

## **Eastern Michigan University Master's Degree Candidate Letter Regarding Orphan Drug Act Survey**

**Dear Organization Director,**

As part of my master's thesis, I would like to request your participation in a survey research.

As a member of the NORD (National Organization for Rare Disorders), you are being asked to participate in a survey concerning the Orphan Drug Act to find whether the Orphan Drug Act and its legislation is really meeting the needs of the rare disease patients. .

Your participation is voluntary and you may choose not to participate. If you decide to participate in this research survey, you may withdraw at anytime. Your participation and individual responses will be kept anonymous. There are no direct benefits associated with your participation, but your input is valued. There is no known risk involved in your participation.

As a researcher I respect your rights to privacy and I hold in the utmost respect your responses to this survey and I will keep your survey results confidential. I am not collecting any kind of personal identifiable information or personal health information during the course of this survey.

The data will be collected via the online survey (Google Docs) and the results of the survey will be held by me. I will hold the data on a password protected personal laptop; there is no access to anyone. I will be protecting the laptop from theft and the word document containing email list for survey is both encrypted and password protected. The folder on my laptop (password protected) containing the results of the survey will be deleted upon the submission of the dissertation and the password protected document containing email list for survey will be deleted upon the completion of survey.

I will be sending the survey to potential participants by using Google docs and the survey tool or document or form containing emails will be deleted forever upon the analysis of results. Privacy Policy of Google <http://www.google.com/intl/en/policies/privacy/>

I have taken all reasonable measures to protect your identity and responses. However, email and the internet are not 100% secure, so it is also suggested that you clear the browser history to protect your privacy after completing the survey.

This survey (6 questions) will take you approximately 5 to 10 minutes to complete. There is no known risk involved with your participation.

Link:

<https://docs.google.com/spreadsheets/viewform?formkey=dEZKZjNUc1F1Y21wWmw0Y1QwOG9TYUE6MQ>

By clicking on the link above, you are indicating that:

- You have read above information.
- You voluntarily agree to participate.

I can provide the results of the survey information at the completion of the study, if you are interested. There is no direct benefit in your participation but your input is valued and I hope you will respond. If you have any questions or concerns about the study, I encourage you to contact Irwin Martin Ph.D., Associate Professor, College of Health and Human Services, Marshall Building, [imartin2@emich.edu](mailto:imartin2@emich.edu).

“This research protocol and informed consent document has been reviewed and approved by the Eastern Michigan University Human Subjects Review Committee for use from February 04, 2013 to February 03, 2014. If you have questions about the approval process, please contact "Gretchen Reeves, PhD, 734-487-3236, [greeves@emich.edu](mailto:greeves@emich.edu)", Chair, College of Health and Human Services Human Subjects Review Committee.

Thank you,

VENKATESH BURLA,

Masters student,

College of Health and Human Services.