

**Jennifer Stokes, BSN, RN, CCRC**  
Assistant Manager  
Clinical Nurse Coordinator

**Amyee McMonagle, BSN, RN, CCRC**  
Clinical Nurse Coordinator

**Heidi Watts, BSN, RN, CCRC**  
Clinical Nurse Coordinator

**Julie Vallati, LPN**  
Clinical Nurse Coordinator

**Jessica Beiler, MPH, CCRC**  
Regulatory Research Compliance  
Coordinator

**Erlee Meyers, BBA**  
Financial Analyst

**Heather Stokes**  
Administrative Secretary

**Cheston M. Berlin, Jr., M.D.**  
University Professor of Pediatrics  
Professor of Pharmacology

**George McSherry, M.D.**  
Associate Professor of Pediatrics

June, 2010

Dear Parents,

Researchers at Penn State Hershey Children's Hospital are working with the *Tourette Syndrome Association (TSA)* to conduct a study on the genetics of Tourette Syndrome. The study is entitled, "**A Genetic Linkage/Association Study of Gilles de la Tourette Syndrome.**"

Your child is being invited to volunteer to participate in this research study because he/she is followed at the Hershey Medical Center by either Dr. Berlin or Dr. Duda. We are recruiting youth (ages 6 to 17) who have been diagnosed with Tourette Syndrome (TS) by a doctor. Participation in research studies include only people who voluntarily choose to take part. The summary below explains this research project.

The National Institute of Neurologic Disorders and Stroke (NINDS) has awarded more than \$1.5 million to the TSA to carry out a nationwide study aimed at finding genes for Tourette Syndrome. We have already found several chromosomes that may contain Tourette Syndrome genes. Now with this new NINDS funding and support of the TSA, we can speed up our search for TS genes. We believe that finding those genes will lead to better treatments for people who suffer from tics and related symptoms.

**The study has 2 main parts:**

**Part 1: A Questionnaire about tics and related behaviors**

You (or you and your child) will answer questions on the computer about your child's tics and related symptoms. If you prefer, you can answer the questions over the phone (see phone number below). The entire questionnaire will take about 20 minutes. All information you give us will be kept confidential. After you have completed the questionnaire, your answers will be reviewed to see if you qualify for the second part of our study. This questionnaire part of the study is done through the TSA and your Penn State Hershey doctors and research staff will not see your answers.

**Part 2: A Donation of Blood**

If your child qualifies for this part of the study, you will be asked to permit your child to give a blood sample for genetic analysis. This will not cost you anything. We will arrange for a blood draw to be done either during one of your child's already scheduled clinic visits or by a member of our team at a separate visit at the Hershey Medical Center. The blood sample will be stored by the NINDS so that future researchers can also use it.

You will be informed after you (or you and your child ) complete the computer/phone questionnaire if you qualify for the blood donation. Researchers at the Hershey Medical Center will also be notified that your child qualifies for the blood donation. Someone from the research staff will either call you or come to your next clinic visit to ask you if your child is interested in participating in this portion of the study.

Finally, a small number of participants will be asked to take part in a longer interview. This can be done in person or over the phone and should take about 1 to 2 hours. Someone from the research staff will contact you to discuss your child's interest in participating in this portion of the study.

Over the last 20 years, we have learned a lot about what might cause TS. We believe that we are very close to finding some genes for TS. Please help us reach our goal of finding genes for TS.

If you would like to learn more about this research or would like to complete the questionnaire please visit our website at [www.findTSgenes.org](http://www.findTSgenes.org) or call **1-TS STUDY E 50 (1-877-883-9350 )** (East Coast recruitment center) or **1-TS STUDY W 50 (1-877-883-9950)** (West Coast recruitment center). You may also call the Pediatric Clinical Research Office at the Penn State Hershey Medical Center with any study questions **717-531-5656**. Please understand that if you call us, you are in no way required to take part in this study.

Sincerely,

Dr. Cheston Berlin, MD  
Dr. Laura Duda, MD  
Jessica Beiler, MPH  
Amyee McMonagle, BSN, RN