

July 2011

Supporting Statement A

for

Tourette Syndrome National Education and Outreach Program

New Request

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## **A. Justification**

### **A. 1. Circumstances Making the Collection of Information Necessary**

#### **Background:**

This data collection activity is a new request and is authorized by Section 301 of the Public Health Service Act (42 U.S.C. 241; Attachment A1). The request is for OMB approval for 2 years of information collection. The proposed information collection is also consistent with the aims of the Children's Health Act of 2000 (Attachment A2) which mandates NCBDDD to promote research on the causes, diagnosis, early detection, prevention, control, and treatment of Autism and related developmental disorders. Tourette Syndrome is a neuro-developmental disorder of considerable interest to NCBDDD. The proposed evaluation of Tourette Syndrome education activities is also consistent with the CDC mission to promote health and quality of life by preventing and controlling disease, injury, and disability by a variety of means, including educating professionals and the public on this disorder.

Tourette Syndrome (TS) is an inherited, neurological movement disorder characterized by involuntary motor and vocal tics that typically manifest during childhood. The exact number of people with TS is unknown. Data from the 2007 National Survey of Children's Health resulted in an estimate that 3 out of every 1,000 U.S. children (about 148,000) 6 through 17 years of age had ever been diagnosed with TS (Centers for Disease Control and Prevention 2009). Higher prevalence estimates obtained from community studies likely mean that there are a significant number of individuals who have TS, but who have not been diagnosed (Comings, Himes et al. 1990; Mason, Banerjee et al. 1998; Kadesjo and Gillberg 2000; Khalifa and von Knorring 2003; Stefanoff, Wolanczyk et al. 2008). TS is three to four times more common among males than females (American Psychiatric Association 2000; Khalifa and von Knorring 2003; Scahill, Sukhodolsky et al. 2005; Centers for Disease Control and Prevention 2009).

There is no known cure for TS. The disorder may express itself with mild symptoms for some, and severe symptoms for others. Depending on the severity and duration, tic symptoms may also be diagnosed as chronic motor or vocal tic disorder, transient tic disorder, and tic disorder not otherwise specified. TS is associated with a high rate of co-morbid conditions. Among children diagnosed with TS, about 80% also have been diagnosed with at least one additional mental health, behavioral, or developmental condition (Scahill, Sukhodolsky et al. 2005; Centers for Disease Control and Prevention 2009). The two most common conditions are attention-deficit/hyperactivity disorder (50% to 70%) and obsessive-compulsive disorder (30% to 50%) (Leckman, Zhang et al. 1998; American Psychiatric Association 2000; Kadesjo and Gillberg 2000; Scahill, Sukhodolsky et al. 2005; Janik, Kalbarczyk et al. 2007; Centers for Disease Control and Prevention 2009). People with TS also have higher rates of depression, anxiety, and learning disabilities (Kadesjo and Gillberg 2000; Janik, Kalbarczyk et al. 2007). Many people with TS have more than one co-occurring condition (Freeman 2007; Janik, Kalbarczyk et al. 2007).

There is a lack of accurate treatment information among the medical community as well as the general public, and a limited number of expert physicians, all resulting in significant under-diagnoses, misdiagnoses, and inadequate treatment with scant follow-up care. It is estimated that a significant proportion of Americans with TS either go undiagnosed or the clinical care they do

receive is inadequate. The under-diagnosis of individuals with TS may be a result of a lack of knowledge by health professionals (Marcks, Woods et al. 2004), and cases missed because of mild symptoms (the majority of cases of TS are described as mild) (Kadesjo and Gillberg 2000; Scahill, Sukhodolsky et al. 2005; Centers for Disease Control and Prevention 2009). In addition, tic symptoms and severity change over time, which may make both diagnosis and treatment more challenging (Jankovic 1997). A delay from symptom onset to diagnosis has been reported in the literature (Erenberg, Cruse et al. 1986; Khalifa and Von Knorring 2005; Janik, Kalbarczyk et al. 2007), and often anecdotally by families, further suggesting challenges with the recognition and diagnosis of TS.

In addition to challenges with diagnosis and treatment, individuals with TS are also met with stigma, and symptoms of tics and co-occurring conditions can impact the success of an individual in educational settings, in peer relationships, and can place stress on the entire family (Bawden, Stokes et al. 1998; Packer 2005; Ginsburg and Kingery 2007).

