OVERVIEW AND MANAGEMENT OF TICS AND TOURETTE SYNDROME

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Disclosures

- No relevant financial disclosures
- I will discuss off-label use of medications/treatments

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"Repeated, individually recognizable, intermittent movements or movement fragments that are almost always briefly suppressible" (Sanger et al. 2010)

- Simple vs complex tics
- Motor (movement) vs vocal (noise- producing)
- Waxing/waning course
- Exacerbating factors
  - Anxiety, stress
  - Fatigue
- Premonitory urge/sensory phenomena
  - 90% of adults, 37% young children
- Suppressible
- Suggestible

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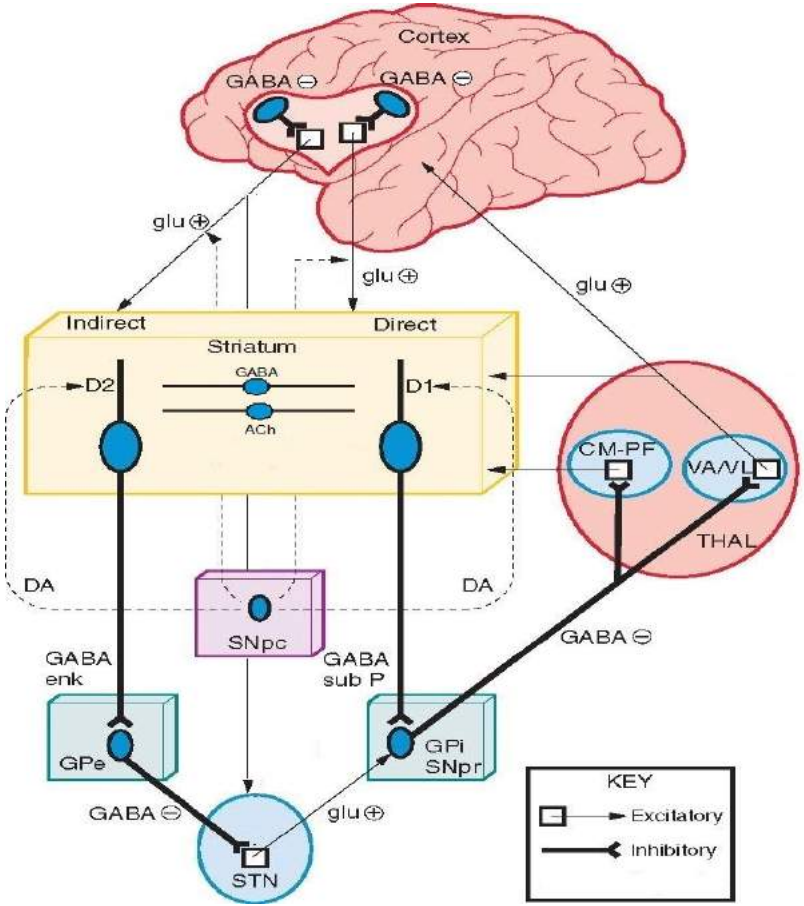
Pathophysiology



- Cortico-striato-thalamo-cortical pathway
- Neurotransmitters
  - DA, 5-HT, GABA, glu
- Genetics

