About the Screening Program...

Why are you studying my child’s growth and development?
An estimated 12 to 16 percent of U.S. children have developmental delays or behavioral problems. Research also has shown that early intervention improves a child’s long-term scholastic and behavioral outcomes. Currently, little is known about what causes these delays in normal development. We hope the information we gather from this program will bring us closer to understanding the causes of growth and/or developmental delays.

What is the ‘Upstate KIDS: Infant Development Screening Program’?
A select group of women who recently gave birth in New York State will be enrolled in this project.

• The three main collaborators of this project include: the New York State Health Department, the University at Albany School of Public Health, and the Eunice Kennedy Shriver National Institute of Child Health and Human Development.
• Approximately 6,600 women will be recruited and asked to participate for up to three years of follow-up.
• We ask participants to complete three types of tasks during their follow-up:
  • Written surveys or questionnaires (which will include information on the mother’s pregnancy, medical history, reproductive history, and lifestyle factors)
  • The “Ages & Stages Questionnaires” or ASQs
  • Short periodic surveys of their child’s development
• With your permission, we will collect information from your child’s pediatrician on any major diagnoses if your child develops any major health conditions.

Why are you surveying mothers? Why not do laboratory studies instead?
There is no way to re-create the many events and exposures that happen during pregnancy or during early childhood development in a lab—only mothers can give us this information.

About the Findings...

How do you interpret results?
• We ask the same questions to all women.
• We don’t look at individual answers; we only consider groups. We calculate averages and other statistics for our analyses.

What will the results show?
The program looks at a large group of women and children. This means findings will apply to “the average child” rather than any specific individual. There are many possible results. We may uncover:
• Risk factors, things that contribute to growth and developmental delays.
• Protective factors, things that lower the chances of growth and developmental delays.
• Neutral factors, things that neither raise nor lower risk of growth and developmental delays.

Can you give an example of a risk factor?
Most people know that smoking cigarettes is a risk factor for developing lung cancer.
• Those with lung cancer are more likely to be smokers.
• Many people smoke and don’t get lung cancer.
• Some people with lung cancer never smoked.

Still, not smoking helps prevent lung cancer. The same will be true for findings from this growth and development survey.

What will you do with the findings?
We will publish our findings in scientific and medical journals. Because growth and developmental delays are of great interest, findings are often covered in the news as well. They may also be used in health education materials. All of our findings pertain to groups of women and children in the screening program; no one will be able to identify you from our reports or publications.

To Participate...
An interviewer will call you in about 2 weeks to give you a general overview of the program, confirm your contact information, and discuss your interest in participating in Upstate KIDS. The following points will be covered:
• This is a statewide, repeated screening program designed to look for clues about the causes of growth and developmental delays.
• As the parent/guardian, you will be asked to complete periodic ASQs. These easy-to-follow, color-coded questionnaires will cover a range of topics including your child’s communication, motor skills, problem solving, and social skills.
• If necessary, you may be referred to the state’s Early Intervention Program (EIP), which offers many helpful services to families.
• Some women participating in this program may experience emotional difficulty when discussing their pregnancies. Additionally, you may feel anxiety or sadness in the event any developmental delays in your child are identified.
• Although taking part in the program may not benefit you or your family directly, the findings may help others prevent growth and/or developmental delays in the future.
• You can choose not to participate or answer any of the specific questions from the surveys. Doing so will not result in any harm to you or your family, and will not affect the care or services you or your family receives.
• All your answers are confidential. Your identity will remain private.

For more information or questions contact: Upstate KIDS Program Office
University at Albany School of Public Health
One University Place, Room 216
Rensselaer, NY 12144
UpstateKIDS@health.state.ny.us
Toll Free: 1-888-870-0247
Do I need to finish the survey during a specific time frame?
Though not all of our questionnaires are time sensitive, the ASQ must be completed within one month of the age the questionnaire is designed to assess, to ensure the accuracy of our assessment of your child.

How will you protect my privacy?
All information you give us during the initial interview and subsequent surveys and other forms completed will be kept confidential. This means:
- Your answers will not be seen by anyone not working on the project.
- Your identity is secret. We will never use your name or your child’s name in any report or publication.
- Information about you will not be shared with anyone not working on the program, including insurance companies or other government agencies.

What does participating in the program involve?
An initial telephone contact verifying your contact information, followed by completion of an initial set of written questions on your reproductive and medical history (these will take about 40-60 minutes to complete). We will also ask you to complete periodic shorter surveys when your child is 4, 8, 12, 18, 24, 30, and 36 months old. These will include ASQs, a short reporting form documenting your child’s most recent visit to his/her pediatrician, an American Academy of Pediatrics-recommended autism screening, and a health journal to record information during your child’s routine pediatric check-ups (each of which will take about 15 minutes to complete).

What do I get for participating?
Although the program results will not benefit you or your family directly, many women feel good about helping to find causes of growth and/or developmental delays. After initial completion of the first survey, you will receive $20 for your time and effort. For successful completion of each subsequent survey, another small gift will be added.

Can’t you get this information from my doctor or my hospital records?
No. Most doctors don’t routinely ask about the topics we are studying. You are the only one who can supply the information we need.

What if I can’t remember the information you’re asking me?
It’s okay to say so. We want you to answer as accurately and honestly as possible.

How did you decide what topics to study? Are these things known to cause growth and/or developmental delays?
We don’t know what causes—or doesn’t cause—most growth and/or developmental delays. The purpose of the project is to find this out. Many topics were chosen because parents frequently have questions about them.

Questions We Have for You...
What will I be asked in the questionnaires?
The questionnaires will cover a wide range of topics, including:
- Your recent pregnancy
- Any past pregnancies
- Your health
- Prescription and non-prescription drugs taken
- Your diet
- Your family background
- Your work and hobbies
- Your lifestyle
- Questions surrounding your child’s growth and development

The surveys ask everyone the same questions in the same way. Sometimes we ask you to answer in your own words; other times, we’ll give you several possible responses to choose from.

We hope you will participate in our program. If you have any additional questions, please feel free to contact us.

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www.albany.edu/upstatekids

Questions You May Have For Us...
How did you get my name?
Your name was obtained through the registration of your child’s birth with the New York State Department of Health.

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Do I have to participate?
No. There will be no harmful effects if you refuse. Your decision will not affect health care services or other benefits you or your family may receive.