

# The Family Experiences with Wandering Study:

## *Additional Information and Frequently Asked Questions*

**Full title:** “A Prospective, Observational Study to Characterize and Evaluate the Family Impact of Wandering in the ASD Population”

The purpose of the Family Experiences with Wandering (“FEW”) study is to improve the medical community’s understanding of why wandering behavior occurs and how to prevent it. Once per week, for 10 weeks, parents who participate in this study will be asked to report whether, and how many times, their child wandered during the preceding week. Any time their child wanders, parents will be asked to record important details about the wandering incident – such as the location, time of day, and duration – in a confidential online system.

### Frequently Asked Questions about the FEW Study

#### 1. What will I be expected to do if I participate in this study? How much time will it take?

As a participant in this study, the only thing you’ll be asked to do is **answer questions online about your child’s wandering behavior, once per week**. All of the questionnaires will be delivered to you via email, so that you may complete them at your convenience and in the comfort of your own home. When you first enroll in the study, you will be asked to spend about an hour providing background information about yourself and your child. Then, once per week, for **ten weeks**, you will be asked to spend a few moments answering questions about whether, and how many times, your child wandered in the preceding week. We expect that these questionnaires will take up no more than **15 minutes of your time each week**. You will be compensated up to \$30, in the form of an Amazon.com eGift card, for completing these questionnaires as scheduled.

#### 2. Can I see the questionnaires before deciding whether to enroll in the study?

Yes. Feel free to contact the research team at [ASDWandering@northwell.edu](mailto:ASDWandering@northwell.edu) if you would like additional information about any of the online questionnaires.



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### 3. Why should I participate? What's in it for me?

Although you will not benefit directly from participating in this study, you will be helping researchers to understand more about wandering, which could help other families like yours in the future.

### 4. Is this study IRB-approved?

Yes. This study has been approved by the Northwell Health Institutional Review Board. Feel free to contact the research team at [ASDWandering@northwell.edu](mailto:ASDWandering@northwell.edu) if you have any questions or would like to receive documentation of this study's approval status.

### 5. Who is eligible to participate in this study?

You may be eligible to participate in this study if you meet all of the following criteria:

1. You are at least 18 years of age, you currently live in the United States, and you are able to read and write fluently in English
2. You are the parent of a child who has been diagnosed with autism spectrum disorder (ASD) by a professional.
3. Your child with ASD has recently wandered away from adult supervision.
4. Your child with ASD is between the ages of 4 and 17.
5. You have reliable access to the internet, and are willing to spend approximately 15 minutes each week answering questions about your child's wandering behavior.

### 6. If I am interested in participating, what should I do next?

To find out if you are eligible to participate in this study, click the link in the email that you received to complete the **Screening Questionnaire**. You may also access the Screening Questionnaire by visiting the following site:

**<https://tinyurl.com/ASDWandering>**



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7. What is the Screening Questionnaire? If I click the link and take the survey, does that mean that I have to enroll in the study?

No. The Screening Questionnaire is designed to help the research team determine whether you meet the eligibility criteria to participate in this study. Completing the Screening Questionnaire does not in any way commit you to participating in the study. If you choose to complete the Screening Questionnaire, a member of the research team will contact you to inform you of your eligibility. If you are eligible to participate, you will then be provided with additional information about the study to help you decide whether you would like to enroll. We encourage you to contact the research team at [ASDWandering@northwell.edu](mailto:ASDWandering@northwell.edu) if you have any questions.



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