

CDC and TSA: PARTNERS

Joint Projects in Research and Education

Historically, the Centers for Disease Control (CDC) have studied the impact of infectious diseases on public health in America. Their work in research and education has changed the way Americans regard many health-related subjects. The CDC helped to shift the allocation of medically-related funds and focused much-needed attention on some of the most important health issues of our time such as childhood vaccination and AIDS prevention. Recently, there has been increased emphasis on the disorders, conditions, and disabilities included in the mandated Children's Health Act of 2000. When Congress funded a project to study TS, a partnership was formed between TSA and one of the CDC's components, The National Center for Birth Defects and Developmental Disabilities (NCBDDD).

The project has three parts: an epidemiological study to determine the prevalence of TS; a quality of life study assessing the impact of TS on the life of adolescents and their families; and an ambitious professional education program offering critical information about diagnosis and treatment to a wide spectrum of physicians, nurses and allied professionals across the United States.

How Many People Have TS?

Associate Professor of Nursing & Child Psychiatry at Yale's Child Study Center and a consultant for the epidemiological study, Lawrence Scahill, Ph.D., believes the study will discover that TS is far more prevalent than we think. "Rather than the figure of one per two thousand, it might be as high as eight or ten per thousand and it is probably between five and eight per thousand," he says.

Knowing the prevalence of TS is "the first step to allocating funds and resources," he states. "It's essential to the understanding of the syndrome's full range. We get the wrong picture by looking only at the cases that present at clinics. These are most often the obvious cases. We have to identify those with TS who've been missed."

Dr. Scahill suggests that we imagine the occurrence of TS as a triangle with the small top portion containing the readily diagnosed. If those at the top are the only ones identified, the picture of how common TS (and its associated disorders) is may be distorted. In order to understand it, and ultimately determine its cause and cure, those in the middle and bottom of the triangle must be identified.

Part of the problem in assessing how many individuals have TS is that the definition of the disorder keeps changing. According to Dr. Scahill, "mild cases are easier to miss and many mild to moderate cases are misclassified or misdiagnosed."

The epidemiological study will go a long way toward the development of a comprehensive picture of TS in America and these

numbers will be very helpful when TSA advocates for change with Congress, health organizations, and pharmaceutical companies.

Life with TS

According to TSA President, Judit Ungar, the need for an effective quality of life study is very clear: "TS is a very intrusive, misunderstood and poorly treated disorder. Family life is disrupted, teachers are unable to teach, employers don't hire and promote, and young couples worry about having children. All these things, and hundreds of others, make life difficult for our members. A quality of life study will assist TSA in understanding how to help our people live the best life possible and overcome the very real challenges they face."

The NCBDDD has awarded Assistant Professor of Pediatrics Samuel Zinner, M.D. (University of Washington School of Medicine, Center on Human Development and Disability) and colleagues a two-year grant to study adolescents with TS. It will be a collaboration of experts in developmental-behavioral pediatrics, child/adolescent psychiatry, and neurodevelopmental psychology at the University of Washington in Seattle and the University of British Columbia in Vancouver.

Youths with TS between the ages of eleven and eighteen (with and without co-morbid conditions, i.e. OCD, ADD) and their immediate family will participate in medical and quality of life interviews. Young adults from age sixteen to twenty-two and their parents will be recruited to participate in one-time focus groups to cross-validate the youth interviews. Information from the study will be used to help develop tools for the identification and treatment of individuals with TS.

"Young folks with TS may experience unexplored effects of the disorder," Dr. Zinner explains. "These effects can be misunderstood or unrecognized not only by their teachers, peers and society, but by their families, their physicians and even by themselves! Tics are the sine qua non of Tourette Syndrome. Yet a large majority of



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