

Michigan Twins Project Follow-up Study
Parent/Guardian Consent Form, twins ages 8-17

Goals: Twins are a very valuable source of information for health research, as their unique relationship allows researchers to pull apart and examine genetic and environmental influences. The current research study is seeking updated, developmentally appropriate information for twins and their families who previously participated in the Michigan Twins Project.

Participation time and compensation: The total participation time will be about 15-20 minutes. As a thank you for your participation, we will send you a \$15 Meijer gift card that is redeemable at all Meijer store locations, as well as online at Meijer.com (check Meijer.com for current online service availability). If you do not have a Meijer store nearby and you would like to discuss other compensation options, please contact us at (517) 432-5604 or msutr@msu.edu.

Your participation: You are asked to complete a follow-up questionnaire that asks for current information about the twins' parents, the twins, and your family history. The latter includes questions on your family's physical and mental health, substance abuse, and your twins' behaviors. We ask that you please do not fill out the questionnaire multiple times, as you will only be compensated for one full completion.

Risks: The primary risk to you is that some people may feel uncomfortable reporting on their twins' behaviors or family history. However, most people find it to be a positive and even fun experience.

Benefits: Our Michigan State University Twin Registry website (<https://msutwinstudies.com>) has fun twin facts, helpful information, and a copy of our Newsletter. Participation in this study will contribute to research aimed at better understanding a variety of conditions that carry significant consequences for individual and public health.

Confidentiality: All information that you give us will be kept strictly confidential. Any paper forms will be kept in locked filing cabinets in a locked office at the Primary Investigator's MSU office. All computer files will be stored on password-protected computers in locked offices. The online database is secure. All survey responses we receive will be treated confidentially and stored on secure servers. Only project administrators and technical support staff (if necessary) are able to log in and access the data.

However, given that the online version of the questionnaire can be completed from any computer, we are unable to guarantee the security of the computer on which you may choose to enter your responses. As a participant in our study, we want you to be aware that certain "keylogging" software programs exist that can be used to track or capture data that you enter and/or websites that you visit.

Your family's identity or individual information will not be revealed in any reports about the registry. Instead, we will summarize information across participants. The MSU Human Research Protection Program may have access to the data you provide. However, your family's confidentiality will be protected to the maximum extent allowable by law.

Deidentified data collected as part of this study may be shared for research purposes with other researchers, at MSU or other institutions. However, these outside researchers will not have access to you or your twins' names, address, or any other identifying information. Data files used by outside researchers will identify your family by ID number only.

The Michigan Department of Health and Human Services (MDHHS) collaborates with MSU in recruiting families for this research project. Your questionnaire responses will not be shared with the MDHHS, except as may be necessary for the MDHHS to send you materials on a future study for which you may be eligible and to ensure consistency regarding mailing records between MSU and the MDHHS. As part of this, the MDHHS will be given a copy of the front page of the questionnaire. Addresses provided to the MSUTR may also be shared with the MDHHS, to facilitate possible future mailings.

Guidelines for participation: Your participation is voluntary in this study. We hope you will be able to complete the entire questionnaire and you may refuse to participate in this study or to answer certain questions. However, you have the right to stop participating at any point with no penalty or negative consequences, except that you may not receive the thank-you payment.

The data from the registry are unique and are being collected to inform and facilitate future twin research. As a result, we plan to store this data indefinitely. Names will not be kept on any data records; all data will be identified only by an ID number. Only study staff/investigators, collaborators at MSU or other institutions, technical support staff (if necessary), and the MSU Human Research Protection Program will have access to your data. Names linked to the ID numbers will be stored in a double password-protected file. Your family's identity or individual information will not be

revealed in any reports about this study. We will summarize information from all participants. You may request that any or all of these data be destroyed at any time. You can make this request by contacting Dr. Alex Burt at (517) 432-5602 or burts@msu.edu, or Dr. Kelly Klump at (517) 432-3665 or klump@msu.edu. Your decision to have your information destroyed will not result in any penalty or negative consequence. All rights and benefits of a participant will still apply.

Describing this Study to other members of the family:

For legal and ethical reasons, it is critical that all family members are aware that one parent will report potentially sensitive information (e.g., certain behaviors, medical history, history of illnesses) about each twin and each parent. Due to the sensitive nature of some of these items, family members must give permission to the parent completing the questionnaire by verbally consenting (in the case of the parent) and assenting (in the case of the twins) to study participation.

In order to obtain permission to participate in the study from your twins, the study must be described to the twins, and each twin must verbally assent to study participation. In terms of the other parent(s), the parent who is completing the questionnaire must describe the study to the other parent and either (a) obtain permission and verbal consent from the other parent, if that person is living, or (b) not answer questions about the parent in your questionnaires. Please note that if the other parent is deceased, no permission is required and questions regarding that parent may be answered. The requirement for permission applies to both biological parents, as well as to other parents the twins may have, if information will be provided about them. Persons other than the parents who have legal guardianship of the twins may participate; however, the same requirements apply for discussion with any family members about whom information will be provided. If their permission is not granted, questions about them should not be answered.

The scripts provided below can be used to discuss the study with your family:

Script for describing the study to the other parent(s): “We have been asked to participate in a follow-up study of twins and their families that is being conducted by professors at Michigan State University. The study asks that you or I complete a questionnaire that includes sensitive information about each of us and our children, including items regarding demographic information, physical and psychological health, and behaviors. Our family’s confidentiality will be protected to the maximum extent allowable by law. In order to participate, one of us will need to complete a brief questionnaire. Do you feel comfortable with one of us completing this? For our time, we will be reimbursed with a \$15 gift card.”

Script for describing the study to your twins: “Professors at Michigan State University have asked our family to help them with a study to learn more about health and twins, similar to the one we completed before, but with new questions, now that you are older. You won’t have to do anything to be in the study, but I or your (mother/father) will be answering questions about you and the rest of our family, like how old you are, things you like and don’t like, the way you act, and any illnesses we have had. Everything we say will be private, and your name will not be kept on anything that has our answers to the questions. Is this OK with you?”

Questions for Researchers: If you have any concerns or questions about this research study, such as scientific issues, how to do any part of it, or to report an injury (i.e., physical, psychological, social, financial, or otherwise), please contact the researchers, Dr. Alex Burt at (517) 432-5602 or burts@msu.edu, or Dr. Kelly Klump at (517) 432-3665 or klump@msu.edu. Dr. Burt and Dr. Klump also can be contacted by regular mail at MSU Twin Registry, Psychology Building, 316 Physics Road – Room 37B, Michigan State University, East Lansing, MI 48824.

Questions about Research Participant Rights: If you have questions or concerns about your role and rights as a research participant, you would like to obtain information or offer input, or you would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University’s Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or e-mail irb@msu.edu or regular mail at 4000 Collins Rd, Suite 136, Lansing, MI 48910.

You indicate your voluntary consent to participate in this study by completing the questionnaire.

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