

Psychoeducation in TS



ESSTS

Zsanett Tárnok

Budapest, Hungary

Vadaskert Child and Adolescent
Psychiatry

2023.

Most common questions from parents of a patient

„What is a tic and what causes them?“

„What can we expect now for my child?“

„Will my child’s tics ever go away?“

“How can we help our child manage the tics so they can have a normal life?“

Recommendation

European Child & Adolescent Psychiatry (2022) 31:403–423
<https://doi.org/10.1007/s00787-021-01845-z>

REVIEW



European clinical guidelines for Tourette syndrome and other tic disorders—version 2.0. Part II: psychological interventions

Per Andrén¹ · Ewgeni Jakubovski² · Tara L. Murphy³ · Katrin Woitecki⁴ · Zsanett Tarnok⁵ · Sharon Zimmerman-Brenner⁶ · Jolande van de Griendt⁷ · Nanette Mol Debes⁸ · Paula Viefhaus⁴ · Sally Robinson⁹ · Veit Roessner¹⁰ · Christos Ganos¹¹ · Natalia Szejko^{12,13,14} · Kirsten R. Müller-Vahl² · Danielle Cath¹⁵ · Andreas Hartmann¹⁶ · Cara Verdellen¹⁷

Received: 9 March 2021 / Accepted: 7 July 2021 / Published online: 27 July 2021
© The Author(s) 2021

The European guidelines recommends embedding each treatment within a psychoeducational and supportive context

Effectiveness on tic severity

ACCEPTED MANUSCRIPT

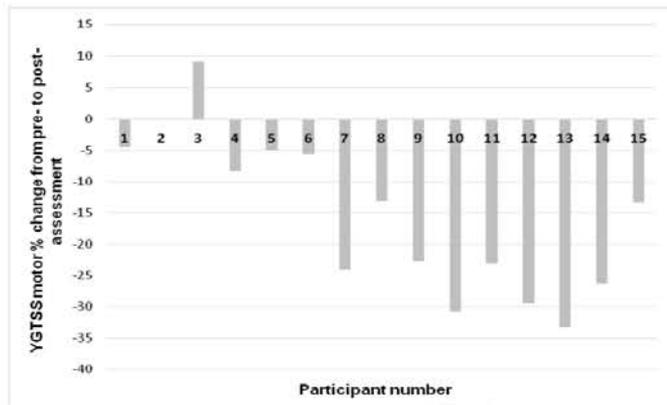


Figure 2: Case-by-case analysis of YGTSS motor tic severity percentage change from pre- to post-assessment (HRT group)

Note. Two participants who did not attend any groups were not included in this analysis.

ACCEPTED MANUSCRIPT

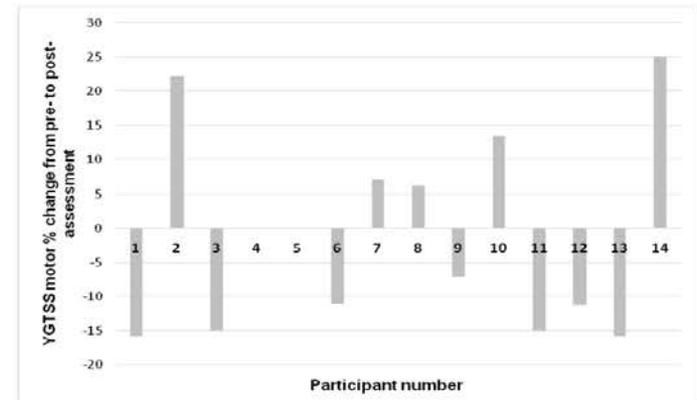


Figure 3: Case-by-case analysis of YGTSS motor tic severity percentage change from pre- to post-assessment (Educational group)

Note. One participant who did not attend sessions, and one lost to follow-up, were excluded from this analysis. Participant #2 had experienced a significant life event. Participant #14 had experienced a change in medication.

- (Yates, 2016)

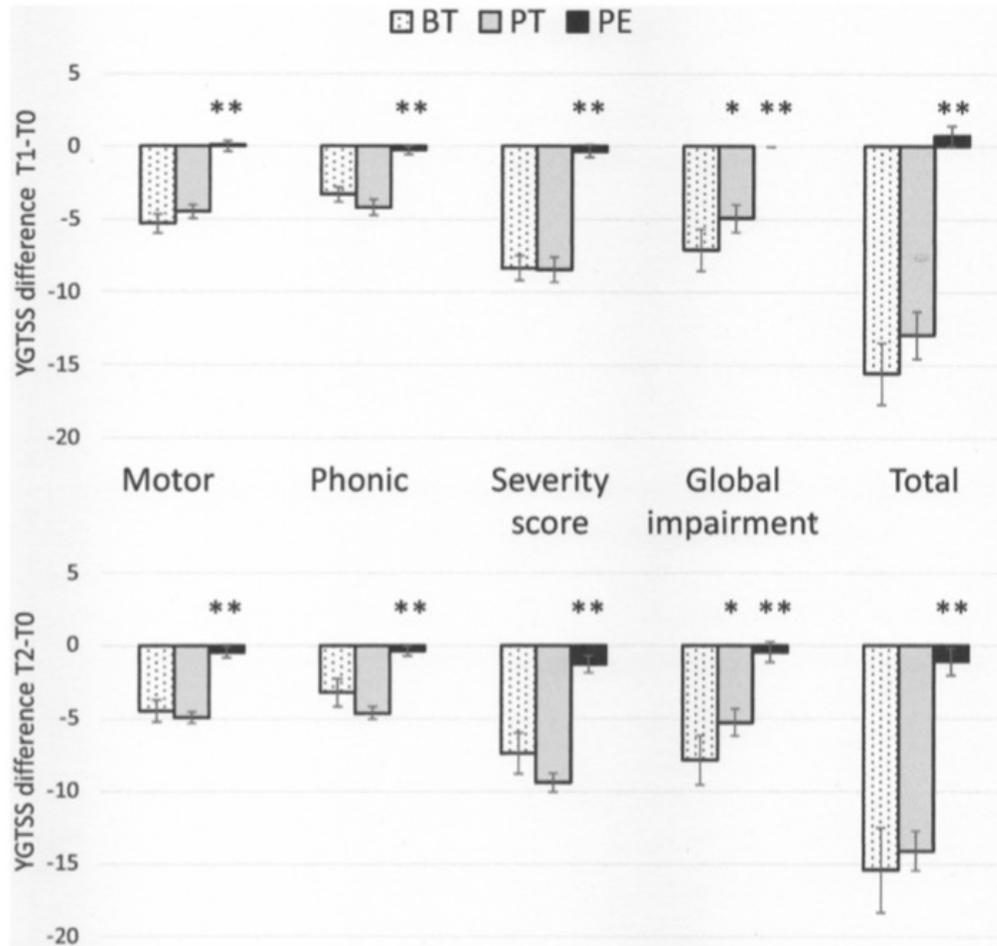


FIGURE 1 | Yale Global Tic Severity Scale score variations (means and SEs) from baseline (T0) to time 1 (T1) and 2 (T2) * $p < 0.05$, behavioral therapy (BT) vs pharmacotherapy (PT); ** $p < 0.01$, psychoeducation vs both BT and PT.