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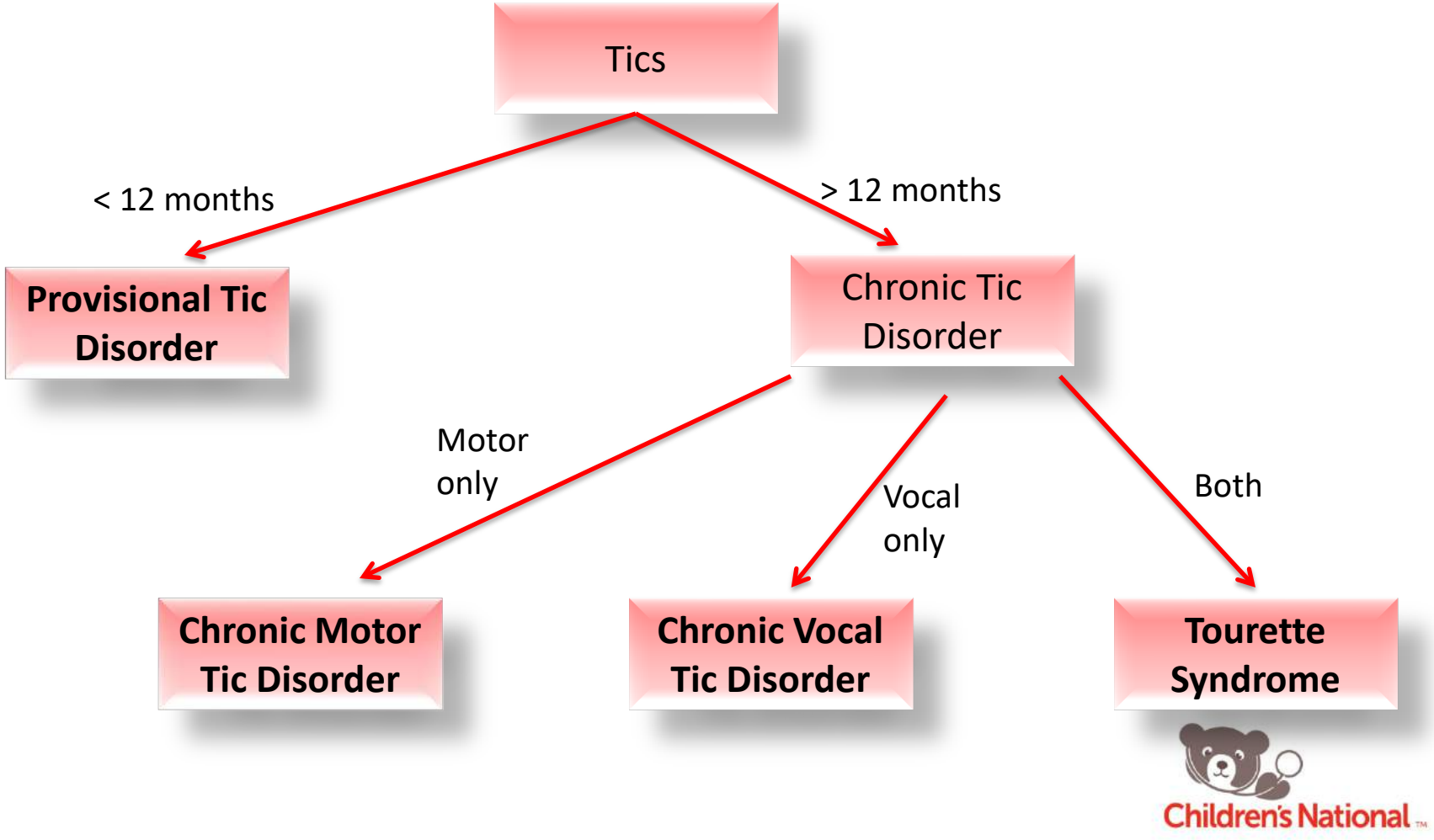
Tics
< 12 months
> 12 months
Provisional Tic Disorder
Chronic Tic Disorder
Motor only
Vocal only
Both
Chronic Motor Tic Disorder
Chronic Vocal Tic Disorder
Tourette Syndrome
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!@#$%^&*

- Coprophenomena
  - < 20% lifetime prevalence
  - Coprolalia (15-19%)
  - Copropraxia (5-6%)
- Males > females
- Associated with ↑ tic severity & comorbidies

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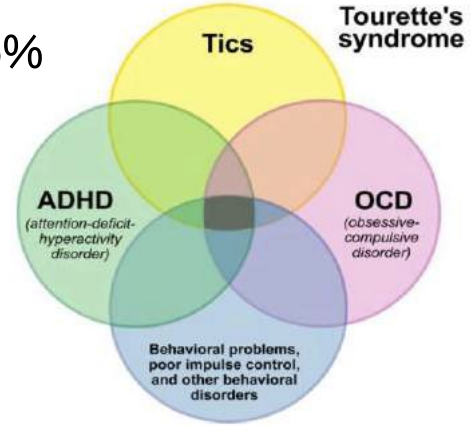
Epidemiology

- Tics: ~15%
- Tourette Syndrome: 0.5%
- Male:Female 3:1 – 4:1
- Occurs across ethnicities
- Onset 4-7 years
- Peak 11-12 years
- Outcome/prognosis:
  - ~ 25-50% resolve by teenage/adulthood
  - ~ 25-50% significant improvement
  - ~ 25-33% continue to have fluctuations into adulthood

Comorbidities

- Lifetime prevalence of psychiatric comorbidity: 85%
  - ADHD 54%
  - OCD 50%
  - Anxiety 36%
  - Mood disorder 30%
  - Disruptive behavior 30%
- 57% met criteria for 2 diagnoses

