Alzheimer’s Disease Development In Adults With Down Syndrome:
A Caregiver’s Perspective

If you are at least 18 years of age and a caregiver of an adult (18 years of age or older) with Down syndrome, we would greatly appreciate your participation in our online research survey!

This study is looking to assess caregiver knowledge and concerns surrounding the development of Alzheimer’s disease in adults with Down syndrome. The principal investigator of this study is Dawn Allain, M.S., Assistant Professor at The Ohio State University, and the co-investigator is Alexandra Ilacqua, a Genetic Counseling Training Program student, also at The Ohio State University.

Participation in this study involves completing an online survey that takes approximately 15-30 minutes to complete. This survey is completely anonymous and voluntary. You may refuse participation as well as quit the survey at any point without consequence. You may also skip any question you feel uncomfortable answering and/or choose the “I prefer not to answer this question” answer choice. This survey is part of a genetic counseling student’s Master’s thesis at The Ohio State University and has received Institutional Review Board (IRB) approval.

You will not be paid for taking part in this study. However, at the end of the survey, you will have the opportunity to enter your email address for a drawing to win one of ten $25 Amazon.com gift certificates. If for whatever reason you decide to withdraw from participating in this study, you will still be eligible to enter the gift certificate drawing.

The only risks associated with study participation are the time it will take to complete the survey and the possible risk of breach of confidentiality by providing your email for the gift certificate drawing. However, this risk is very minimal. Any email addresses provided will be detached from survey responses before data analysis begins and will be disposed of after the announcement of winners.

There are no direct benefits to participating in this study. However, results of this study will shed some light on how to better care for both adults with Down syndrome and their caregivers, while also directing professionals on how to better provide guidance for caregivers in these difficult medical situations.

If you are interested in participating in this study, you can access the survey at the following URL: https://www.surveymonkey.com/r/ADDS

Your time and consideration are very much appreciated!

If you have any questions or concerns about this study, please contact:

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The Ohio State University
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(614) 352-5471

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.