- (Rizzo, 2018)

- (Sukhodolsky, 2017)

Table 4 Rates of positive response on Clinical Global Impression-Improvement scale by tic medication status in combined sample (n = 248)

	Positive response, n (%)	Negative response, n (%)	Test, p value	Unadjusted odds ratio
Overall				
CBIT	56 (45.2)	68 (54.8)		
PST	16 (12.9)	108 (87.1)	$\chi^2 = 29.77, p < 0.0001$	5.56
Not on tic medication				
CBIT	43 (51.2)	41 (48.8)		
PST	10 (11.5)	77 (88.5)	$\chi^2 = 31.49, p < 0.0001$	8.07
On any tic medication				
CBIT	13 (32.5)	27 (67.5)		
PST	6 (16.2)	31 (83.8)	$\chi^2 = 2.74, p = 0.098$	2.49
On $\alpha 2$ agonists				
CBIT	8 (47.1)	9 (52.9)		
PST	5 (25.0)	15 (75.0)	Fisher exact, $p = 0.188$	2.66
On antipsychotics				
CBIT	3 (21.4)	11 (78.6)		
PST	1 (9.1)	10 (90.9)	Fisher exact, $p = 0.604$	2.73

Abbreviations: CBIT = Comprehensive Behavioral Intervention for Tics; PST = psychoeducation and supportive therapy.



Importance of PE

- „Appropriate education of patients and families on the phenomenology, natural history, impact on social, academic, and professional functioning, relation to environmental factors, behavioral comorbidities, and therapeutic options is a fundamental phase in the management of tic disorders”

Martino, 2017

How does psychoeducation help? A review of the effects of providing information about Tourette syndrome and attention-deficit/hyperactivity disorder

C. Nussey,* N. Pistrang† and T. Murphy‡

*Brent Older Adult Service, London, UK

†Department of Clinical, Educational and Health Psychology, University College London, London, UK, and

‡Tourette Syndrome Clinic, Great Ormond Street Hospital NHS Trust, London, UK

Accepted for publication 3 December 2012

Abstract

Tourette syndrome (TS) and attention-deficit/hyperactivity disorder (ADHD) are common neurodevelopmental disorders that often co-occur. They are both stigmatized and misunderstood conditions. This review critically appraises studies examining intervention approaches in TS and ADHD. Studies examining the

Keywords

ADHD, Tourette syndrome, ADHD, TS

Effectiveness of PE

Chapter 2

Psychoeducation About Tic Disorders and Treatment

Monica S. Wu, PhD¹ and Joseph F. McGuire, PhD^{1,2}

¹UCLA Semel Institute for Neuroscience and Human Behavior, Los Angeles, CA, United States,

²Department of Psychiatry and Behavioral Sciences, Johns Hopkins University School of Medicine, Baltimore, MD, United States

When patients, parents, and families first present to a clinician's office, they often have many questions about tics and tic disorders. These questions can cover a variety of topics such as etiology ("What is a tic and what causes them?"), clinical course ("What can we expect now for my child?"), prognosis

Needs to be measured differently

Has nontypical effects

not directly affect tic severity

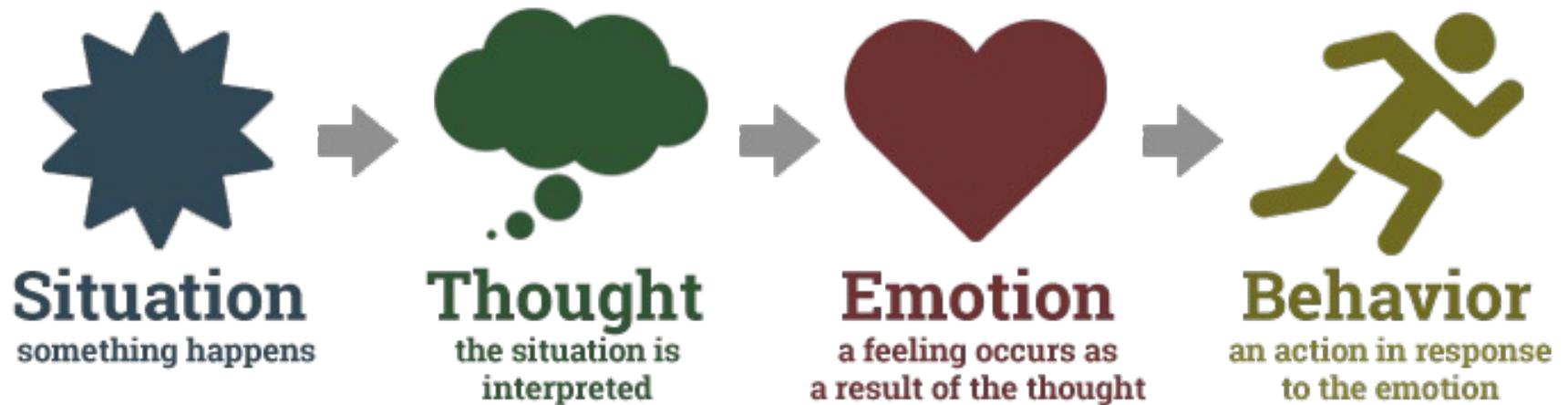
But is essential in therapy

Evidence of what specific elements to address is missing

Effectiveness of psychoeducation

- Different tools have different efficiency (video more salient than written information)
- Children require more information than adults for attitude change
- Further research is required to design more effective psychoeducational interventions

(Nussey, Pistrang, Murphy,2012)



Treatment of tics is severity-dependent

In case of very mild tics or lack of services psychoeducation alone may also be useful

Not all tics need to be treated!



Why Psychoeducation?

- Resolve misunderstanding, uncertainty and stigma in TS
- Improve knowledge, attitudes and behaviours
- Help the patient/environment to identify personal strengths
- Provide the child with the tools to explain to others (especially teachers and schoolmates)
- Help to understand the aim and the method of therapy
- Provide educators with general information about TS



Diagnosis

When?

- Right after the diagnosis

For who?

