

July 2, 2025

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 or Tourette syndrome (PTD/TS). This project is being conducted by the Tourette Association of America Centers of Excellence and the Centers for Disease Control and Prevention (CDC).

You were identified by the clinic as a person with PTD/TS or as the primary caregiver of a child with PTD/TS. We would like you to complete a 30-60-minute survey about your/your child's health, quality of life, and treatment of PTD/TS and related conditions, as well as a clinical assessment of PTD/TS symptoms. Children aged 9-17 years will also be asked to complete a separate survey. The information will help us identify outcomes of PTD/TS among children, adolescents, and young adults.

None of your or your child's answers will be linked to your names. Your names will never be released as having PTD/TS, or your child having PTD/TS. Your names will never be released as having completed the survey or having been asked to participate. As a reminder, you may skip any questions you do not want to answer. We know your time is valuable. If you complete the survey, you will receive a \$20 gift card.

Across the country, hundreds of parents and caregivers of children and adolescents with PTD/TS and young adults with PTD/TS are taking part in this survey. Everyone's answers are important to us and will add to what we learn about how PTD/TS affects children, adolescents, and young adults. The findings from the survey may help identify unmet needs of children, adolescents, and young adults with PTD/TS. This information may also help individuals with PTD/TS and their families plan for the future.

If you have questions about the survey, please contact [name of site project coordinator at phone number]

Thank you for completing this important survey.

Sincerely,

[add signature]

[add signature for optional 2nd contact]

PI or Site Lead
Site

Name, degree 2nd contact
Affiliation for 2nd contact

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.