

Attachment B:

**2014 NS-DATA
Advance letter/FAQ,
Refusal Conversion letter
and Thank You letter**

Advance Letter and FAQs

20782

NS-DATA Advance Letter

Dear Parent or Guardian,

Thank you for your help!

Your household participated in the 2011-2012 National Survey of Children's Health over the telephone. Based on the answers you provided during this survey, your household is eligible for an important survey on children who have ever been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) or Tourette Syndrome (TS). Information about the child in your care will help the U.S. Department of Health and Human Services develop programs to promote the health and well-being of these children and their caregivers in your state and throughout the United States.

In the next few weeks, the National Center for Health Statistics (NCHS), part of the Centers for Disease Control and Prevention (CDC), will call your household and ask to talk to the same caregiver who completed the previous telephone survey, or another parent or guardian of the child who currently lives with the child. The survey will take about half an hour to complete.

In appreciation for your continued time and effort, we will send you \$20 once the survey is complete.

Participation is voluntary. We hope you will share this important information about your child by phone when an interviewer calls to ask you to take part in the study. If you do, you can choose not to answer any questions you do not wish to answer. All information collected for this study is confidential and protected by federal law. The back of this letter provides answers to some questions you may have and ways to get more information about the survey.

To learn more about the study or to take part right away, call 1-877-259-4326, toll-free. You can also visit the study's website for additional study information – www.cdc.gov/nchs/slaits.htm.

Thank you very much for your help with this important research!

Sincerely,

1Charles J. Rothwell, MBA, MS
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

If you prefer to use TTY



call the AT&T Relay Service at 1-800-855-2880 and request that

1-877-259-4326 be called. The call is toll-free.

National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome

Frequently Asked Questions

What is the purpose of this study?

The purpose of this study is to improve the process by which children with ADHD or Tourette Syndrome (TS) are diagnosed and treated. This study also aims to describe the types of services and supports these children use, and to identify any problems they have in getting the care they need. People have very different experiences with their children's health and health care. In order to improve children's health and well-being overall, it is important that we learn about diagnosis and treatment. This study is authorized by Section 306 of the Public Health Service Act and funded by the National Center on Birth Defects and Developmental Disabilities.

Why do I qualify for this study?

Your household participated in a telephone survey about the health and health care of children. Based on the answers provided in this survey, a child in your household *has or had been diagnosed with* ADHD or TS. If we are contacting your household in error, we would greatly appreciate talking to a parent or guardian so we can confirm that your household should not be a part of this study.

How will you protect my privacy?

We are bound by law to maintain strict confidentiality standards. Your identifiable information and the child's identifiable information will never be associated with any published information from this study.

If you would like more information about the confidentiality of the research or the federal laws that ensure the protection of your information, including the Public Health Service Act and the Confidential Information Protection and Statistical Efficiency Act, these are described in detail at:

<http://www.cdc.gov/nchs/about/policy/confidentiality.htm>. If you want to know more about your rights as a study participant you may call 1-800-223-8118, toll-free. This is the number for the Research Ethics Review Board at NCHS. You will be asked to leave a message and say you are calling about Protocol XXXX-XX.

How will this information be used?

Maternal and child health agencies in your state will use this information to improve diagnosis and treatment of children with neurodevelopmental conditions. The federal government will also use this information to learn about the types of support services that states need for these children.

You may visit **<http://www.cdc.gov/nchs/slits.htm>** to find general information about the study.

Is there a toll-free number to learn more?

To learn more about the study or to take part right away, call **1-877-259-4326**, toll-free. The National Center for Health Statistics has hired NORC at the University of Chicago to conduct the survey. You can call NORC's toll-free number to take part in the study right away, learn more about the study, and hear what you will be asked.

Refusal Conversion Letter

20782

NS-DATA Refusal Conversion Letter

Dear Parent or Guardian,

The CDC needs your help!

Recently, your family was asked to participate in the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome. We hope you will reconsider our request. Information about the child in your care and others will help the Department of Health and Human Services develop programs to promote the health of children in your state and throughout the United States.