- Patient (child,adult)
- Parents / partner
- Siblings
- Teachers
- Classmates
- Relevant others



MALES ARE
4x
MORE LIKELY TO DEVELOP
TOURETTE SYNDROME



 Tourette Syndrome
Association of Australia Inc.

This infographic features a dark blue background. On the left, a white circle contains the text 'MALES ARE' above a large '4x'. To the right of the circle is a red silhouette of a person. Below the circle, the text 'MORE LIKELY TO DEVELOP TOURETTE SYNDROME' is written in white. At the bottom left is the logo for the Tourette Syndrome Association of Australia Inc., which includes a stylized figure and the organization's name.

What?

- Prevalence

Fast Fact:
A CDC study found that:

1 of every **360**
children ages 6-17 had been diagnosed with
Tourette syndrome



This graphic features a blue background with white text. The text reads: 'Fast Fact: A CDC study found that: 1 of every 360 children ages 6-17 had been diagnosed with Tourette syndrome'. On the right side, there is an overhead photograph of five diverse children of various ethnicities lying on their stomachs on green grass, all smiling and looking towards the camera.

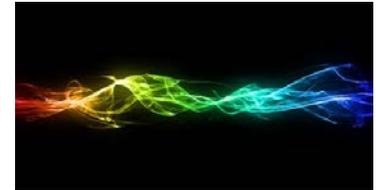
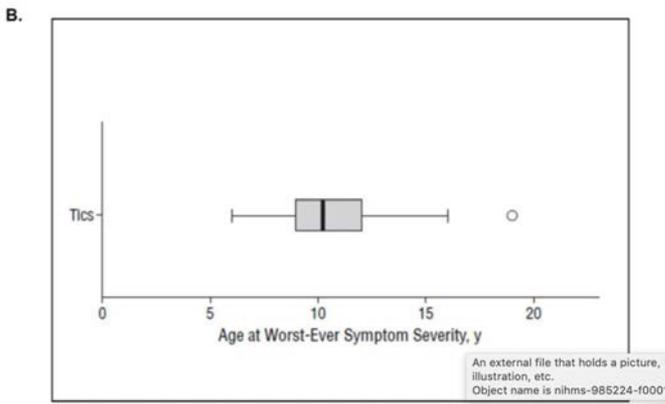
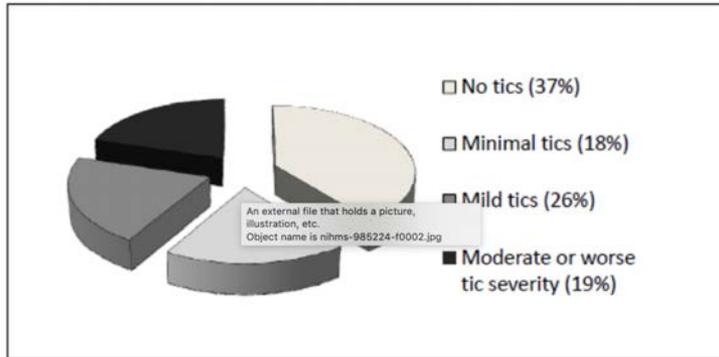


Figure 2.



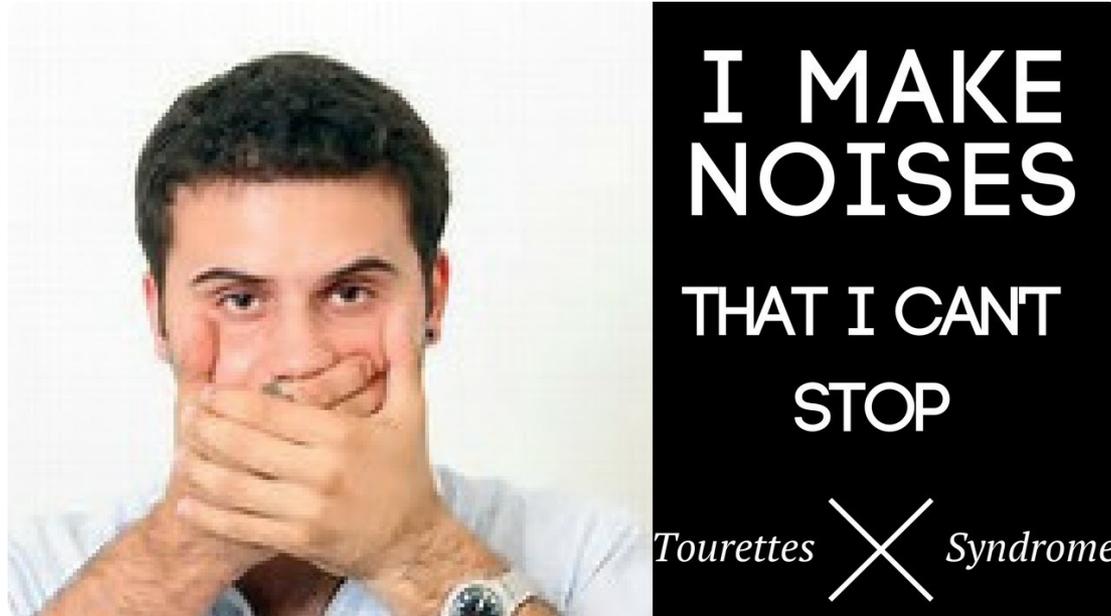
Tic Outcomes in Early Adulthood.

Tic severity in early adulthood (N=82). Adulthood tic severity class is defined by Yale Global Tic Severity Scale [Total Tic Score] (YGTSS): no tics (YGTSS: 0), minimal tics (YGTSS: 1-9), mild tics (YGTSS: 10-19), moderate or greater tics (YGTSS: ≥20). By contrast, all individuals had moderate or greater severity tics in childhood. Less than 5% of individuals reported having worse adulthood tics than in childhood. Adapted from Fig 2. in Bloch & Leckman [7].



What?

- Symptoms and natural history of TS
- Explain that tics can wax and wane over time, and the role of stress and fatigue in moderating these fluctuations
- Leckman, 2014



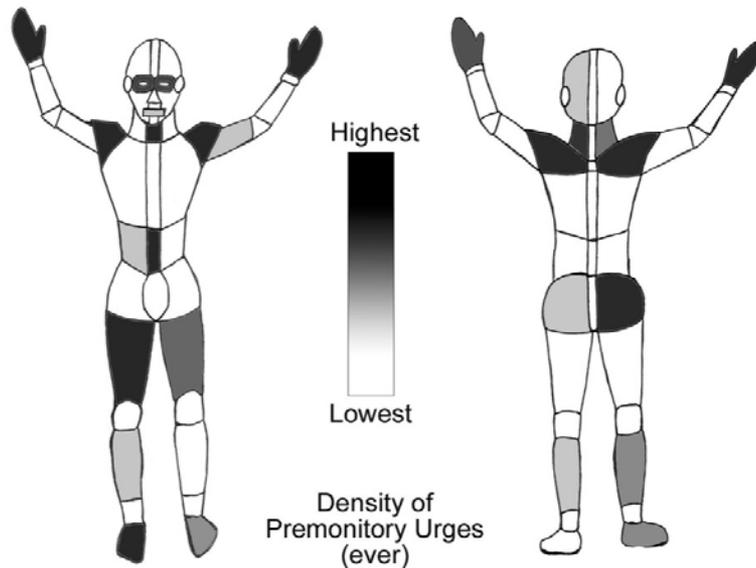
What?