(Hirschtritt et al, 2015)



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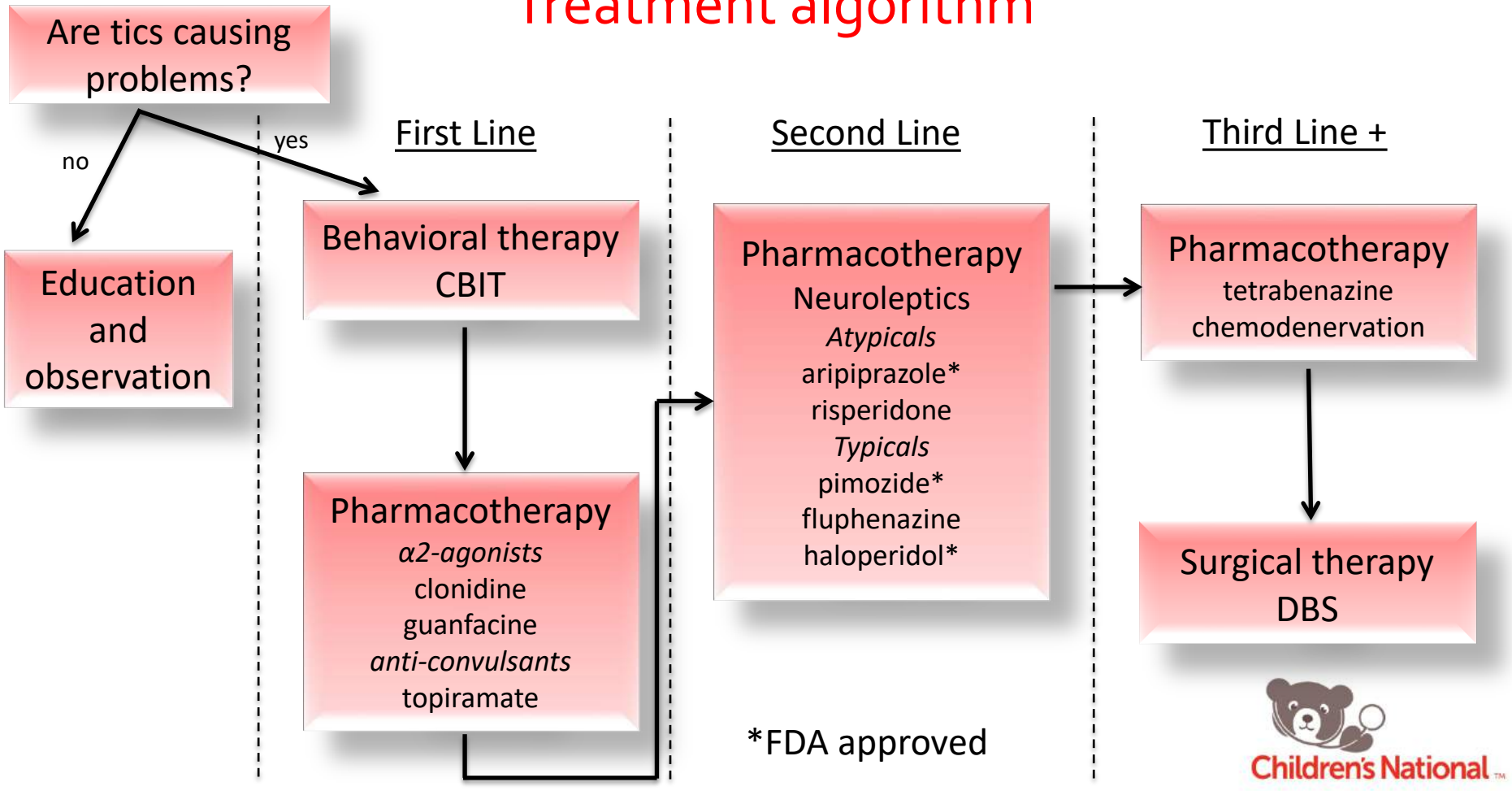
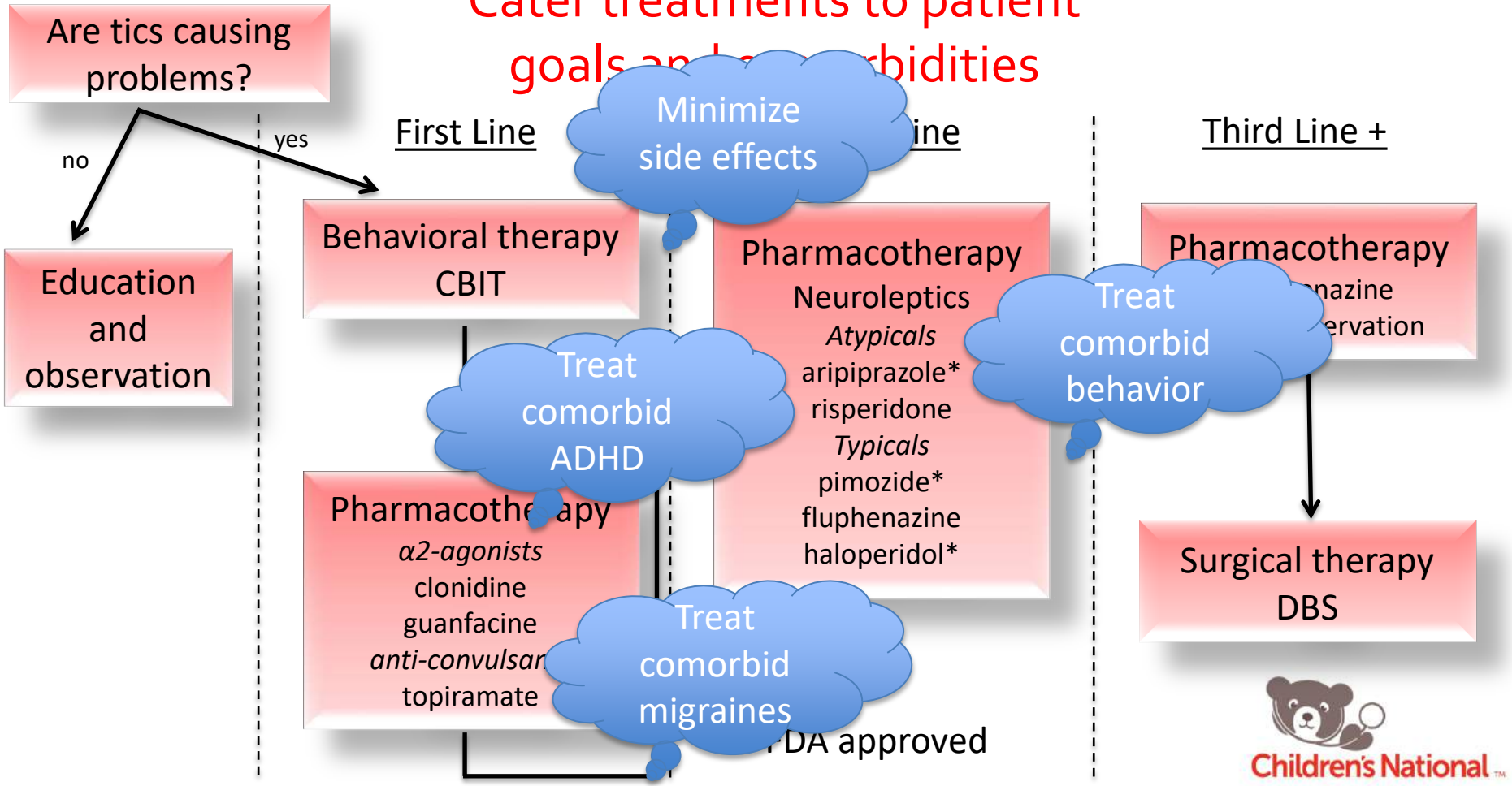
Treatment algorithm



