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Reviews the film, I Have Tourette's, but Tourette's Doesn't Have Me by Ellen Goosenberg Kent (Director) (2005). Produced in association with the Tourette Syndrome Association, I Have Tourette's, but Tourette's Doesn't Have Me provides a glimpse into the life of children growing up with Tourette's Syndrome (TS). In this 30-min documentary, the children speak openly about living with TS and unravel a spectrum of physical tics and obsessive-compulsive behaviors that characterize the disorder. In a society in which many parents and educators do not recognize the symptoms of TS and in which the syndrome often goes undiagnosed or misdiagnosed, this carefully crafted documentary makes a long-overdue contribution. The reviewer trusts that this excellent and aesthetic production will appeal to the general public with its message of compassion and educate the masses about a syndrome for which we have medications that can help only with some of the symptoms, at the cost of unpleasant side effects. (PsycINFO Database Record (c) 2009 APA, all rights reserved)

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Recent Perspectives on Tourette's Syndrome : Breakthrough Genetics, a Broadway Musical, and an Educational Documentary

Review By: Amir Raz

Review of: I Have Tourette's, but Tourette's Doesn't Have Me
By: Ellen Goosenberg Kent (Director), (2005).

Most people who have heard about Tourette's syndrome (TS) know that it is a motor disorder involving tics and obscene vocalizations. Fewer appreciate that TS is an inherited, neurobiological disorder that is frequently misunderstood and misdiagnosed. Fewer still have insight into its debilitating emotional impact following the painful ridicule and scorn that children with TS experience from their peers or even from adults.

Produced in association with the Tourette Syndrome Association, *I Have Tourette's, but Tourette's Doesn't Have Me* provides a glimpse into the life of children growing up with TS. In this 30-min documentary, the children speak openly about living with TS and unravel a spectrum of physical tics and obsessive–compulsive behaviors that characterize the disorder. In a society in which many parents and educators do not recognize the symptoms of TS and in which the syndrome often goes undiagnosed or misdiagnosed, this carefully crafted documentary makes a long-overdue contribution. I trust that this excellent and aesthetic production will appeal to the general public with its message of compassion and educate the masses about a syndrome for which we have medications that can help only with some of the symptoms, at the cost of unpleasant side effects.

That children are featured in a documentary on TS is no coincidence. TS is a developmental neuropsychiatric disorder. The symptoms of TS typically peak in severity early in the second decade of life, but by the age of 18 years, symptoms have improved dramatically in approximately 90 percent of persons with TS, and they have remitted entirely in more than 40 percent. Adults who remain symptomatic therefore represent a minority of those who have a lifetime diagnosis of TS.

The pathophysiology of TS is believed to involve disturbances in cortico–striatal–thalamo–cortical (CSTC) circuits, a network of loops projecting from the cerebral cortex to the subcortex and back to specific regions of the cortex. These circuits, which encompass the prefrontal cortex, basal ganglia (caudate nuclei, putamen, and globus pallidus), and thalamus, subserve a wide range of functions, including modulation of neural activity that subserves self-regulation, including the inhibition of unwanted behavior. Moreover, CSTC circuits anatomically and functionally connect subcortical components with areas that subserve higher brain functions (i.e., prefrontal cortex), which suggests that, in addition to controlling motor acts, they may also participate in affective and cognitive experience. Dysfunction of these circuits also may contribute to obsessive–compulsive disorder and attention-deficit/hyperactivity disorder, which commonly co-occur in persons who have TS.

It remains unclear how adults with persistent TS differ from other individuals with TS, whose symptoms remit or substantially attenuate by adulthood. Both children and adults with TS have caudate nuclei that, on average, are reduced in volume, which suggests that these structures may be involved in tic genesis. In addition, TS is accompanied by smaller volumes of the basal ganglia in adults and some children. However, volumetric measurements of specific components of CSTC circuits differ between children and adults with TS. Children with TS, compared with healthy controls, have larger volumes of dorsolateral prefrontal and parietal cortices (DLPFC) and a smaller size of the corpus callosum, whereas adults with TS, compared with healthy controls, have smaller volumes of DLPFC and a larger corpus callosum. These volumetric increases in children with TS may represent a compensatory process that allows the behavioral inhibition of tics. Indeed, anatomical imaging studies of individuals with TS suggest that maturation of and neural plasticity within the prefrontal cortex support improved self-regulatory processes and enhanced behavioral inhibition of unwanted tics. However, these same studies suggest that the reduced volumes found in adults may be associated with insufficient compensatory response.

Whether for children or for adults, TS is not a popular condition, and individuals with TS often carry deep social scars; society can be hurtful and unaccepting. Although the entertainment business rarely puts an individual with TS at the fulcrum of a show, *In My Life*—a new Broadway musical that premiered on October 20, 2005, at the Music Box Theater in New York City—is doing just that (Brooks, 2005). Joseph Brooks, whose son has TS, is single-handedly responsible for the music, lyrics, book, and direction of this latest piece. A Broadway musical featuring TS can communicate a strong educational message to the general public. Indeed, when a production is done well—as is *I Have Tourette's*—it may aid in demystifying and humanizing what it is like to have TS. In *In My Life*, a young man with TS is in the spotlight and goes through the vicissitudes of a romantic relationship for everyone to see. Despite their widespread publicity, involuntary obscene utterances and gestures are uncommon with tic disorders, but I guess that would not make as good a sell on Broadway. Nonetheless, art connoisseurs, who probably know less about TS than about what makes a good Broadway hit, handed this musical critical reviews that may fetter its popularity.

Motor and vocal tics are outside the patient's control and are often preceded by a discomfort or premonitory urge in the affected body area that steadily increases in intensity until the person succumbs to performing the tic, thereby feeling immediate but transient relief, only to repeat anew the cycle of impulse and behavioral capitulation. Most individuals with TS have some control over their symptoms. This control, however, may just delay more severe outbursts of symptoms. Tics are experienced as irresistible and (as with the urge to blink one's eyes) eventually must be expressed. People with TS often seek a secluded spot to release their symptoms after delaying them in school or at work. Whereas the severity of tics is often exacerbated by emotional stress, fatigue, or excitement, tics often subside substantially when patients concentrate on a task or during sleep. Thus, impulse control (e.g., tantrums; verbal outbursts; or obsessive, unusual behaviors) may be a good lens through which to examine TS.

On October 14, 2005, researchers reported in *Science* about a gene mutation that appears to lead to TS in some individuals (Abelson et al., 2005). Following a genetic analysis of one boy with a known chromosomal abnormality who was diagnosed with TS, researchers were able to pinpoint a specific gene, SLITRK1, on Chromosome 13 that is associated with at least some forms of TS. This gene is expressed in several areas in the brain, especially in the prefrontal cortex and basal ganglia (i.e., brain areas involved in TS symptomatology). In healthy individuals, this gene is involved with the growth of neurons in these regions.

These are exciting times for TS research and awareness. In the course of one month we have witnessed a significant breakthrough in understanding the genetic underpinnings of the syndrome, the premiere of a Broadway musical focusing on an individual with TS, and the debut of an outstanding educational documentary. I hope that these recent steps, together with the continuing conviction and support of the Tourette Syndrome Association, will serve as good public relations—a service that, in the current absence of a cure, individuals with TS sorely need.

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