- Types of tic disorders (DSM-5)
- Types of tics
- Differential diagnosis of repetitive behaviors



What?

- Internal factors: premonitory urges, stress, anxiety
- External factors: fatigue, motor activities, social situation



Leckman 1993

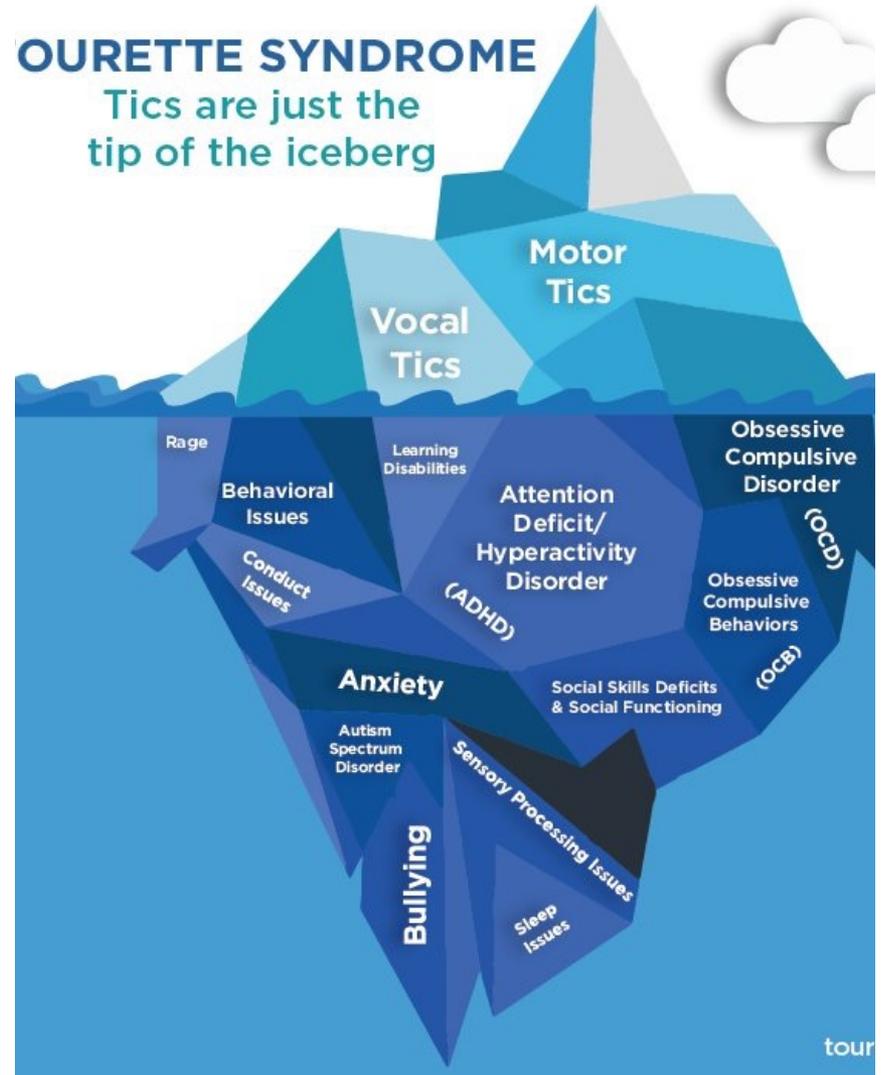
Tourette syndrome and other tic disorders. Graphic shows the relative likelihood of lifetime sensory tics in a given region, as based on self-report of patients with Tourette syndrome. Overt tics are distributed similarly.

What?

- Comorbidity

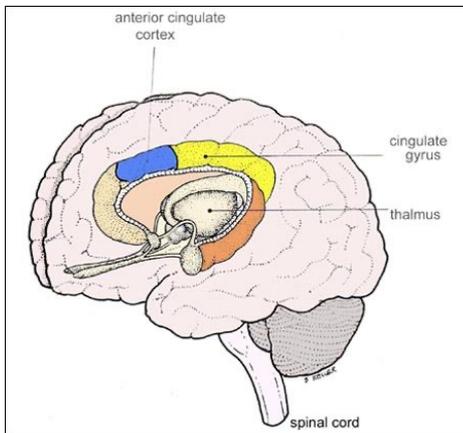
TOURETTE SYNDROME

Tics are just the tip of the iceberg



What?

- Causes of Tourette Syndrome



News Release

Friday, March 1, 2019

Major genetic study confirms that many genes contribute to risk for Tourette's syndrome

Collaborative investigation reveals genetic spectrum of tic disorders, with more risk variants leading to more severe symptoms