Tourette Syndrome Association, Inc. (TSA). The TSA is a national membership organization addressing the needs of children, families and individuals affected by TS since 1972. A main mission is to provide authoritative scientific and medical knowledge to physicians, allied professionals and scientists working in clinical practice and research and to educators and professionals in school-based settings, as well as to persons with TS, their families and the community. Over the years, the TSA developed a national network of physicians, allied medical and other professionals including researchers and clinicians, thirty chapters and 150 support groups.

TSA monthly statistical data consistently indicate that the greatest number of inquiries TSA receives from individuals and families continue to be about new diagnoses, the need for a diagnosis and improved treatment, as well as how to locate a physician to treat and manage the condition. The next most frequent area of inquiry from affected families who contact TSA, concerns managing and accommodating the condition in school settings.

Over the past six years, TSA and the U.S. Centers for Disease Control and Prevention (CDC) have engaged in a program partnership which has facilitated and enhanced outreach efforts to provide accurate information on TS to a wide national population. The TSA/CDC partnership has provided over 434 evidence-based training and health education programs about TS on both national and local levels in every state, to over 27,000 professionals. Health education programs have been developed for 3 groups of audiences: Health professionals, education professionals, and people with TS and their families. The format includes general education programs for the 3 groups, as well as two more in-depth medical training programs for physicians on TS and on the Comprehensive Behavioral Intervention for Tics (CBIT) treatment. Additional activities have included development and dissemination of a range of professional health education materials in various formats and extensive website development including several unique video and audio programs. Factoring in initiatives such as exhibits and targeted mailings to professionals, the program has reached over 60,000 professionals.

The proposed evaluation surveys (Attachment C) are an important component of the health education programming, intended to document whether the programs met the health education objectives and the needs of the audience for health related information specific to TS.

## **1.1 Privacy Impact Assessment**

### **i. Overview of the Data Collection System**

The TSA will be collecting evaluation information on the series of workshops and resources produced to educate three groups of participants: Health professionals, Education professionals, and the public, which includes persons with TS and family members of persons with TS in addition to the general public. The following components will be evaluated: 1) Medical Program (workshop), 2) Teacher Education Program (workshop), 3) Family Education Program (workshop), 4) Physician Training Retreat (workshop), 5) CBIT training (workshop and online formats) and 6) Education Resources (e.g., DVDs and brochures).

The following evaluation methods will be employed: Evaluation surveys in pencil-and-paper format will be given to all participants of TS education workshops at the end of the workshops as well as all consumers of TS health education resources once they have received those resources. The surveys will be administered by the workshop organizers. In addition, participants of full day medical training workshops will also be given a pre-post-test of knowledge in pencil-and-paper format, and a 3 month follow up survey using an online survey tool to assess the impact of the education programs on behavior. The online version of the CBIT training will be evaluated using an online survey tool. Education resources such as DVDs and brochures will also be evaluated using an online survey tool. The invitation to complete the online survey tool will be sent to the participants via email.

### **ii. Items of Information to be Collected**

For the purpose of the evaluation, no individually identifiable information is being collected. The TSA routinely collects contact information from participants to inform them of upcoming education opportunities, and to contact participants of medical training workshops 3 months after the workshops to invite them to participate in the follow up survey. None of the identifying data will be linked to any evaluation information collection.

### **iii. Identification of Website(s) and Website Content Directed at Children Under 13 Years of Age**

No website content directed at children under 13 years of age is involved in this information collection request.

## **A. 2. Purpose and Use of Information Collection**

The goal for TSA is to provide quality services and products for this systematic educational outreach effort. In order to assess whether the workshops and materials reach the intended goals, information must be collected to assess whether participants are satisfied with these workshops and materials and whether their knowledge and behavior have changed. Information will be collected after participants in the educational efforts have completed workshops or completed the review of materials. Information from participants of full day medical training workshops will also be collected for a 3 month follow up. Thus, the information collection will be a one-time event for participants other than those in the medical training workshops, who will be participating twice, once at the end of the training, once 3 months later. The results from the surveys regarding the effectiveness of the messages provided in the workshops will be used to

identify strengths and weaknesses in the health education programs and products and to identify areas of improvement and expansion. Each evaluation instrument addresses the key goals of each workshop and thus it will be possible to identify if any of the goals are not met sufficiently. The information gathered by the surveys will assist TSA in program planning, including revisions to the curriculum and the workshop delivery. Without this program evaluation component, it will not be possible to ascertain whether the programs are effective in improving the lives of people with TS.

