**INVITATION TO PARTICIPATE IN A RESEARCH PROJECT**

***“Family Factors and Quality of Life in Children and Adolescents***

***with Down Syndrome”***

 We are inviting you to take part in a research project that we are conducting with parents of children with Down syndrome. The purpose of this study is to learn about how parents view family functioning and quality of life of children with Down syndrome.

**Who can participate?**

 If you are a parent of a child with Down syndrome aged 4-21 years and live in the same household as the child, you are invited to participate. Also, you must understand English, be at least 18 years old, have an email account, and have access to the internet.

**What will we ask you to do?**

 We will ask you to complete online questionnaires. You will be given an individualized electronic link for online survey (Qualtrics), which entails the consent form and all the questionnaires: general family information, family demand, family appraisal, family resources, family coping, and children’s quality of life. It will take approximately 30-40 minutes. Once you complete them, the link will become inactive.

 This project has been reviewed by the institutional review board for human subjects research at the University of North Carolina at Chapel Hill. If you agree to take part, all information you give will be confidential. No-one except the research team will have access to your information.

**To participate, please email Anna Lee**.

 If you wish to be involved in this research, please email me to register at annalee@email.unc.edu. Many thanks for your kind consideration.

**Anna Lee, RN, PhD(c)**

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**Marcia Van Riper, PhD, RN, FAAN**

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