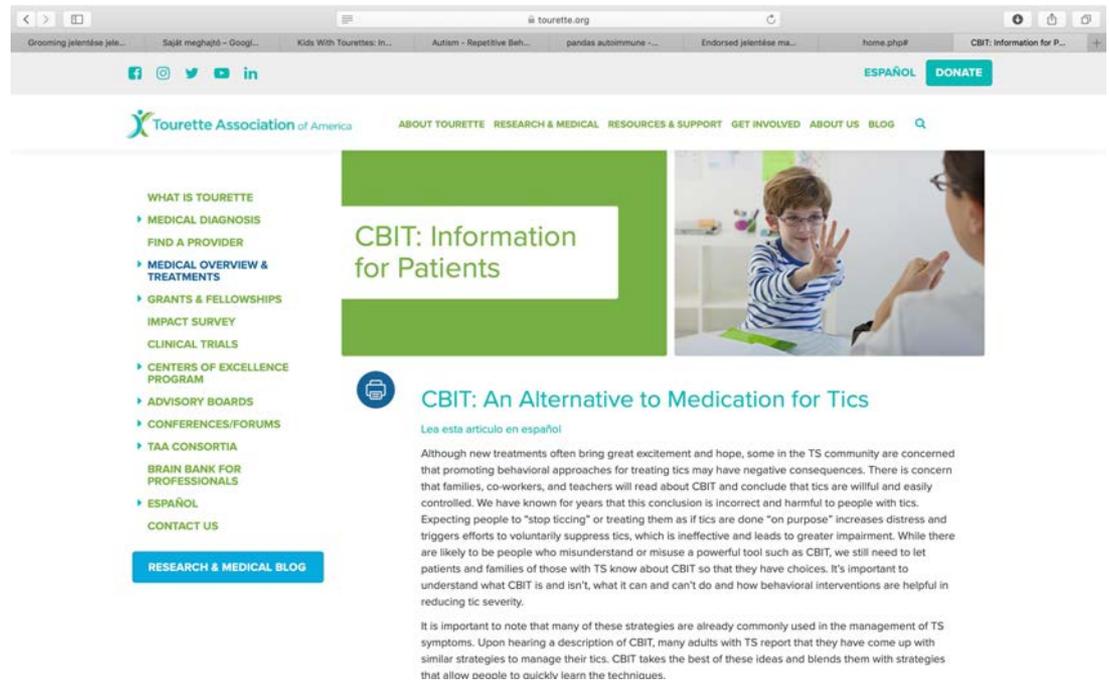
A meta-analysis of multiple studies into the genetic background of Tourette's syndrome (TS) – a neurodevelopmental disorder characterized by chronic involuntary motor and vocal tics – finds that variants in hundreds of genes, working in combination, contribute to the development of the syndrome and suggests that Tourette's is part of a continuous spectrum of tic disorders, ranging from mild, sometimes transient tics to severe cases that can include psychiatric symptoms.

The report from an international team – led by investigators at Massachusetts General Hospital (MGH), the University of California at Los Angeles (UCLA), the University of Florida and Purdue University – also describes finding that individuals with more TS-associated variants are more severely affected, raising the possibility of predicting whether children with mild tic disorders will develop full-blown TS in the future.

Am J Psychiatry. 2019 Mar 1;176(3):217-227

What?

- Treatment
- Provide patients and families with a clear understanding of the natural history and therapeutic options available for tics
- Pharmacotherapy
- Behavioral therapy



The screenshot shows the website of the Tourette Association of America. The page is titled "CBIT: Information for Patients" and features a green header with the organization's logo and navigation links. A sidebar on the left lists various resources, including "WHAT IS TOURETTE", "MEDICAL DIAGNOSIS", "FIND A PROVIDER", "MEDICAL OVERVIEW & TREATMENTS", "GRANTS & FELLOWSHIPS", "IMPACT SURVEY", "CLINICAL TRIALS", "CENTERS OF EXCELLENCE PROGRAM", "ADVISORY BOARDS", "CONFERENCES/FORUMS", "TAA CONSORTIA", "BRAIN BANK FOR PROFESSIONALS", "ESPAÑOL", and "CONTACT US". A blue button labeled "RESEARCH & MEDICAL BLOG" is positioned below the sidebar. The main content area includes a photograph of a young boy with glasses and a striped shirt, who is gesturing with his hands while talking to an adult. Below the photo is a section titled "CBIT: An Alternative to Medication for Tics" with a sub-link "Lee este artículo en español". The text discusses the benefits and challenges of CBIT, noting that while new treatments bring hope, some in the TS community are concerned about promoting behavioral approaches. It emphasizes the importance of understanding what CBIT is and isn't, and how behavioral interventions can be helpful in reducing tic severity. A final note states that many of these strategies are already commonly used in the management of TS symptoms, and CBIT blends them with other techniques to help people learn the techniques.

How?

- Educate parents on the effects of different emotional reactions to their children's tics.
- Concept of „tic-neutral environment”



How?

- Discuss the impact of tics on social, academic, or professional activities



How?

- Encourage patients and families to focus on the individual's strengths and interests while sustaining efforts to better manage tics and related disorders



How?

- Increase parents' awareness of the dynamics of stigma and discriminating attitudes toward tics within the school environment

TOURETTE SYNDROME

THE #@&%ING TRUTH

WHAT IS TOURETTE SYNDROME?

IT IS A NEUROLOGICAL DISORDER CHARACTERIZED BY REPETITIVE, STEREOTYPED, INVOLUNTARY MOVEMENTS AND VOCALIZATIONS **CALLED TICS.**

IT IS NOT RANDOMLY UTTERING SWEAR WORDS.

IN FACT, ONLY

10%

OF TOURETTE'S PATIENTS EXHIBIT THIS SYMPTOM.

WHAT SHOULD YOU KNOW?

AFFECTS APPROXIMATELY

THE **CAUSE OF**

How?

- Wherever necessary and feasible, direct the psychoeducational intervention toward the school through focused meetings in order to prevent stigma and discrimination



How?

- Discuss with adult patients the opportunity of promoting a psychoeducational intervention toward employers and colleagues



Common misconceptions



- All children with TS curse?
- Talking about tics or focusing attention on tics makes tics worse.
- Tic suppression leads to an increase in tic frequency.
- If my child can suppress his/her tics, then he/she should be able to do it all the time.
- Targeting tics with behavior therapy will make other tics or symptoms worse.
- Behavior therapy and pharmacotherapy will make tics go away.
- Once the tics go away, my child will no longer have any more problems.

