheexpert](http://www.chadd.org/asktheexpert)

# This is a presentation of the



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