

Tic Information Collection System (TICS) – Participant Information Sheet

RESPONSIBLE ORGANIZATIONS:

The Tourette Association of America (TAA), University of South Florida, (*tentatively*: Mount Sinai Tourette TAA Center of Excellence, Washington University TAA Center of Excellence, University of Miami Miller School of Medicine TAA Center of Excellence) and the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC).

PURPOSE:

We invite you to take part in the Tic Information Collection System (TICS), a project to examine outcomes among children, adolescents, and young adults with persistent tic disorders and Tourette syndrome (PTD/TS). This project focuses specifically on outcomes related to co-occurring disorders, suicidality, cost and service use, and transition from pediatric to adult healthcare. This project is being conducted by the Tourette Association of America Centers of Excellence and the Centers for Disease Control and Prevention (CDC). Across the country, hundreds of parents and caregivers of children and adolescents with PTD/TS, and children, adolescents, and young adults are taking part in this project, which includes a survey and a clinical assessment of current PTD/TS symptoms. Everyone's answers are important to us and will add to what we learn about how PTD/TS affects children, adolescents, and young adults with PTD/TS. The findings from the project may help identify unmet needs of children and adolescents, and young adults with PTD/TS. This information may also help children, adolescents, and young adults with PTD/TS and their families plan for the future.

PROCEDURES:

Completing the survey and clinical assessment is up to you. Nothing will happen if you decide not to complete the survey or assessment. We will take your completion of the survey as your consent to be part of this project, although sites may also require your written consent. The complete assessment including the survey and clinical assessment will take about 60 minutes, but the exact time depends on your answers. It would be helpful if you completed the entire survey. However, you can refuse to answer any question and can stop at any time.

RISKS:

There are no known risks to you for completing the survey. If you do not want to answer a question, you do not have to. All of your personal information (name, date of birth, address, and email address) will be kept private and stored separately from your other survey answers.

BENEFITS:

There is no benefit to you for completing the survey, but your answers are important to others with PTD/TS. The information may help identify the outcomes of PTD/TS and can be used to inform future activities aimed at improving the health and wellbeing of individuals with PTD/TS. We will share what we learn at meetings and through reports. We will never share information that could identify you.

CONFIDENTIALITY:

On the survey, we ask for your email address if you are interested in receiving project updates in the future. You may decline to be re-contacted now or at any time in the future.

All of the answers you provide will be kept private to the extent allowed under federal laws [Privacy Act of 1974 (5 U.S.C. § 552a)]. These laws do not prevent the project staff from reporting information needed for evaluating or auditing the project.

We will assign your survey a number. Only certain project staff will have access to your name and address information. None of your answers to survey questions will be linked to your name or address. If you choose to provide your email address on the survey, we will store your email address separately from the rest of your survey responses. In reports, your answers will be combined with the answers from everyone else that took part in the survey.

All the completed surveys and clinical information will be stored on a secure, password-protected server with limited access by the project staff.

COSTS/COMPENSATION:

We know your time is valuable. If you choose to return your completed survey via mail, we will send you a gift card worth \$20.00 to thank you for your time and effort.

RIGHT TO REFUSE OR WITHDRAW:

Your participation in this survey is up to you. Nothing will happen if you decide not to take part. You can refuse to answer any questions and you can stop at any time. If at any time you would like to have your survey answers destroyed or removed from the project, please call [site specific phone number TBD].

If you have any questions, please contact:

Site Lead/PI
Site
Contact Information

Optional second contact
Affiliation
Contact Information

If you have questions about your rights as a participant in this project, please call the CDC's Office of the Deputy Associate Director for Science at 1-800-584-8814. Leave a message including your name, phone number, and refer to Project ID 0900f3eb821bf062, and someone will call you back as soon as possible.

Contact information specific to each site to be inserted above

Site 1a: Adam Lewin, Ph.D. ABPP, University of South Florida Division of Pediatric Neuropsychiatry – Rothman Center, St. Petersburg, FL, 727-828-6420

Site 1b: Name, degree, University of South Florida Division of Pediatric Neurology, Tampa, FL, phone number, or Adam Lewin, Ph.D. ABPP, University of South Florida Division of Pediatric Neuropsychiatry – Rothman Center, St. Petersburg, FL, 727-828-6420

Site 2 (tentative, to be confirmed): Kevin J. Black, M.D., Washington University School of Medicine Tourette Association Center of Excellence, St. Louis, MO; 314-362-5041, or Katrina Hermetet, Ph.D., NCSP. Tourette Association of America. 718-224-2999, ext. 250.

Site 3 (tentative, to be confirmed): Barbara J. Coffey, M.D., M.S.; Miami Miller School of Medicine Tourette Association Center of Excellence, Miami, FL, 305-243-4136, or Katrina Hermetet, Ph.D., NCSP. Tourette Association of America. 718-224-2999, ext. 250.

Site 4 (tentative, to be confirmed): Joohi Jimenez-Shahed, M.D., Mount Sinai West, Mount Sinai Tourette Association of America Center of Excellence, New York, NY, 212-523-8335, or Katrina Hermetet, Ph.D., NCSP, Tourette Association of America. 718-224-2999, ext. 250.