Forms of PE

- Individually to patient / family



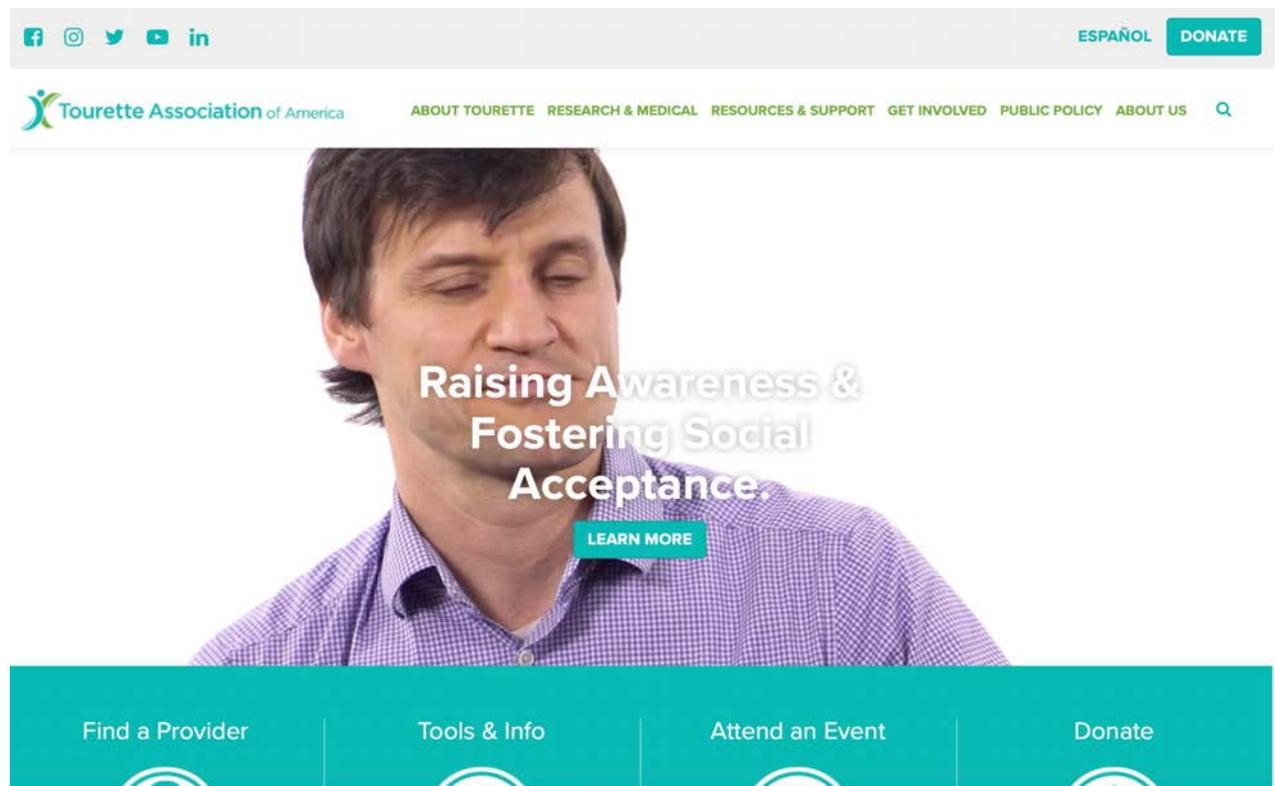
Forms of PE

- In group (support group, parents group)



Forms of PE

- Presentations



The screenshot displays the website for the Tourette Association of America. At the top, there is a navigation bar with social media icons for Facebook, Instagram, Twitter, YouTube, and LinkedIn on the left, and 'ESPAÑOL' and a 'DONATE' button on the right. Below this is a secondary navigation bar with the organization's logo and menu items: 'ABOUT TOURETTE', 'RESEARCH & MEDICAL', 'RESOURCES & SUPPORT', 'GET INVOLVED', 'PUBLIC POLICY', and 'ABOUT US', along with a search icon. The main content area features a large image of a man with his eyes closed, overlaid with the text 'Raising Awareness & Fostering Social Acceptance.' and a 'LEARN MORE' button. At the bottom, a teal footer contains four buttons: 'Find a Provider', 'Tools & Info', 'Attend an Event', and 'Donate', each with a circular icon below it.

JUMPING

Some examples of tics

Blinking

Coughing

Shrugging

touching

sniffing, sn, sn

hair flicking

..... clicking, ^{AHEM}clearing your

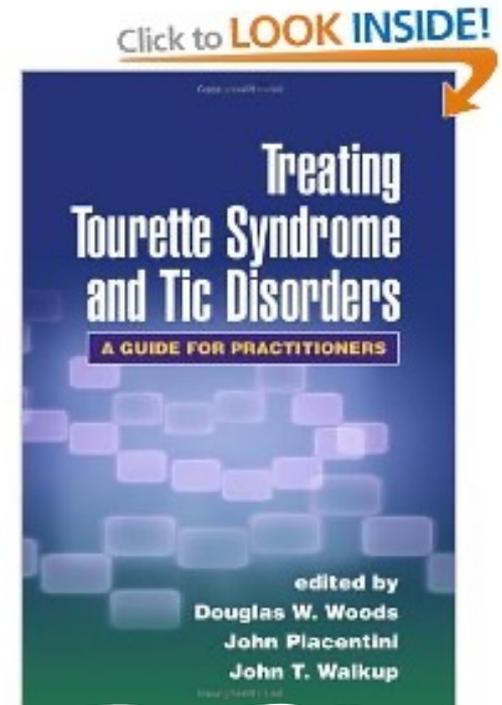
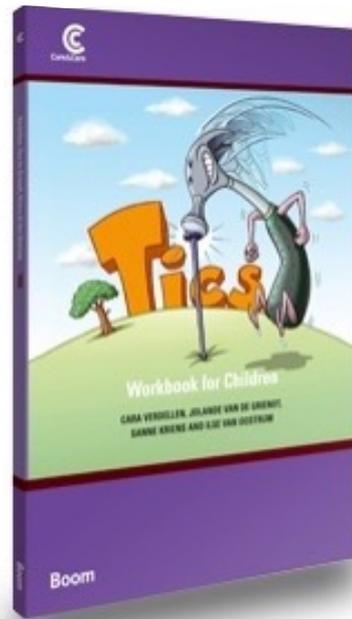
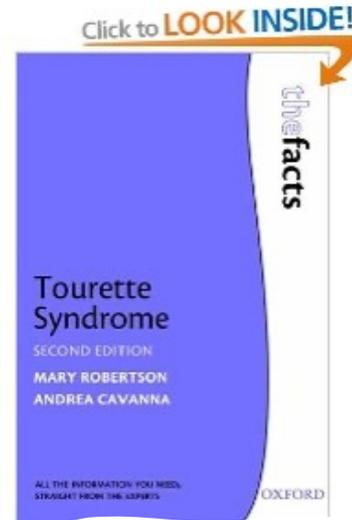
throat ^{AHEM} saying the same word over and over
over and over over and over over and over over and over over
and over over and over over and over over and over over
over and over over and over over and over over and over
and over over and over over and over AND OVER
AND OVER AND OVER AND OVER AND OVE

