

Prenatal Microarray Follow-Up Study

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PURPOSE OF THIS STUDY

The purpose of this study is to determine the effect of copy number variants (CNV), identified by prenatal microarray testing, on your child's health and development. CNVs are deletions or duplications of genetic material. Until now, the only information we could give families who had a CNV identified at the time of prenatal diagnosis came from research done on children who were tested by microarray because they already had medical and/or learning problems. This may not show the full range of the effects of specific CNVs. Studying children with specific CNVs identified during pregnancy through prenatal microarray testing will allow us to better understand the effect of these CNVs (if any) on children. By identifying these children before they have symptoms, we may also learn why some children develop difficulties and others don't. The information gained through this study will be valuable to counsel families about the possible effects of specific CNVs on a child's health and development.

An on-line prenatal microarray resource center (www.prenatalarray.org) has been developed where you can get information, ask questions and connect with other families.

HOW DO I JOIN THIS STUDY?

Joining the study is easy! There are two easy ways you can let us know you may be interested in the study:

- 1) Tell your genetic counselor, medical geneticist or doctor that you want to join this study. He/she will provide us with your name and contact information.
- 2) Contact us directly to let us know you want to join the study.

You can contact us directly by calling 1-855-77-ARRAY (1-855-772-7729) or e-mailing us at abr2143@columbia.edu.

WHAT HAPPENS WHEN I JOIN?

Once your questions are answered and you decide to join the study we will ask you to:

- Confirm your willingness to participate in the study by signing a consent form,
- Sign medical release forms for your obstetrician, your child's pediatrician and any specialists your child may see. We may contact your pediatrician throughout the study to get more specific details about your child's growth and development.

We will check-in with you:

- Every 6 months to see how your child is doing and to answer any questions you may have.
- When your child turns 2 years old, we will mail you a questionnaire about his/her development.
- Around your child's 3rd birthday we will:
 1. Conduct a telephone interview asking questions about your child's social skills and development. This will be performed by a trained professional.
 2. Schedule an in-person evaluation to get more detailed information about your child's development. All travel expenses will be paid. We will try our best to make this appointment as convenient as possible for you.
 3. Send you a \$100 gift card once you've completed the telephone interview and the in-person evaluation described above.

At your request, we will provide you with summary reports from these evaluations. These summaries may be helpful to those professionals taking care of your child or for obtaining services. We will never send this information to anyone, unless you specifically request it.

It is important to know that all of the information we collect will be kept confidential and used for research purposes only.

We are more than happy to address any questions or concerns you have now or at any time. You can contact us at:

Telephone: 1-855-77-ARRAY (1-855-772-7729)

E-mail: abr2143@columbia.edu

FAX: 1-610-449-4857

Website: www.prenatalarray.org