

SUMMARY EXPLANATION OF RESEARCH

Penn State College of Medicine
The Milton S. Hershey Medical Center

Title of Project: The Evaluation of Feeding Problems for Children with Spina Bifida: Do Feeding Problems Relate to Gastrointestinal Difficulties

Principal Investigators: *Keith E. Williams, Ph.D. and Kimberly A. Schreck, Ph.D.*

You and your child are invited to volunteer to participate in a research study. Research studies include only people who voluntarily choose to take part. This summary explains information about this research. You are urged to ask questions about anything that is unclear to you.

Currently, there is no research involving the eating and diet habits of children with spina bifida. Obesity in spina bifida has, to date, been largely attributed to the limited mobility and lack of activity found in this population. This research will help determine if this is true, and further, which factors are most related to obesity in children with spina bifida. Additionally, the chronic constipation found among many persons with spina bifida has been attributed primarily, often solely, to their neurological impairment. This research will help determine if other factors, such as diet quality and activity level, also play a role in constipation. This research will involve completing a questionnaire. The questionnaire asks about eating and diet habits, mobility, and bowel habits of your child.

There are no risks to participation. You may choose not to answer any question that makes you feel uncomfortable.

While you and your child may not benefit from taking part in this research study, the results of this research may guide the future treatment of children with spina bifida. It is estimated that it will take 15 minutes to complete the attached questionnaire.

No identifying information is being collected. The focus of this research is not on the information from one person, but rather on group data.

You can ask questions about the research by contacting Keith Williams, Ph.D. at either (717) 531-7117 or feedingprogram@hmc.psu.edu . If you have questions regarding your rights as a research participant or concerns regarding your child's privacy, you may contact the research protection advocate in the HMC Human Subjects Protection Office at 717-531-5687.

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You and your child do not have to participate in this research. Taking part in the research study is voluntary. Your decision to participate or to decline the research will not result in any penalty or loss of benefits to which you and your child are entitled.

Your completion of the questionnaire implies your voluntary consent to participate and your permission for your child to take part in the research.