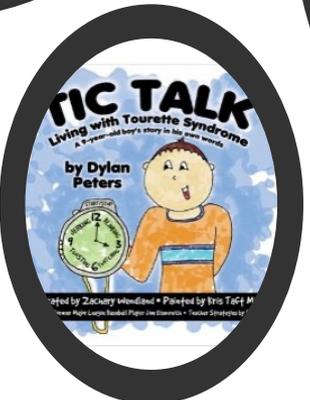
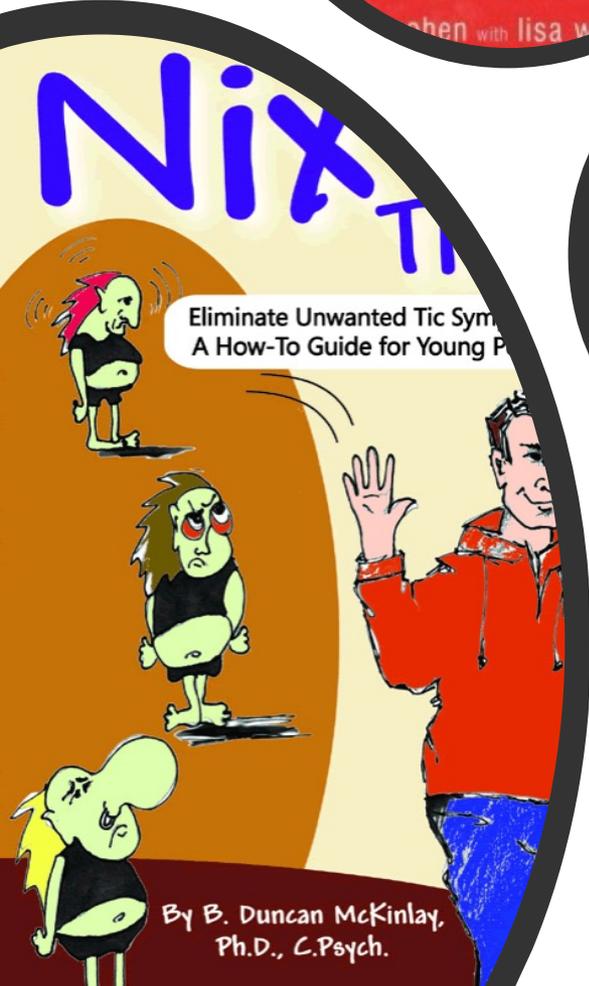
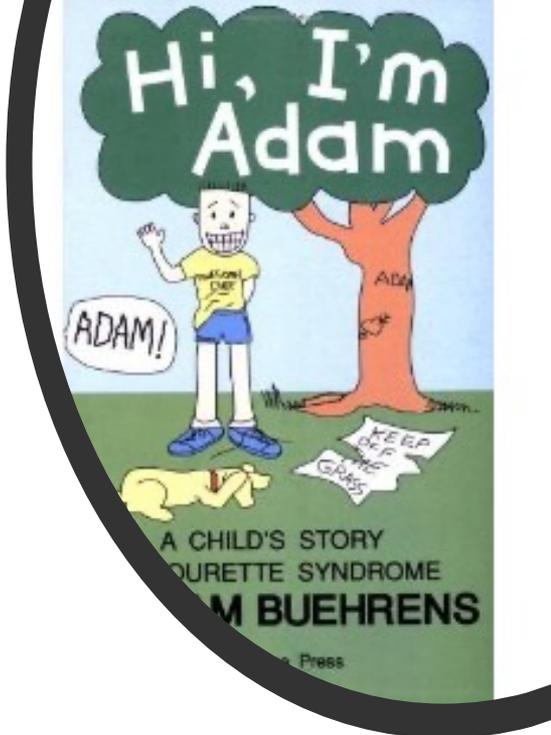
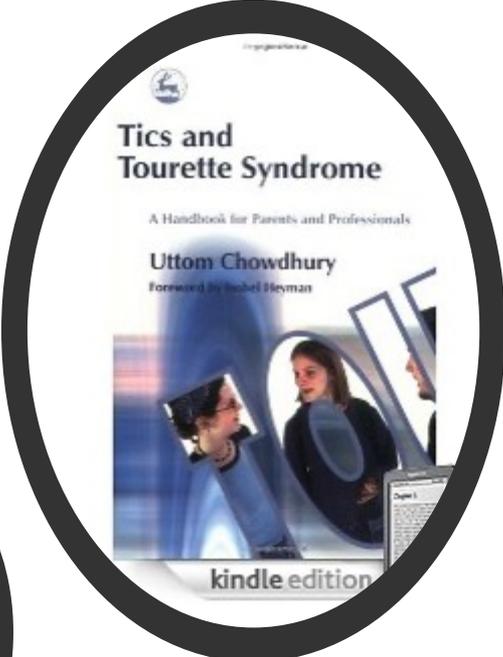
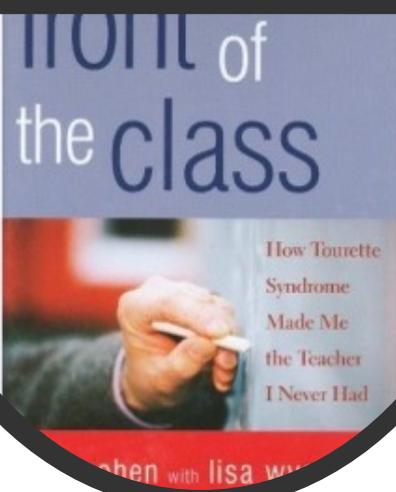
twirling

