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SUBJECT: TOURETTE'S SYNDROME IN IDENTICAL TWINS

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**PURPOSE:** The purpose of this study was to better understand the nature of Tourette's syndrome in order to find its cause and hopefully to develop new treatments in the future.

**METHOD:** The neurological, psychological and radiological findings in twins suffering from Tourette's syndrome were studied. The study involved examinations by neurologists, psychiatrists and clinical psychologists. The twins were interviewed, videotaped and asked to complete questionnaires. Also, one blood test and a magnetic scan of the brain (MRI) were performed.

#### BACKGROUND INFORMATION:

Several families with twins having Tourette's syndrome were identified from NOMOTC members; however we have had no feedback from Dr. Hyde to let us know if any of these families completed the study. Three articles have been published from this research, and they are summarized in this Research Report.

Gilles de la Tourette's syndrome, or Tourette's syndrome, is a chronic neurologic movement disorder characterized by both motor and vocal "tics." The onset of symptoms is before the age of 21, with the median age at onset being 7 years. The disorder is often lifelong.

The motor tics usually involve the head or neck, but can also involve the torso, arms and legs. These motor tics are repetitive, involuntary stereotyped movements, such as forceful eye blinking or repetitively bending over and touching the ground.

The vocal tics are often short bursts of unintelligible sounds, such as sniffing, grunting or throat clearing. They can also be complex, such as uttering whole phrases repetitively. Less common seen are coprolalia (involuntary swearing), copropraxia (involuntary use of obscene gestures), echolalia (involuntary repetition of the speech of others), echopraxia (involuntary imitation of the actions of others), and palilalia (involuntary repetition of parts of the individual's own speech).

Tourette's syndrome is often associated with ADHD (Attention-Deficit, Hyperactivity Disorder), Obsessive-Compulsive Disorder, and other behavioral problems.

1. "Relationship of birth weight to the phenotypic expression of Gilles de la Tourette's syndrome in monozygotic twins," T.M. Hyde, M.D., Ph.D.; B.A. Aaronson, M.D.; C. Randolph, Ph.D.; K.C. Ricker, M.D.; and D.R. Weinberger, M.D., *NEUROLOGY*, Vol. 42, March 1992, pp. 652-657.

Dr. Hyde and his associates studied 16 pairs of monozygotic (identical) twins in whom at least one twin had Gilles de la Tourette's syndrome (TS). Their ages ranged from 8 to 26 years, with the mean age of 12.8 years. There were 4 female twin pairs and 12 male twin pairs.

The concordance rate for TS (both twins having TS) was 56%. The concordance rate for tic disorders was 94%, thus supporting a genetic basis for TS and tic disorders. Thirteen of the pairs had differing birth weights, and the twin with the lower birth weight had more severe tics in 12 of these pairs. The larger the difference in birth weights, in fact, reflected itself in a larger discrepancy in the severity of the disorder between twins. This difference could not be explained by any medical events after the twins' birth.

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**CONCLUSION:**

The findings of this study suggest that crucial events affecting the phenotypic expression (the severity of the disorder) of Tourette's syndrome occur in utero, and that the factors causing the birth weight difference also are related to tic severity.

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- 2. "Age-related prognostic factors in the severity of illness in Tourette's syndrome in monozygotic twins," T.M. Hyde, M.D., Ph.D.; E.K. Fitzcharles, B.S.; and D.R. Weinberger, M.D.; JOURNAL OF NEUROPSYCHIATRY, Vol. 5 (2), Spring 1993, pp. 178-182.

Eighteen pairs of monozygotic twins were involved in this study which tried to identify prognostic factors that may predict the subsequent severity of Tourette's syndrome (TS). Age of onset of vocal and motor tics, current severity of the tics, and the degree of functional impairment were examined.

Among the twin pairs, the one who displayed the tics at a younger age was the one most likely to have a more severe course of illness. However, among these 10 sets concordant for TS (both twins had TS), the twin who had vocal tics before the co-twin had a more severe course of the illness by only one index studied.

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**CONCLUSION:**

An early age of onset of motor tics may be the strongest predictor of a more severe life-time course of this tic disorder.

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- 3. "Tourette's syndrome - a model neuropsychiatric disorder," T.M. Hyde, M.D., Ph.D. and D.R. Weinberger, M.D., JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, Vol. 273 (6), February 8, 1995, pp. 498-501.

This article is a case report about one set of monozygotic twins for a section of JAMA titled, "Grand Rounds at the Clinical Center of the National Institutes of Health." Anthony and Brian (not their real names) were born by spontaneous vaginal delivery at full term following an unremarkable pregnancy. Brian, who was breech, delivered 8 minutes after Anthony, who was vertex. Brian weighed slightly less than Anthony, 3000 grams to Anthony's 3254 grams.

Up to two years of age their milestones were normal, and no neuropsychiatric problems were evident. At about 2 years of age, Brian was easily distracted, and his gross motor skills (large muscle movements) also appeared to be less refined than his twin. Brian developed motor tics (eye blinking) at age 6, and vocal tics (sniffing) at age 9. Anthony developed motor tics (eye blinking) at age 7, and he has never shown any vocal tics.

At 12 years and 10 months of age, the twins underwent extensive evaluation at the National Institute of Mental Health Neuroscience Center. Brian's motor tics then consisted of eye blinking, side-to-side head turning, foot stomping, and repetitively putting his fingers into his mouth. He continued to have sniffing tics (vocal tics). Anthony's motor tics consisted of eye blinking, smelling his hands, and smelling novel objects. He still had no vocal tics.

Both twins were able to voluntarily suppress their tics, and both had an increase in tic severity when they were stressed or fatigued. Brian fulfilled criteria for the diagnosis of Tourette's syndrome, while Anthony fulfilled the criteria for a chronic motor tic disorder. Blood tests confirmed that they were monozygotic. The twins' father had had childhood motor tics, and now had only occasional eye blinking and finger tapping when fatigued or stressed.

Psychiatric interviews revealed that Brian had moderate ADHD and mild obsessive-compulsive symptoms (counting rituals and checking behaviors).

On neuropsychological tests, Brian performed worse than his twin on tests of attention, visual and spatial perception, and motor function. MRI scans of the twins revealed subtle differences in the twins' brains.

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**CONCLUSIONS:**

Tourette's syndrome is a unique example of a medical disorder in which genetic and environmental factors can influence brain development and function to produce a complex neuropsychiatric illness. The clinical presentation and prognosis can be influenced by factors other than genetics. Optimizing the environment in utero (with excellent prenatal care and delivery) or addressing other as yet unidentified environmental factors may lessen the phenotypic expression of Tourette's syndrome.

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