## **2.1 Privacy Impact Assessment**

For the purpose of the evaluation, no individually identifiable information is being collected. Contact information will only be collected to request follow up survey completion from the participants of the medical training workshops. Data collection, including for the 3 month follow up, will be anonymous; the evaluation forms themselves will have no identifying information or any link to names or contact information. Contact information will be stored in a secure manner and separate from the data. Therefore the data collection is not anticipated to have any impact on the respondent's privacy. Descriptive summaries of the responses will be used for quality control reports and submitted to CDC. None of the contact information will be submitted to CDC.

### **A. 3. Use of Improved Information Technology and Burden Reduction**

For practical purposes, the evaluation forms for the workshops will be administered via pencil-and-paper questionnaire. The evaluation of the educational resources as well as the 3 month follow up surveys for participants of the CBIT and Physician Training workshops will be conducted via web-based survey forms. This means that 30% of data collection (1000 of 4450 surveys) will be taking place via advanced information technology. See Burden Table in section A12. This will reduce the burden to the participants by allowing instant submission of responses and by not requiring responses to be returned via mail. It is not feasible to conduct the evaluation at the end of the workshops electronically, since computer access cannot be made available and response rates for surveys to be completed later from a different location rather than immediately at the end of the workshop would be significantly lower.

### **A. 4. Efforts to Identify Duplication and Use of Similar Information**

There are no similar data. Extensive literature reviews on all data collected on children and families affected by TS has shown that this information is not available elsewhere. The workshops held by TSA are unique and not held by other organizations, and are continuously updated, so ongoing data collection on quality of workshops is needed.

### **A. 5. Impact on Small Businesses or Other Small Entities**

No small businesses will be involved in this data collection.

### **A. 6. Consequences of Collecting the Information Less Frequently**

The information will be collected at the end of the workshops for each participant, as well as after a 3 month follow up period for participants in the full day medical training workshops. Thus, the information collection will be a one-time event for participants other than those in the

medical training workshops, who will be participating twice, once at the end of the training, once 3 months later. It is important to assess the effectiveness of the health messages for all participants, and it is necessary to conduct a follow up survey to assess whether the messages were effective to allow change in actual behavior in medical professionals via the health messages included in the training workshops. Collecting information less frequently would not allow accurate evaluation of the workshops and educational resources.

#### **A. 7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5**

There are no special circumstances with this information collection package. This request fully complies with the guidelines of 5 CFR 1320.5

#### **A. 8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency**

A. A copy of the agency's 60-day Federal Register Notice is attached (*60-day Federal Register Notice Attachment B*). The notice, as required by 5 CFR 1320.8 (d), was published on February 11, 2011 (volume 76, number 29, pages 7860-7862). One non-substantive public comment was received in response to this notice.

B. This data collection effort has been developed in collaboration with the TSA and thus represents consultation outside of the agency. The TSA has both a medical and a scientific advisory board who review and consult with TSA on all of their activities including the educational outreach component. Scientific and medical advisory boards meet annually to discuss existing knowledge and future directions.

The following members of TSA, the TSA scientific advisory board, the TSA medical advisory board, and the TSA education committee, have participated in the development and review of the information collection procedures:

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#### **A. 9. Explanation of Any Payment or Gift to Respondents**

This collection of information does not involve any pay or gift to respondents.

#### **A. 10. Assurance of Confidentiality Provided to Respondents**

This submission has been reviewed by the NCBDDD Privacy Officer, who determined that the Privacy Act does not apply.

This information collection involves anonymous data collection. Contact information is collected from participants on a voluntary basis for the purpose of communication with the TSA in general, and to allow contact for requesting participation in the 3 month follow up surveys. However, the evaluation forms themselves will have no identifying information or any link to names or contact information. Descriptive summaries of the responses will be submitted to CDC. None of the contact information will be submitted to CDC.

IRB Approval. This information collection has been determined not to involve research.

#### Privacy Impact Assessment Information .

All data are collected and stored anonymously. The contact data are collected via sign-in sheets customarily distributed at all programs. These data are then entered into the TSA “Sage” database. The contact information for participants of workshops for which follow up information is to be collected will be stored in the TSA database with no other information associated other than attendance at the workshops. The information is retained in a password protected program and resides on an internal TSA server. It can only be accessed by authorized TSA staff. Information cannot be accessed by anyone from the outside. All TSA Sage Database information is kept in a secure manner. It is not shared by TSA with outside parties for any purpose.

All participants are informed that completing the evaluation surveys is voluntary and anonymous and that the collected information will be used to improve future workshops.

#### **A. 11. Justification for Sensitive Questions**

No sensitive data will be collected.

