July 2011

Supporting Statement A

for

Tourette Syndrome National Education and Outreach Program

New Request

Primary Contact:

Rebecca H. Bitsko, PhD

CDC/NCBDDD

1600 Clifton Road,

Atlanta, GA 30333

dvk2@cdc.gov

404-498-3556

Fax 404-498-3060

**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 additional 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 settlings.

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**

1. 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.

1. 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.

1. 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**

1. 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:

TSA collaborators:

*Barbara Coffey, M.D., M.S., Director, Tics and Tourette’s 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, Bayside, NY 11361, 718-224-2999,* *Giordano6300@aol.com*

*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, Bayside, NY 11361, 718-224-2999, 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., TSA SAB, 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.,TSA MAB Chair,* *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., TSA MAB, Professor of Psychology, University of Wisconsin, Milwaukee, Box 413,* *Milwaukee, WI 53201*, *414-229-5335, dwoods@uwm.edu*

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

CDC collaborators

*Rebecca H. Bitsko, Ph.D., Health 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 30333404-498-3005, RPerou@cdc.gov*

**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 ofRespondents | Number ofresponses/respondent | Average Burden/ response(in hours) | ResponseBurden(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*(Attachment C12)*  | 800[[1]](#footnote-1) | 1 | 3/60 | 40 |
| Education Post-test*(Attachment C13)*  | 800 | 1 | 3/60 | 40  |
| Education Resource Dissemination*(Attachment C14)*  | 210 | 1 | 2/60 | 7 |
| Public | Family/Public Education Program Evaluation*(Attachment C15)* | 250 | 1 | 2/60 | 8 |
| Family/Public Medical Program Evaluation*(Attachment C16)* | 250 | 1 | 2/60 | 8 |
| Public | Family Resource Dissemination*(Attachment C17)* | 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>

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **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 |
| 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.

|  |  |
| --- | --- |
|  | **Total ($)** |
| **Federal Government****Personnel costs** | 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 |
| **Grantee****Direct Labor** | 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 |
| **Personnel Cost Subtotal including Fringe** |  | $376,648 |
| **Other Grantee Direct Cost** | SuppliesTravel and Subsistence Other Costs | $73,852$59,550$289,950 |
| **Subtotal, Grantee Cost** |  | $800,000 |
|  |  |  |
| **Total Cost** |  | $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:

|  |
| --- |
| **A.16.—Project Time Schedule**  |
|  |
| **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.

**References**

American Psychiatric Association (2000). Diagnostic and statistical manual of mental disorders. Washington, DC, American Psychiatric Association.

Bawden, H. N., A. Stokes, et al. (1998). "Peer relationship problems in children with Tourette's disorder or diabetes mellitus." J Child Psychol Psychiatry **39**(5): 663-668.

Centers for Disease Control and Prevention (2009). "Prevalence of diagnosed Tourette syndrome in persons aged 6-17 years - United States, 2007." MMWR Morb Mortal Wkly Rep **58**(21): 581-585.

Comings, D. E., J. A. Himes, et al. (1990). "An epidemiologic study of Tourette's syndrome in a single school district." Journal of Clinical Psychiatry **51**(1): 463-469.

Erenberg, G., R. P. Cruse, et al. (1986). "Tourette syndrome: an analysis of 200 pediatric and adolescent cases." Cleve Clin Q **53**(2): 127-131.

Freeman, R. D. (2007). "Tic disorders and ADHD: answers from a world-wide clinical dataset on Tourette syndrome." European Child & Adolescent Psychiatry **16**: 15-23.

Ginsburg, G. S. and J. N. Kingery (2007). Management of familial issues in persons with Tourette syndrome. Treating Tourette syndrome and tic disorders: A guide for practitioners., New York, NY, US: Guilford Press**:** 225-241.

Janik, P., A. Kalbarczyk, et al. (2007). "Clinical analysis of Gilles de la Tourette syndrome based on 126 cases." Neurol Neurochir Pol **41**(5): 381-387.

Jankovic, J. (1997). "Tourette syndrome. Phenomenology and classification of tics." Neurol Clin **15**(2): 267-275.

Kadesjo, B. and C. Gillberg (2000). "Tourette's disorder: Epidemiology and comorbidity in primary school children." Journal of the American Academy of Child & Adolescent Psychiatry **39**(5): 548-555.

Khalifa, N. and A.-L. von Knorring (2003). "Prevalence of tic disorders and Tourette syndrome in a Swedish school population." Developmental Medicine & Child Neurology **45**(5): 315-319.

Khalifa, N. and A.-L. Von Knorring (2005). "Tourette syndrome and other tic disorders in a total population of children: clinical assessment and background." Acta Paediatrica **94**(11): 1608-1614.

Leckman, J. F., H. Zhang, et al. (1998). "Course of tic severity in Tourette syndrome: the first two decades." Pediatrics **102**(1 Pt 1): 14-19.

Marcks, B. A., D. W. Woods, et al. (2004). "What do those who know, know? Investigating providers' knowledge about Tourette's Syndrome and its treatment " Cognitive and Behavioral Practice **11**(3): 298-305.

Mason, A., S. Banerjee, et al. (1998). "The prevalence of Tourette syndrome in a mainstream school population." Developmental Medicine & Child Neurology **40**(5): 292-296.

Packer, L. E. (2005). "Tic-related school problems: Impact on functioning, accommodations, and interventions." Behavior Modification **29**(6): 876-899.

Scahill, L., D. G. Sukhodolsky, et al. (2005). "Public health significance of tic disorders in children and adolescents." Advances in Neurology **96**: 240-248.

Stefanoff, P., T. Wolanczyk, et al. (2008). "Prevalence of tic disorders among schoolchildren in Warsaw, Poland." European Child & Adolescent Psychiatry **17**(3): 171-178.

1. The pre-post test will be given to participants in workshops that last 2 hours or longer [↑](#footnote-ref-1)