Cater treatments to patient goals and [illegible]rbidities



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Monitoring for side effects

- α2-agonists
  - Blood pressure
  - Heart rate
- Atypical antipsychotics
  - Fasting lipids, glucose
  - BMI
  - Extrapyramidal signs

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When should a patient be seen in the movement disorder program?

- For any help in diagnosing, classifying tic disorders
- If any additional education or counseling needs to be provided
- For initiation of any treatments beyond those provided by the primary provider

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Referrals

- Child Neurology Movement Disorder Program

  (202) 476-3611
- ltochen2@childrensnational.org

Additional Resources for patients

Tourette Association of America

Awareness. Research. Support.

- www.tourette.org
- https://www.cdc.gov/ncbddd/tourette/index.html
- https://dystonia-foundation.org/

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Tourette Syndrome
CBIT
Comprehensive Behavioral Intervention for Tics

Lauren M. Dome MSN, RN, MHS, CPNP
Children's National Medical Center
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What is CBIT

- CBIT is a non-drug treatment consisting of three important components
- Training the patient to be more aware of tics
- Training patients to do competing behavior when they feel the urge to tic
- Making changes to day to day activities in ways that can be helpful in reducing tics

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Who is a good fit for CBIT

- Patients over 10 years of age
- Patients who's symptoms of comorbidities are well controlled
- Patients that are excited to try CBIT
- **Patients and Families that are committed to weekly or bi-weekly sessions**
- Patients and families with realistic expectations

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Comprehensive Approach

School

- **504 Plan**
- Education for teacher or peers
- Ignoring tics when possible
- Tic breaks
- Untimed tests
- Private room for tests
- Seating preference
- Flash Pass

Home and family

- **Family education**
  - Avoid pointing out tics
  - Set realistic expectation
  - Mange families emotional response to tics
  - Educate siblings

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Evaluation of Antecedents and Consequences

Antecedent; stimuli that immediately precede tics

- Internal antecedents include mood states:
  (e.g., anxiety, excitement), thoughts (e.g., "If I don't tic, it will bother me more than when I do tic"), and premonitory urges.

- External antecedents include specific settings (e.g., classroom, home, public places), activities (e.g., exercise, sedentary activities), and the presence of specific people.

Consequences; Consequence variables are outcomes that occur after tics (i.e., contingent on tics) that may make tics more or less likely to occur, within a particular antecedent context

Patient: " I always tic when I watch TV with my brother
Me: "what happens then"
Patient: " my brother makes fun of me"
Me: and then??
Patient: "my mom gets mad and sends my brother to his room

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Scales

1. The Yale Global Tic Severity Scale (YGTSS; Leckman et al., 1989

2. Premonitory Urge for Tics Scale (PUTS) By Douglas Woods, Ph.D.

3. SUD Subjective Unites of Distress Joseph Wolpe in 1969.

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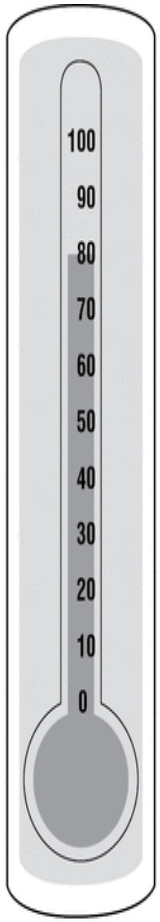
Tic Hassle/Sud Score

Tic Hassle		Suds Rating (From 0 to 100) 0 – No Distress 100– Maximum Distress	
Session #:			
Date:			
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
11.			
12.			
13.			
14.			
15.			



100 – Highest anxiety/distress that you have ever felt

90 – Extremely anxious/distressed

80 – Very anxious/distressed; can't concentrate. Physiological signs present.

70 – Quite anxious/distressed; interfering with functioning. Physiological signs may be present.

60 – Moderate-to-strong anxiety or distress

50 – Moderate anxiety/distress; uncomfortable, but can continue to function

40 – Mild-to-moderate anxiety or distress

30 – Mild anxiety/distress; no interference with functioning

20 – Minimal anxiety/distress

10 – Alert and awake; concentrating well

0 – No distress; totally relaxed

Note: "SUDS" stands for "**Subjective Units of Distress Scale.**" Physiological signs may include, for example, sweating, shaking, increased heart rate or respiration, gastrointestinal distress.

The **SUD**-level;Joseph Wolpe in 1969.

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Competing Response (CR) Training

- Choose a competing response that will prevent the tic from happening. It needs to use the same muscles but in a different way so it is not possible to do the tic at the same time. Have someone else model the competing response so you can see if any problems might occur.

- Remember to do the competing response:

a.) as soon as you do a tic

b.) as soon as you notice a warning sign.

c.) Do the Competing response for one minute or until the urge fades away

Woods et al., 2008

Examples of Competing Response

Tic	Competing Response , CR
Arm movements	Push hand down on thigh or torso and push elbow towards hip
Eye blinking	Controlled, voluntary, soft blinking at a rate of one blink per 3-5 seconds
Head jerks	Head in central position, contract neck so head tilts downwards
Mouth/facial movements	Clench jaw and press lips together
Vocal tics	Purse lips together, or breathing deeply if this is not possible

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Mindfulness, Yoga, and Breathing techniques.