#### **A. 12. Estimates of Annualized Burden Hours and Costs**

The information will be collected from three general types of respondents: Health Professionals, Teachers/Educators, and the Public. The Public is likely to include persons with TS and family members of persons with TS, but will also include other members of the public. Burden estimates are based on previous experience with the evaluation forms used as part of OMB No. 0920-0572, which have been adapted for the present information request. See Attachment D for a list of items that were used as part of the previous information collection forms and have been adapted for the present information collection. Every participant of education programs or workshop will receive a copy of the evaluation survey to complete at the end of the program.



Each recipient of educational resource materials will also be invited to go online and complete a survey.

For Physician Training retreat and CBIT workshop participants, a knowledge pre-post test and a 3 month follow-up survey will be also be administered, hence these participants will be giving 3 sets of responses. See Attachment E for a sample invitation to complete the online survey.

### Estimated Annualized Burden Hours

Type of Respondent	Form Name	Number of Respondents	Number of responses/ respondent	Average Burden/ response (in hours)	Response Burden (in hours)
Health professionals	Medical Program Evaluation (Attachment C1)	1,200	1	2/60	40
Health Professionals	Physician Training Retreat Pre-test (Attachment C2)	50	1	3/60	3
	Physician Training Retreat Post-test (Attachment C3)	50	1	3/60	3
	Physician Training Retreat 3 Month Follow-up (Attachment C4)	30	1	2/60	1
Health Professionals	CBIT Program Evaluation (Attachment C5)	500	1	2/60	17
	CBIT Pre-test (Attachment C6)	500	1	3/60	25
	CBIT Post-test (Attachment C7)	500	1	3/60	25
	CBIT Online Program Evaluation (Attachment C8)	50	1	1/60	1
	CBIT Program 3 Month Follow-up (Attachment C9)	300	1	1/60	5
Health professionals	Medical Resource Dissemination (Attachment C10)	210	1	2/60	7
Teachers/ Educators	Education Program Evaluation (Attachment C11)	1,200	1	2/60	40
	Education Pre-test	800 <sup>1</sup>	1	3/60	40

	<i>(Attachment C12)</i>				
	Education Post-test <i>(Attachment C13)</i>	800	1	3/60	40
	Education Resource Dissemination <i>(Attachment C14)</i>	210	1	2/60	7
Public	Family/Public Education Program Evaluation <i>(Attachment C15)</i>	250	1	2/60	8
	Family/Public Medical Program Evaluation <i>(Attachment C16)</i>	250	1	2/60	8
Public	Family Resource Dissemination <i>(Attachment C17)</i>	200	1	2/60	7
Total		7,100			277

#### Estimates of annualized cost to respondents

Estimates of annualized cost to respondents for the burden hours for collections of information, identifying and were based on the hourly wage cost from the U.S. Department of Labor’s “May 2008 National Occupational Employment and Wage Estimates.” Because it is unknown what occupations TS patients/family members or education resource recipients may have, the estimate for that row was based on the average for all occupations. See

[http://www.bls.gov/oes/current/oes\\_nat.htm#b00-0000](http://www.bls.gov/oes/current/oes_nat.htm#b00-0000)

Type of Respondent	Survey Instruments	Annual Burden in Hours	Average Hourly Rate	Respondent Cost
Health professionals	Medical Program Evaluation	2/60	\$33.51	\$1.17
Health professionals	Physician Training Retreat Pre-test	3/60	\$33.51	\$1.68
	Physician Training Retreat Post-test	3/60	\$33.51	\$1.68
	Physician Training Retreat 3 Month Follow-up	2/60	\$33.51	\$1.17
Health professionals	CBIT Program Evaluation	2/60	\$33.51	\$1.17
	CBIT Pre-test	3/60	\$33.51	\$1.68
	CBIT Post-test	3/60	\$33.51	\$1.68
	CBIT Online Program Evaluation	1/60	\$33.51	\$0.56

<sup>1</sup> The pre-post test will be given to participants in workshops that last 2 hours or longer

	CBIT Program 3 Month Follow-up	1/60	\$33.51	\$0.56
Health professionals	Medical Resource Dissemination	2/60	\$33.51	\$1.17
Teachers/Educators	Education Program Evaluation	2/60	\$23.81	\$0.79
	Education Pre-test	3/60	\$23.81	\$1.19
	Education Post-test	3/60	\$23.81	\$1.19
Teachers/Educators	Education Resource Dissemination	2/60	\$23.81	\$0.79
Public	Family/Public Education Program Evaluation	2/60	\$20.90	\$0.70
	Family/Public Medical Program Evaluation	2/60	\$20.90	\$0.70
Public	Family Resource Dissemination	2/60	\$20.90	\$0.70

#### **A. 13. Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers**

There are no other annual cost burdens to respondents or record keepers.