n
o
d
d
i
n
g

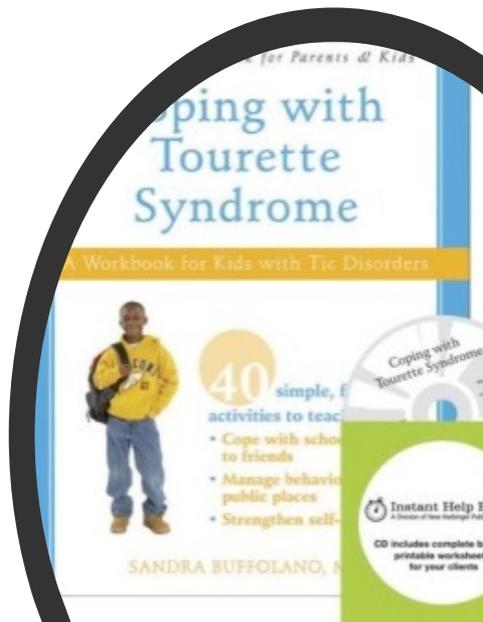
Forms of PE

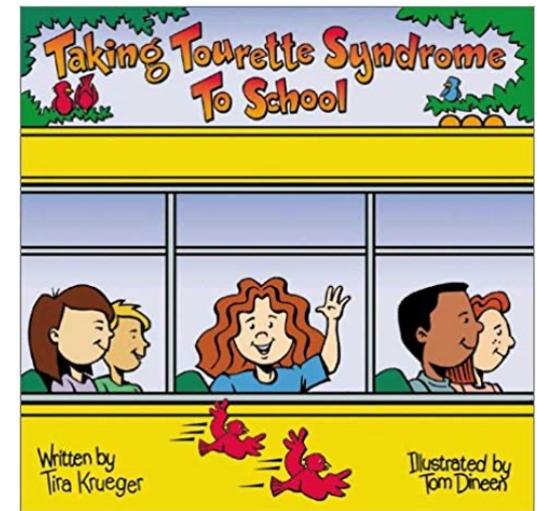
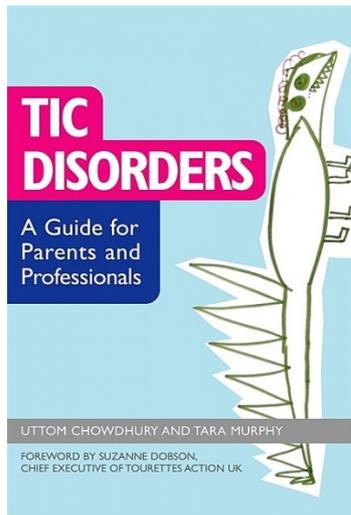
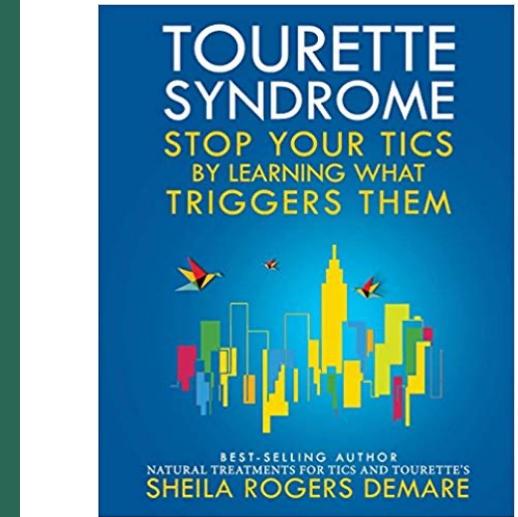
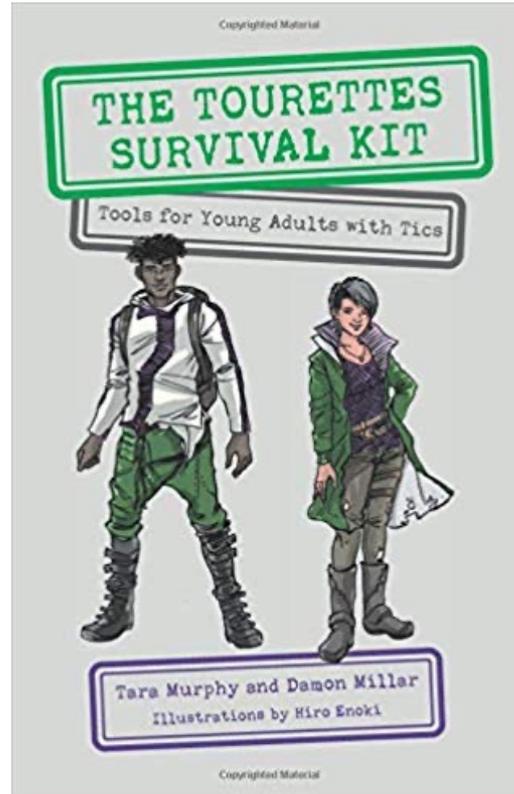
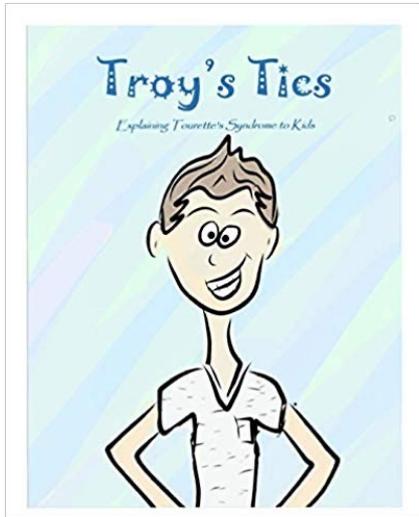
- With workbooks – also as the first phase of CBIT (Cara Verdellen, Jolande Van De Griendt et al.: Tics)





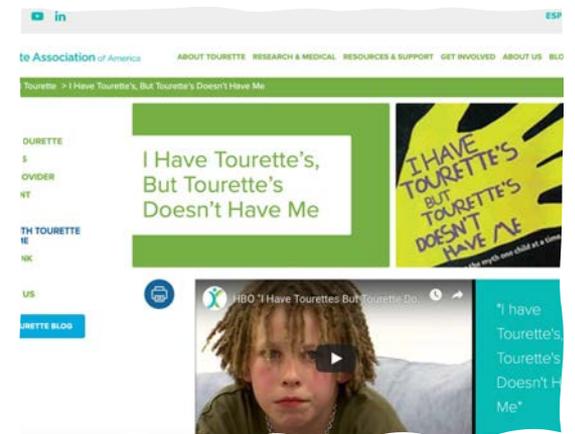
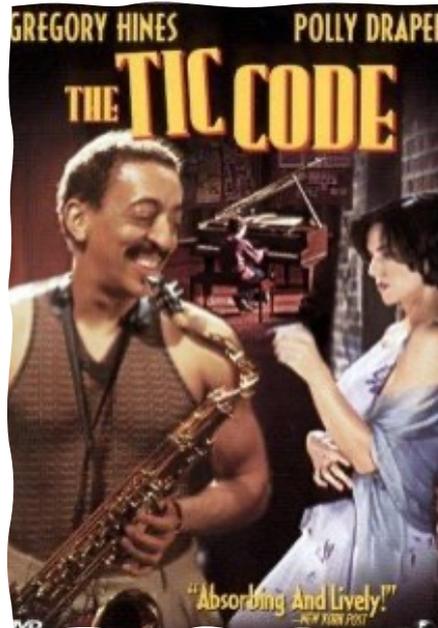
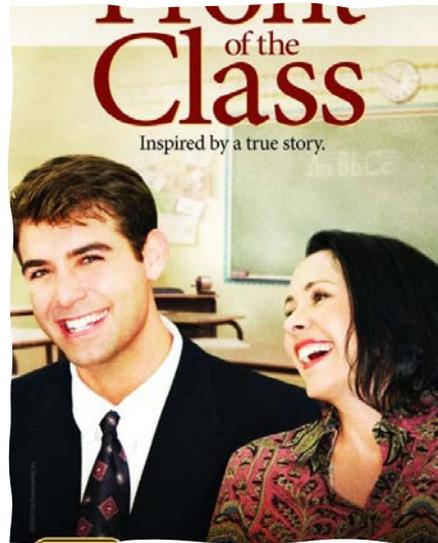
Forms of PE





Forms of PE

- Videofotage



Main message

- Give information about the natural course of TS and complex etiology
- Reduce guilt about the symptoms
- Provide support (therapy, patient organizations)
- Dispel myths in order to reduce stigma and uncertainty about TS

