Help us find the genes that cause Tourette Syndrome

We are members of the Tourette Syndrome Association International Consortium for Genetics (TSAICG). The TSAICG is a group of clinicians and scientists who have been working together, trying to find genes that cause Tourette Syndrome (TS).

In the last few years, we have identified some chromosomes that may hold TS genes. Now, we want to follow up those findings and identify the genes that cause TS. In order to do this, we need to collect information about tics and other symptoms and DNA from thousands of people with TS. Finding the genes that cause TS is a key step to improving diagnosis and treatment for people with TS.

We need you to help us reach this goal!
Thanks for taking the time to consider participating in our study!

If you are interested in being a part of our study, we need you to complete the short questionnaire.

In order to take the questionnaire, you must either have:

- Tourette Syndrome and be 18 or over
- or be a parent or legal guardian of a child or adolescent with Tourette Syndrome and filling it out about your child

Because we want only one person per family participating in this study, if you are a parent of more than one child with TS, please complete the questionnaire on just one of your children. If you are an adult with siblings, parents and/or children with TS, please be sure that only one person in your family completes the questionnaire.

If you, or your child, are a good fit for this study, you will be given information on how to have blood drawn. If you, or your child, are not right for this study, you or they may still be a good fit for other ongoing research into the genetics of Tourette Syndrome. If this is the case and you agree, we'll contact you.

Regardless, the information you provide will help us to learn more about those with Tourette Syndrome.
About Consent

Please read this section before starting the questionnaire. It explains in more detail what our study is about and what will be asked of you. This is called informed consent. At the end of this section, there are some questions for you to answer before starting the questionnaire. This ensures us that you fully understand what taking part in this study means before you agree to fill out the questionnaire.

If at any time you decide you do not want to participate (even if you have started to answer the questions), just let us know by checking the box next to: "I No Longer Want to Participate," which can be found on the last page of this packet. Then check "I Am Not Interested in Participating, Please Don't Contact Me Anymore" or "I Am Not Interested in Participating, But May Be Interested in Future Studies." If you ask us not to contact you anymore, we will destroy any information you may have already provided.

What Will Happen If You Participate in the Study

If you agree to participate:

You (the person with Tourette Syndrome or the parent or legal guardian of a child with TS, age 6-17) will fill out the attached questionnaire about your or your child's tics, related symptoms (including obsessive, compulsive, and attentional symptoms), and basic medical information. If you prefer, you may also answer the questions in a phone interview (see the phone numbers at the end of this section). Filling out the questionnaire either in this paper packet or by phone will take less than an hour.

If you are found to be eligible based on your responses in the questionnaire, we will contact you to explain the genetic part of the study, obtain your consent for that portion, and arrange for a blood draw.

In some cases, if you are willing, we may ask you to participate in a more in-depth clinical interview. This will take place either in person or on the phone. During this interview, you will be asked more detailed questions about your or your child's tics and related symptoms. You will also be asked more about your or your child's medical history. This will take about 1-2 hours. At the end of this consent, we will ask if you are willing to participate in the in-depth interview.

If you or your child are not eligible to participate in this study, you may be eligible to participate in future TS studies. If you are interested and agree, we will keep your information on file and possibly contact you in the future. At the end of this consent, we will ask if you are willing to be contacted about future TS studies.

What are the Potential Risks and Possible Discomforts from Taking Part in this Study?

Although unlikely, it is possible that answering questions about your or your child's symptoms can bring up uncomfortable feelings. If this becomes too difficult, you may skip those questions or end your participation at any time. If you want to talk with someone about those feelings or have questions, you can call the numbers at the end of this consent to talk to one of the doctors on the study staff. If you are filling out the questionnaire in a clinic, there is also the possibility that you may speak with a staff clinician.

In any research, there is a possible risk of loss of privacy. We do our best to keep all of your information confidential (see the next section for how we do this). The information you give us will not be entered into your medical record or shared with your doctor unless you ask us in writing to do so. Also, the only people who will know that you are participating in this study are members of our research team.

How Will You Keep My Medical Information Confidential and Protect My Privacy?

We do our best to protect all of your personal information. Everything you tell us is treated confidentially and stored securely in a password protected computer database. Also, we separate your name from your information, which is identified only by a number in order to keep it anonymous. Finally, only the researchers on this study have access to this information.

None of your information will be given to others without your written permission, except in cases where it is: necessary to protect your rights or welfare (for example, if you are injured and need emergency care); or when we are required by law (for example, if you tell us that you have abused your child).

Your name and other identifying information will not be used when the results of this study are published or presented at meetings.
Other Questions About Participation

**What are the Possible Benefits from Participating in this Study?**
You do not get any direct benefit from participating in our study. However, we hope that what we learn will help in the treatment of future TS sufferers.

**Will I Be Paid to Take Part in This Research Study?**
No. Neither you nor your family will be paid for taking part. To thank you for your time, we will give you a small gift.

**Are There Any Costs If I Take Part in this Research Study?**
No, there is no cost to you when you take part. Also, your insurance company will not be charged for any of the study activities.

**Will I Get Feedback or Results of this Study?**
You will not get back specific information about yourself (or your child) from this study. General results of the study will be published in the TSA newsletter and scientific magazines.

**Whom Do I Contact if I Have Questions About This Research Study?**
If you have any questions, please contact the project directors:

**EAST COAST**
Susan Marakovitz, Ph.D.
1-877-883-9350 (1-TS STUDY E 50)

**WEST COAST**
Eve Kupferman, Ph.D.
1-877-883-9950 (1-TS STUDY W 50)