

## **SUPPORTING STATEMENT PART B**

for

Tourette Syndrome National Education and Outreach Program

### **B. Collections of Information Employing Statistical Methods**

#### **B. 1. Respondent Universe and Sampling Methods**

The universe of respondents is all participants of education programs, workshops, and educational resources over the 3 year period of the cooperative agreement. Every program participant and recipient of educational resources will be invited to complete the evaluation. Based on previous information, of the participants of education programs, approximately 72% usually complete the evaluation form at the end of the program. Among recipients of educational materials, usually 7% respond to the invitation to complete an evaluation survey online. Among participants of the physician training and CBIT workshops, usually 60% complete the evaluation. The 3 month follow up for Physician Training and CBIT is new and therefore estimates for completion are not clear. The rate of completion for surveys of educational resources is low, however, these data are still useful because those who responded in the past have provided useful information about questions raised by the materials, or need for further information. Data will not be weighted, only summary descriptive data will be reported.

#### **B. 2. Procedures for the Collection of Information**

Every program participant will receive an evaluation form to complete at the end of each program from the presenter or from a TSA staff member assisting with organization. Participants of the Physician Training, CBIT, and Educator programs will also be given the TS knowledge pre-test at the beginning of the training as well as the end of the training. To link the pre-test to the post-tests, participants will be assigned a temporary unique number that links the two forms, but that is otherwise not linked with any information about the participant. In addition, participants of the Physician Training and CBIT programs will receive an email invitation to complete an online survey for the 3 month follow up evaluation.

For review and planning, the data will be summarized across respondents for each workshop. For rating and categorical scales, the percent of each answer chosen compared to the total number of answers given will be reported per item. For pre- and post-test, the change in correct responses will be calculated and then summarized. Further, for the annual report, the data will also be summarized for all respondents for a given form, to provide an overall descriptive summary of answers. For same or similar items that are collected on multiple forms, descriptive summaries will also be provided (e.g., overall percent of responses that indicate the content of the workshops or resources was new to the respondent).

#### **B. 3. Methods to Maximize Response Rates and Deal with Non-response**

The program presenters will include a statement of the purpose of the evaluation and the need for collecting this information to improve programs and resources. Participants for the Teacher/Educator and Medical Program workshops are also offered to receive Continuing Education Credits (CEU), for which completing the evaluation is a requirement (OMB No. 0920-

0017). Since the completion of the evaluation is conducted anonymously, it is not feasible to deal with non-response.

#### **B. 4. Tests of Procedures or Methods to be Undertaken**

The workshop evaluation forms have been adapted from the evaluation forms used as part of OMB No. 0920-0572, Health Message Testing System, and from portions of the evaluations used for the CEU provided for the teacher education workshops, OMB No. 0920-0017. See Attachment D for a description of retained or changed items in these forms.

#### **B. 5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data**

Questionnaires and protocols were developed in collaboration with and are reviewed by staff of the National Center on Birth Defects and Developmental Disabilities and by members of the TSA Scientific Advisory Board:

##### CDC collaborators

*Rebecca H. Bitsko, Ph.D., Behavioral Scientist, Child Development Studies Team,  
DHDD/NCBDDD/CDC, 1600 Clifton Road, MS E-88, Atlanta, GA 30333 404-498-3556,  
dvk2@cdc.gov*

*Jeannette Bloomfield, M.S., Public Health Analyst, Child Development Studies Team,  
DHDD/NCBDDD/CDC, 1600 Clifton Road, MS E-88, Atlanta, GA 30333 404-498-3003,  
JBloomfield@cdc.gov*

*Angelika H. Claussen, Ph.D., Research Psychologist, Child Development Studies Team,  
DHDD/NCBDDD/CDC, 1600 Clifton Road, MS E-88, Atlanta, GA 30333 404-498-3557,  
AClaussen@cdc.gov*

*Ruth Perou, Ph.D., Team Leader, Research Psychologist, Child Development Studies Team,  
DHDD/NCBDDD/CDC, 1600 Clifton Road, MS E-88, Atlanta, GA 30333 404-498-3005,  
RPerou@cdc.gov*

##### TSA collaborators: staff and advisors

*Barbara Coffey, M.D., M.S., Director, Tics and Tourette Clinical and Research Program;  
Associate Professor, NYU School of Medicine, Department of Child and Adolescent  
Psychiatry, 577 First Ave, New York, NY 10016, Barbara.coffey@nyumc.org*

*Leon Dure, M.D., Professor of Pediatrics & Neurology, 1600 Seventh Avenue, South, 314 CH,  
Birmingham, AL 35233, 205-996-7850 – Fax: 205-996-7867, ldure@peds.uab.edu*

*Kathy Giordano, B.A., TSA Education Specialist, Tourette Syndrome Association, 42-40 Bell  
Blvd, Suite 205, 718-224-2999, Bayside, NY 11361*

*Patricia Finnerty, M.S., Senior Project Developer, Tourette Syndrome Association, 42-40 Bell  
Blvd, Suite 205, Bayside, NY 11361, 718-224-2999, Patricia.finnerty@tsa-usa.org*

*Gary Frank, ACSW, LCSW, Executive Vice President, Tourette Syndrome Association, 42-40  
Bell Blvd, Suite 205, 718-224-2999, Bayside, NY 11361, gary.frank@tsa-usa.org*

*Ellen Meyers, M.S., M.Ed., TSA Education Committee Member, Tourette Syndrome Association, 42-40 Bell Blvd, Suite 205, Bayside, NY 11361, 718-224-2999, esmeyers@charter.net*

*Jonathon Mink, M.D., Ph.D., Chief, Child Neurology, University of Rochester Medical Center, 601 Elmwood Ave., Box 631, Rochester, NY 14642, Jonathan\_Mink@URMC.Rochester.edu*

*Judith Peterson, B.S., TSA Education Committee Member, Tourette Syndrome Association, 42-40 Bell Blvd, Suite 205, 718-224-2999, Bayside, NY 11361*

*Nancy Quinn, B.A., Project Developer, Tourette Syndrome Association, 42-40 Bell Blvd, Suite 205, Bayside, NY 11361, 952-920-2383, tsa.quinn@earthlink.net*

*Dan Rostan, Vice President Field Services, Tourette Syndrome Association, 42-40 Bell Blvd, Suite 205, Bayside, NY 11361, 718 224 2999, dan.rostan@tsa-usa.org*

*John Walkup, M.D., Vice Chair, Department of Psychiatry, Director, Division of Child & Adolescent Psychiatry, Weill Cornell Medical College & New York Presbyterian Hospital, 525 E. 68th Street, Room F-1100, New York, NY 10065, 212-746-3995, jtw9001@med.cornell.edu*

*Douglas Woods, Ph.D., Professor of Psychology, University of Wisconsin, Milwaukee, Box 413, Milwaukee, WI 53201, 414-229-5335, dwoods@uwm.edu*

*Samuel H. Zinner, M.D., Associate Professor – Pediatrics, University of Washington CHDD - Box 357920, Seattle, WA 98195-7920, 206-598-3986, szinner@u.washington.edu*