In appreciation for your time and effort, we have enclosed \$5. As promised, we will send you an additional \$20 once the survey is complete.

We hope you will share this important information with us by telephone when an interviewer calls to ask you to participate in the study. If you would like to participate immediately, please call the toll-free telephone number **1-877-259-4326**.

Your household is very important to the study because it has been scientifically selected and cannot be replaced. All information collected for this study is confidential and protected by federal law. The back of this letter provides answers to some questions you might have and ways to get additional information about the survey.

Thank you very much for your help with this important research.

Sincerely,

1Charles J. Rothwell, MBA, MS
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

[BACK PAGE FOR INCENTIVE LETTERS]

Why is this study being conducted?

The Department of Health and Human Services is committed to improving children's health and well-being. State and federal health authorities are depending on the results of this study to help them understand how best to meet children's needs.

How do I know that my information will remain private?

By law, all information that you provide is kept confidential. The collection of information in this survey is authorized by Section 306 of the Public Health Service Act. The Public Health Service Act is Volume 42 of the US Code, Section 242k. The confidentiality of your responses is assured by Section 308(d) of this Act.

Information that you provide is used for statistical research only. The results of this research are published only in the form of summary statistics. Your identifiable information and your child's identifiable information are never associated with any published information.

Participation in the study is voluntary. You may choose not to answer any question that you do not wish to answer or to end your participation at any time.

How can I find out more about this survey?

If you have any questions about this research study, please call **1-877-259-4326**.

If your questions are about your rights as a participant in this research study, you may also call the office of the Research Ethics Review Board at the National Center for Health Statistics, toll free, at 1-800-223-8118. Please leave a brief message with your name and phone number. Say that you are calling about Protocol # XXXX-XX. Your call will be returned as soon as possible.

Thank you Letters

NS-DATA thank you letter - \$20 (One Survey)

[DHHS Letterhead]

Dear Caregiver:

Thank you for your participation in a recent national survey. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children with ADHD and Tourette Syndrome throughout the United States. In appreciation for the time and effort you spent answering our questions, we are enclosing \$20.

If you would like more information about the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, you can visit the study's web site at XXXXXX or call the toll-free telephone number for the study at 1-877-259-4326.

Thank you again for your help with this important research.

Sincerely,

1Charles J. Rothwell, MBA, MS
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

NS-DATA thank you letter - \$40 (Two Surveys)

[DHHS Letterhead]

Dear Caregiver:

Thank you for your participation in a recent national survey. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children with ADHD and Tourette Syndrome throughout the United States. In appreciation for the time and effort you spent answering our questions, we are enclosing \$40.

If you would like more information about the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, you can visit the study's web site at XXXXXX or call the toll-free telephone number for the study at 1-877-259-4326.

Thank you again for your help with this important research.

Sincerely,

1Charles J. Rothwell, MBA, MS
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

NS-DATA thank you letter - \$25 (One Survey + Refusal Conversion)

[DHHS Letterhead]

Dear Caregiver:

Thank you for your participation in a recent national survey. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children with ADHD and Tourette Syndrome throughout the United States. In appreciation for the time and effort you spent answering our questions, we are enclosing \$25.

If you would like more information about the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, you can visit the study's web site at XXXXXX or call the toll-free telephone number for the study at 1-877-259-4326.

Thank you again for your help with this important research.

Sincerely,

1Charles J. Rothwell, MBA, MS
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

NS-DATA thank you letter - \$45 (Two Surveys + Refusal Conversion)

[DHHS Letterhead]

Dear Caregiver:

Thank you for your participation in a recent national survey. The information that you gave about your child will help the Centers for Disease Control and Prevention develop programs to promote the health of children with ADHD and Tourette Syndrome throughout the United States. In appreciation for the time and effort you spent answering our questions, we are enclosing \$45.

If you would like more information about the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome, you can visit the study's web site at XXXXXX or call the toll-free telephone number for the study at 1-877-259-4326.

Thank you again for your help with this important research.

Sincerely,

1Charles J. Rothwell, MBA, MS
Director, National Center for Health Statistics
Centers for Disease Control and Prevention