

**Participant Letter for Anonymous Surveys  
NSU Consent to be in a Research Study Entitled**

*The Impact of the Delivery Style of a Down syndrome Diagnosis on Familial Attitudes*

**Who is doing this research study?**

The persons doing this study are Palak Bhargav and Rehan Contractor with the Kiran C. Patel College of Osteopathic Medicine, Nova Southeastern University. They will be helped by Kristi Messer, D.H.Sc., M.P.H., M.S.W., LCSW and Dr. Jose Llanga M.D., M.S., LSSBB

**Why are you asking me to be in this research study?**

You are being asked to take part in this research study because you are a parent of a child diagnosed with Down syndrome by a healthcare professional.

**Why is this research being done?**

The purpose of this study is to find out the delivery of a Down syndrome diagnosis by a healthcare professional impacts familial attitudes. We hope to use the results of this study to identify the best practices for delivering a Down syndrome diagnosis, so families are well informed on their child's condition and how to manage it.

**What will I be doing if I agree to be in this research study?**

You will be taking a one-time, anonymous survey. The survey will take approximately 10 minutes to complete.

**Are there possible risks and discomforts to me?**

This research study involves minimal risk to you. To the best of our knowledge, the things you will be doing have no more risk of harm than you would have in everyday life.

**What happens if I do not want to be in this research study?**

You can decide not to participate in this research and it will not be held against you. You can exit the survey at any time.

**Will it cost me anything? Will I get paid for being in the study?**

There is no cost for participation in this study. Participation is voluntary and no payment will be provided.

**How will you keep my information private?**

Your responses are anonymous. Information we learn about you in this research study will be handled in a confidential manner, within the limits of the law. All data will be stored on a private REDCap database server which will not be accessible to the public. This data will be available to the researcher, the

Institutional Review Board and other representatives of this institution, and any granting agencies (if applicable). All confidential data will be kept securely on a REDCap database server. All data will be kept for 36 months from the end of the study and destroyed after that time by deleting all the collected data from the REDCap form/survey.

**Who can I talk to about the study?**

If you have questions, you can contact Palak Bhargav, Rehan Contractor, Dr. Kristi Messer, or Dr. Jose Llanga at 813-406-9225, 813-420-2847, 954-262-1072, and 954-554-5609 respectively.

If you have questions about the study but want to talk to someone else who is not a part of the study, you can call the Nova Southeastern University Institutional Review Board (IRB) at (954) 262-5369 or toll free at 1-866-499-0790 or email at [IRB@nova.edu](mailto:IRB@nova.edu).

**Do you understand and do you want to be in the study?**

If you have read the above information and voluntarily wish to participate in this research study, please click on the following link for the REDCap survey:

<https://redcap.nova.edu/redcap/surveys/?s=N9LJKHW88KAWY893>