



“Parental Management of Adrenal Crisis in Children with Congenital Adrenal Hyperplasia”

We are inviting you to take part in a research project that we are conducting with parents (or primary caregivers) of children with classic congenital adrenal hyperplasia (CAH). The purpose of this study is to better understand how parents view and manage adrenal crisis episodes in their children with CAH. Additionally, how parents are prepared by health care providers on managing their child’s adrenal crisis and the impact on the family of having a child with a life threatening condition will be explored.

Who can participate? If you are the parent of a child with classic CAH age 0-18, you are invited to participate. If your child is not between the ages of 0-18 or has additional complex medical conditions, you are not eligible for this study at this time. In addition, you must speak English, be at least 18 years old, have an email account, and have access to the Internet. Please contact Louise Fleming at lkfleming@email.unc.edu with any questions.

What will we ask you to do? We will ask you to complete four online questionnaires, and may interview you, if you are willing. The questionnaires include one with general family information (such as where you live, how old your child(ren) is, etc.) as well as the Family Management Measure (FaMM)-View of Condition Impact scale, which has 10 items; *the FaMM Management Ability Scale, which has 12 items*; and the PedsQL-Family Impact Module, which has 36 items. They will measure the impact that you feel your child’s CAH has on your family, how well you feel you manage your child’s CAH, and they should take about 15-20 minutes to complete. The interview will be a telephone interview at a time that is convenient for you. The interview will take approximately 45-60 minutes.

The project has been approved institutional review board for human subjects research at University of North Carolina at Chapel Hill and is supported by the CARES Foundation. If you agree to take part, all information you give will be confidential. No one except the research team, which includes the chair of my dissertation committee, Marcia Van Riper, PhD, RN, FAAN, will have access to your information.

If you wish to be involved in this research or have any questions, please contact Louise Fleming. Email is lkfleming@email.unc.edu or telephone (919) 272-7174.

Many thanks for your kind consideration,

A handwritten signature in black ink that reads "Louise".

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