

Sample of Introduction (aka Heads Up Letter) to Parents of Juvenile Twin Pairs

Dear Parents of Twins,

We are sending this letter to let you know that we will be contacting you soon by phone regarding a new study opportunity for MATR twins. The MATR is collaborating with Dr. Roberson-Nay and her colleagues at Virginia Commonwealth University on a study about factors that impact the development of internalizing disorders, such as depression and anxiety. The research team hopes to recruit adolescent and young adult twin pairs and their parents/legal guardians. Participants are selected for study invitations based on the ages of the twin pair and potential proximity to the research site. The study will need twins with and without signs of behaviors related to internalizing disorders.

Why is this study necessary?

Internalizing disorders can greatly reduce the quality of life of the individuals that are affected by them as well as their family and friends. Very little is known about what causes some individuals to develop internalizing disorders and not others. This study has the potential to not only provide a deeper understanding of these causes, but also to pioneer new ways in which doctors attempt to treat and prevent conditions like depression and anxiety.

How do you participate?

A MATR Interviewer will call you soon about this study. When calling, MATR Interviewers always identify themselves by name and say that they are calling from Virginia Commonwealth University and/or from the Mid-Atlantic Twin Registry. During the call, the Interviewer will provide information about the study, such as what participation involves and about study compensation. S/he will then request your permission to ask a short series of questions about your twins and ask if you would be interested in having the study contact you with more information. The entire phone call will take approximately twenty minutes.

If you think your family might be interested, please share this letter and the information printed on the back of the letter with your twins and take a few minutes to talk to them about this prior to receiving our phone call. They may have questions they would like you to ask us during the call.

Does your family have to participate?

You do NOT have to participate in the phone call or the study. We are sending this letter just to let you know to expect to hear from us. Please keep in mind that even if you do not want to participate in the phone call, it is helpful to answer or return our call so that you can tell us that you prefer not to participate in this study. That way, we know not to try and call you back or contact you further about this study.

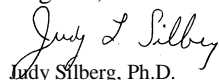
How do you tell us that you may want to participate in this call?

You're welcome to call our toll-free MATR number, provided below, and leave us a message letting us know you are interested in hearing from us. Included with this letter, we have provided a form that will allow you to update your contact information and preferences. Please return this form using the enclosed, self-addressed, postage-free envelope.

Questions for the MATR?

Please call our toll-free telephone number, 1-800-URA-TWIN (1-800-872-8946). When calling, please reference the barcode number [«barcode»] and/or say that you are calling in regards to the Adolescent and Young Adult Twin Study (AYATS).

Regards,



Judy Silberg, Ph.D.

Scientific Director, Mid-Atlantic Twin Registry

Adolescent & Young Adult Twins General Study Information

This document is to give you some *general* information about the study we will be contacting or will have contacted you about. Much of this information will be discussed in our phone conversation with you about the study.

Who is doing this research and why is the study needed?

The National Institute of Mental Health (NIMH) which is part of the National Institutes of Health (NIH) has provided grant funding to Dr. Roxann Roberson-Nay to research the development of internalizing disorders (IDs), such as anxiety and depression. This is important because IDs impact a large portion of our population and thus society. While advances have been made on finding ways to treat these conditions there is still much that is not known about why some individuals develop IDs as well as why some with IDs seem to experience longer bouts and more intense anxiety and depression than others. Improved research techniques now offer researchers opportunities for an even deeper level of understanding about ID development. Specifically, this study is being conducted to learn more about the genes and other factors that could influence the likelihood of someone developing an internalizing disorder. To help accomplish this, the researchers are inviting parents/legal guardians and their twins, ages 15 through 20 years old, to participate in this study (participation can continue through 23 years of age). The researchers hope that information gained by your participation will provide groundbreaking insights into how and why some individuals develop internalizing disorders. They ultimately hope that their findings will lead to improved treatment programs and potentially to the development of early interventions to prevent or minimize the severity of internalizing disorders.

Who can participate?

- Full pairs of Caucasian twins currently within the age range of 15 through 23 years old, *living at home with their parents/legal guardians*
- Parent(s)/Legal Guardian(s) of the twin pairs (*required* for juvenile twins, *optional* for adult (18+) twins)

What does participation involve?

- *All levels of participation are voluntary.*
- Complete a phone call with a MATR Interviewer—this call will include more information about study participation, a set of questions for parents to answer about their adolescent twins (or adult twins to answer about themselves) to determine study eligibility (includes questions about health, learning, medications, personality/moods), and telling the MATR whether or not you'd be interested in learning more from the study staff.
- If willing and eligible following the MATR call, the participants would need to come to VCU to complete the study (which takes about 4 to 5 hours). Note: directions to the site and parking which is typically next to building (or within a block's walk) will be provided.
 - Study tasks for parents generally includes: providing consent & answering questionnaires about your twins; there is also an optional questionnaire about the parents themselves.
 - Study tasks for twins include: answering questionnaires, participating in computer-based tasks that will test: startle reflex, frustration levels, ability to read emotions in others, etc. There will also be tasks to measure stress response which includes: speaking in front of others and a breathing task where researchers change the concentration of normal compounds in air. Researchers will also collect a few physiological measures like heart rate, skin conductance, and measures of stress-related hormones in your saliva, etc. They will also request an optional blood sample from your for obtaining your DNA/RNA. *Remember—all tasks are voluntary!*

How does compensation work?

- Amounts vary and depend upon the study tasks completed; amounts range from \$10.00 to \$100.00.
- Generally though, if all or most tasks are completed, compensation could *add up to* \$170.00 per twin and *up to* \$20 to \$70 for parent(s).
- Families that travel more than 30 miles to the research site will also be reimbursed the allowable State mileage rate per mile at the time of travel to help with travel costs. Also, if major tolls (costing \$10.00 or more) are necessary, then study will reimburse the toll cost.

This information is just to provide an overview of some of the topics that you and your twins may be interested in knowing about prior to completing a phone call with a MATR Interviewer. We will be contacting you soon by phone to discuss this further and to see if you might be willing to allow the study staff to contact you about participation.