Diaphragmatic or "belly breathing"

1. Lay on the floor or sit up straight with your feet supported.
2. Put one hand on your chest and the other hand over your belly.
3. Exhale all your air, until your belly pulls in slightly.
4. Imagine you have a balloon underneath your belly button that inflates as you inhale and deflates as you exhale.
5. Breath in through your nose and pull the air deep into your lungs. Feel your belly expand, like a balloon blowing up. Exhale slowly through your mouth. Feel you belly
go back in, like a balloon deflating. Say "haa" as you exhale.
6. Breath in slowly inhale to the count of 3 seconds and exhale to the count of
7. Keep your shoulders as relaxed as possible; they should not rise as you inhale

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Yoga

5. Upward Mountain

With your feet connected to the ground, bring your arms overhead into Upward Mountain, palms facing each other. Take a deep breath in and out. Saying to yourself, *"I am strong."* Feel that strength in your body.

6. / 7. Fold Forward and Upward Mountain

Now fold your body in half so your head goes below your heart and take three deep breaths. Saying to yourself, *"I feel my body stretch."* Gently bring your body up into Upward Mountain with arms overhead and bring your hands together and in front of your heart. Saying to yourself, *"I can do this."*

Do this three times, coming into Upward Mountain and bending into Forward Fold. Each time you fold forward let go of anything that is bothering you.

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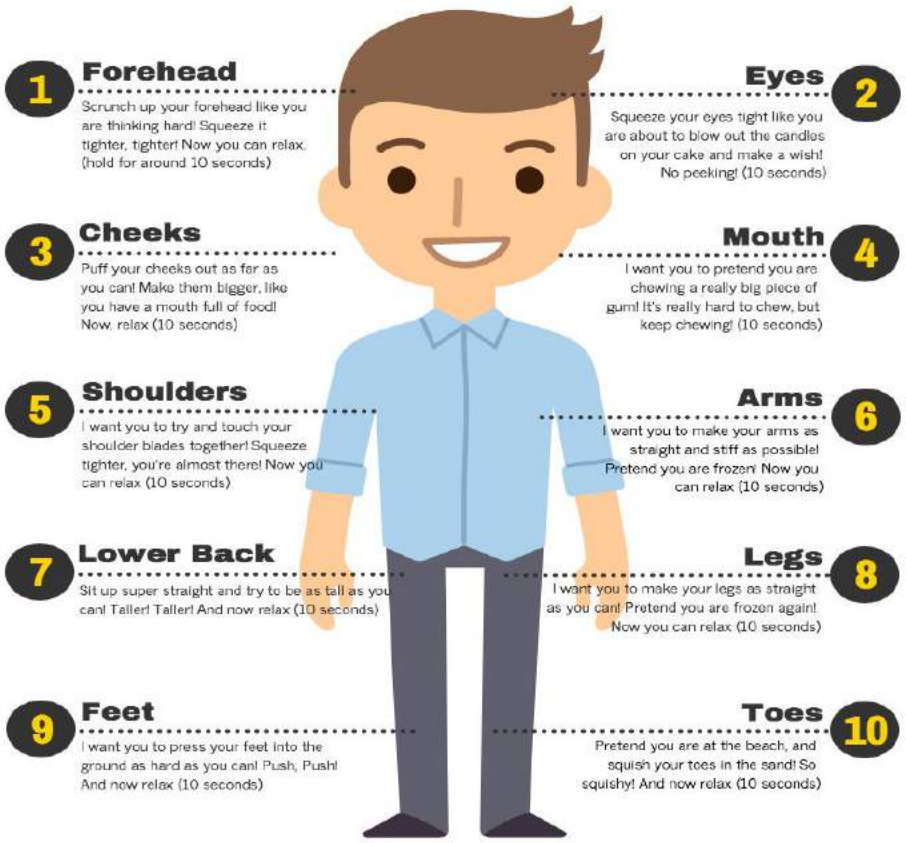
Progressive Muscle Relaxation PMR

Progressive Muscle Relaxation

Whole Body Script



Tykes of Tomorrow

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Scheduling

- To Schedule an appointment with Lauren M. Dome CPNP for CBIT patients should call 301-765-5469.
- To schedule a CBIT appointment with:

  Laura Gray, PhD

  Sarah Hornack, PhD

  Mi-Young Ryee, PhD

Call: 202-476-5980, opt. 2 for psychology

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