

Tourette Syndrome Study Reply Form

(All information provided is kept strictly confidential)

Name: _____

Address: _____

Best times to be reached: _____

Home phone: _____

Work phone: _____

Cell phone: _____

For the following questions, please do not include the names of the family members, but please be specific about relationship. (e.g. sibling, parent, or my first cousin on my mother's side).

1. Which members of your family have a current or past history of tics (i.e., twitches, grimacing, blinking, or noises) or been diagnosed with Tourette Syndrome?

2. Which members of your family have ever been bothered by unpleasant thoughts that kept recurring against their wishes, excessive checking, cleaning or hoarding, repeating actions that seemed senseless to them, or had other symptoms of obsessive-compulsive disorder (OCD)?

3. Which members of your family have had difficulty sustaining concentration at school or work or have been evaluated for attention deficit hyperactivity disorder (ADD or ADHD)?

Please complete and return in a sealed envelope to:

NJCTS Sharing Repository

145 Bevier Road

Rutgers University

Piscataway, New Jersey 08854-8082



**New Jersey Center for
Tourette Syndrome
and Associated Disorders, Inc.**

A collaboration among TSANJ,
Rutgers University and hospitals
throughout the state of New Jersey

For more about NJCTS programs
and referrals, please call:

908 575 7350

or visit

www.njcts.org

Rutgers University
Department of Genetics

145 Bevier Road

Piscataway, NJ 08854-8082

732-445-1027



Funded, in part, by the New Jersey Department of Health and Senior Services



**New Jersey Center for
Tourette Syndrome
and Associated Disorders, Inc.**

A collaboration among TSANJ,
Rutgers University and hospitals
throughout the state of New Jersey

Help us find the cause of Tourette Syndrome

New Jersey
Center for Tourette Syndrome
Sharing Repository

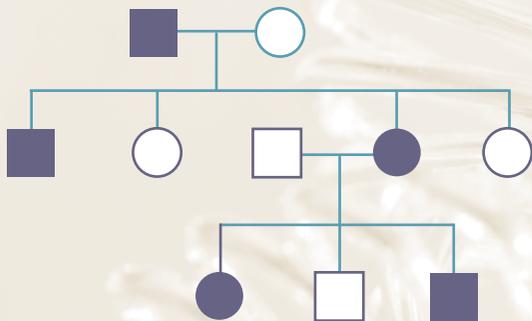
New Jersey Center for Tourette Syndrome Sharing Repository

What is Tourette Syndrome?

Tourette Syndrome (TS) is an inherited, neurological disorder characterized by repeated involuntary movements and uncontrollable vocal (phonic) sounds called tics. In a few cases, the vocal tics can include inappropriate words and phrases. Symptoms generally appear before the individual is 18 years old and can affect people of all ethnic groups; males are affected 3 to 4 times more often than females. It is estimated that 200,000 Americans have full-blown TS, and that perhaps as many as 1 in 200 show a partial expression of the disorder, such as chronic multiple tics or transient childhood tics. The natural course of TS varies from patient to patient. Although TS symptoms range from very mild to quite severe, the majority of cases fall in the mild category.

What is this study about?

The ultimate goal of this study is to identify genetic (inherited) factors that play a role in causing TS and related disorders such as Chronic Tics (CT), Obsessive-Compulsive disorder (OCD) and Attention Deficit Hyperactivity Disorder (ADHD). Previous studies suggest that Tourette Syndrome has a strong inherited component. The purpose of the research is to understand the relationship between genes, Tourette Syndrome and the associated disorders.



Our study is being done, in part, to try to find out why some individuals in a family are affected with these disorders and others are not. Therefore, both affected and unaffected members of a family are important to this study.

To achieve this goal, we established a sharing resource of clinical and genetic data, the **New Jersey Center for Tourette Syndrome Sharing Repository**, which can be accessed by qualified researchers from throughout the world. In the future, the DNA and cell lines could become part of the *National Institutes of Health Repository at Rutgers University* as a national resource. The *National Institutes of Health* would provide samples to qualified scientists around the world to study how genes cause Tourette Syndrome. We are gathering information from approximately 1000 persons who either seem to have TS or are related to someone with TS, in order to make this research possible.

Who can participate in this study?

Families may participate if:

- A member of their family has TS
- The participating family members are English-speaking

What will I be asked to do if I take part in this research study?

If you (and your family) agree to participate in this study, you will be asked to complete a survey questionnaire and to come to Rutgers University in Piscataway to do the following:

1. Review your responses on the survey questionnaire with a member of the research team and answer specific questions about your physical and mental health. This interview should take between 30-60 minutes.
2. Answer questions about your family members so that we can make a family tree. If you agree, we may ask for your permission to contact some of your relatives to invite them to also participate.

3. Have a sample of your blood (or saliva) drawn. The amount of blood to be drawn from a vein in your hand or arm is approximately 3 tablespoons, which is the amount typically drawn during a routine medical exam. The purpose of this blood sample (or saliva) is to examine whether specific segments of DNA or genes are associated with Tourette Syndrome and related behaviors.

What are the risks of taking part in this study?

Participating in any study has some risks.

Blood Draw: There is a possibility that when getting blood drawn from a vein there may be a slight pain, a small amount of bleeding or bruising at the site where the needle is inserted.

Interview and questionnaires: The information being requested in this study (such as any emotional difficulties) is of a sensitive and personal nature. Some people get upset answering personal questions. You can choose whether or not to answer those questions. The information you provide will be kept completely confidential.

Please consider participating in our study if members of your family have tics, Tourette Syndrome, OCD, or ADHD. If you would be willing to talk with a member of our professional staff, please complete and return the attached reply form in a sealed envelope to:

NJCTS Sharing Repository

145 Bevier Road
Rutgers University
Piscataway, New Jersey 08854-8082