

**ATTACHMENT L**  
Project Recruitment Pamphlet

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*What are the risks in this study?*

There are no known risks for participating. You may feel uncomfortable talking about your child to somebody you do not know. Please know that you can skip any question you do not want to answer or stop the interview at anytime.

*What are the benefits in this study?*

You will most likely not benefit directly. However, sharing your experiences and opinions may be used to help other families who have a child with spina bifida. Families will receive a payment in appreciation of their time.

*How can I learn more or sign up to be in the project?*

Call Dr. Kari Carris toll-free at 1-xxx-xxx-xxxx or email her at carris-kari@norc.org to learn more or to sign up to be in the project. We will be happy to answer any questions you may have about the project!

(insert picture of child)

# **The Natural History of Spina Bifida in Children Pilot Project**

{ insert picture of child }



Funded by the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention (CDC)

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*What is this project about?*

Little is known about what life is like for children who live with spina bifida and their families. The information collected in this project will help teach us what it is like to grow up with spina bifida in the United States today.

*Who is doing the project?*

The National Spina Bifida Program housed at the Centers for Disease Control and Prevention (CDC) is sponsoring the project. The National Opinion Research Center at the University of Chicago (NORC) is assisting the CDC with this project.

*Who can be in this project?*

Any family living in Georgia who has a 3-, 4-, or 5-year-old child with spina bifida (myelomeningocele) can participate.

*What are the goals of the project?*

The goals are to learn about development, health, learning, medical problems, physical activity, services available, mobility and functioning among children with spina bifida. It is a pilot project so we are very interested in receiving your feedback on how the project can be improved.

*If I decide to be in the project, what will I have to do?*

There are two ways for families to contribute. One option is for you, the parent, to be interviewed over the phone. The other option is for you and your child to come see us in person. Your child will participate in some screening tests related to development and learning and you will be interviewed and fill out some questionnaires. You decide if you want to do the phone survey or come and see us in person! Please note that only the phone

*Do I have to be in this project?*

No, you don't. It is totally up to you. But please know that your participation is invaluable to us and can be very important to future families who will have a child with spina bifida.

*What about my privacy?*

Your privacy will be protected according to federal laws. Your privacy is our top concern! We are depending on volunteers like you for this type of research and we understand that people will not volunteer their time if their information is not kept confidential. The information we gather will be used in statistical analyses but will not be associated with your name or other private information. The results will be reported for groups of people, and not for individuals.

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survey is currently available in  
Spanish.

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