

Please Help Us Improve Parents' Experiences with the Diagnosis of Their Children

Are you a parent of a child diagnosed with Velo-cardio-facial syndrome or a similar condition within the last ten years? Are you interested in helping to improve the diagnostic process for other parents?

I am a graduate student in the Genetic Counseling Program at Brandeis University in Waltham, Massachusetts. I am conducting a study on parents' experiences with the diagnosis of their child with a genetic condition. Many studies have explored how parents prefer to be given unexpected news. However, most of these studies focus on parents' preferences for the setting, the professional involved, and the amount and quality of information provided during the session. This study will focus on the specific information parents were provided during the diagnostic process and the information they would have liked to receive. I hope this study will help professionals providing genetic diagnoses to better meet parents' needs.

Participation in the study involves completing an anonymous online survey and an optional interview. The survey will ask for details about parents' experiences with the diagnostic process, as well as pertinent demographic information about the parent and child. The interview will allow parents to discuss their experiences with diagnosis more in depth.

Participation is open to one or both parents of a child diagnosed with a genetic condition within the last ten years. The criteria for parental participation are:

- The child must be the first individual in the family diagnosed with the condition,
- The child's diagnosis must have been given within the last ten years,
- The child must have been between the ages of two and 11 years at diagnosis, and
- The participating parent/s must be the biological parents.

If you are interested in participating in this study you can access the survey by clicking on the following link or pasting it into your browser:

www.surveymonkey.com/s.asp?u=48759359621

If you have questions about participation, please contact me at etaylor@brandeis.edu. I hope to have received all surveys by approximately **March 20, 2003**.

Participation in this study is completely voluntary. Your responses to the survey are anonymous. You may stop your participation at any time or choose to not answer specific questions without any consequence.

A summary of the results of the study will be made available to you through your support group. The results of this study may be included in a paper submitted to a published professional journal or a presentation at a professional conference.

I appreciate your participation and look forward to hearing from you.

Regards,
Elizabeth Taylor
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