#### **A. 14. Annualized Cost to the Government**

The average annualized cost to the Government to conduct the full cooperative agreement is \$1,131,326 for the 2011-2012 approval period. The following table uses quantification of hours of effort for the full project. The project involves the CDC Project Officer, who is responsible for the programmatic approach and project oversight including guidance of the educational outreach planning efforts. The CDC Research Psychologist is responsible for technical assistance on the planning and review of all information collection involved. The effort of the CDC public health analyst will be required for fiscal and managerial tasks. For the grantee, the majority of costs are involved in the development, coordination, and implementation of the workshops, including travel cost.

The above text and table below reflects the costs associated with the entire cooperative agreement. For the collection of evaluation information, the costs are estimated to be substantially less. The CDC personnel investment for the information collection (evaluation) is expected to be 0.05 FTE for the project officer, 0.05 FTE for the public health analyst, and 0.10 FTE for the research psychologist, for an annual cost of \$18,916 (for years 1-3). The annual TSA personnel investment for the evaluation activities (information collection) is expected to be 10% of the project directors commitment to the CDC project, 25% of the project coordinators commitment to the project, and 10% of the administrators commitment to the project, for a total of \$22,047 (for years 1-3). Thus, the overall cost for personnel at CDC and TSA for information collection is \$40,963.

		<b>Total (\$)</b>
<b>Federal Government Personnel costs</b>	CDC Project Officer GS13 (.10 FTE)	\$9,404
	CDC Research Psychologist GS13 (.10 FTE)	\$10,260
	CDC Public Health Analyst GS12 (.10 FTE)	\$7,908
<b>Grantee Direct Labor</b>	Project Director (.50 FTE)	\$57,455
	Project Coordinator (1.00 FTE)	\$65,648
	Project Coordinator (1.00 FTE)	\$57,784
	Project Coordinator (1.00 FTE)	\$38,950
	Education Specialist (.60 FTE)	\$28,843
	Field Service Manager (.05 FTE)	\$3,150
	Administrative Personnel (.45 FTE)	\$18,558
	Administrative Personnel (.20 FTE)	\$12,499
	Administrative Personnel (.10 FTE)	\$6,039
	Accounting	\$11,100
	Bookkeeper	\$3,728
<b>Personnel Cost Subtotal including Fringe</b>		\$376,648
<b>Other Grantee Direct Cost</b>	Supplies	\$73,852
	Travel and Subsistence	\$59,550
	Other Costs	\$289,950
<b>Subtotal, Grantee Cost</b>		\$800,000
<b>Total Cost</b>		\$1,131,326

#### **A. 15. Explanation for Program Changes or Adjustments**

This is a new data collection.

#### **A. 16. Plans for Tabulation and Publication and Project Time Schedule**

The descriptive data collected will be summarized to inform TSA planning activities and to improve future programs. This information is for internal use only and will not be published. Summary reports on the findings will be submitted to CDC as part of quarterly and final reports.

The project timeline is summarized here:

<b>A.16.—Project Time Schedule</b>

Activity	Timeframe	
Identify and invite participants to workshops	Identify venues and organizations for workshop	Starts 1–2 months after OMB approval, ongoing
	Identify and invite participants	Starts 1–2 months after OMB approval, ongoing
Conduct workshops	Deliver curriculum	Starts 1–2 months after OMB approval, ongoing
	Conduct post-surveys	Starts 1–2 months after OMB approval, ongoing
Conduct follow up survey	Finalize web survey	1 month after OMB approval
	Conduct follow-up survey	3 months after each training
Disseminate resources	Finalize web survey	1 month after OMB approval
	Disseminate resources	Starts 1–2 months after OMB approval, ongoing
	Conduct resource evaluation survey	Starts 1–2 months after OMB approval, ongoing
Analyze and Report Data	Draft Report	Quarterly after start of programs
	Final Report	At end of budget period
Integrate findings into workshop curriculum	Draft Revised Curriculum	1-3 months after quarterly reports
	Final Revised Curriculum	At end of budget period

For the reports, data will be summarized across respondents. For rating and categorical scales, the percent of each answer chosen compared to the total number of answers given will be reported per item. Open ended questions will be reviewed and summarized by themes.

**A. 17. Reason(s) Display of OMB Expiration Date is Inappropriate**

The OMB expiration date will be displayed.

**A. 18. Exceptions to Certification for Paperwork Reduction Act Submissions**

There are no exceptions to the certification.

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