



CYTOGENOMIC MICROARRAY TESTING AND THE ISCA CONSORTIUM DATABASE

Your doctor has ordered a cytogenomic microarray test as part of a medical evaluation for you or your child. This test is used to look for a genetic cause of problems in the physical, intellectual, and behavioral development of children and adults. It has significantly improved our ability to find the underlying cause of many developmental and medical problems, allowing families to learn about their specific results and make informed plans for medical and/or educational interventions.

The cytogenomic microarray test is a way for the laboratory to look at the entire genetic makeup of a person in order to find missing (loss) or extra (gain) pieces of chromosomes. Many of the losses and gains found by microarray testing are common, and their associations with medical problems are well understood. However, some findings have not been seen before. In these cases, it is not possible to determine if a particular rare result will cause medical problems.

More information is needed to understand rare results, and you can help!

A sample from you or your child will be sent to the ARUP Genomic Microarray Laboratory for microarray testing. ARUP Laboratories is a member of the International Standard Cyto-genomic Array (ISCA) Consortium, an organization of more than 100 laboratories working together to gather the information needed to understand the meaning of rare cytogenomic microarray results. ARUP contributes to the central ISCA Consortium by sending results from all microarray tests performed, along with the reason for testing (such as autism or heart defect). The central ISCA Consortium database is maintained by the National Institutes of Health.

Privacy is of the utmost importance. **All patient identity information is removed** (de-identified) before your results are submitted to the ISCA Consortium database to ensure confidentiality of your information. Researchers must request permission from the Data Access Committee, appointed by the National Institutes of Health, to use the de-identified information in the database.

On occasion, the physician who ordered your microarray test may contact you about specific research projects sponsored by the ISCA Consortium. You may be interested in participating and/or receiving information about some of these research studies. If so, your physician can give you the researcher's contact information. At no time will any researcher have access to contact information for you or your ordering physician.

The ISCA Consortium database is only possible through the results received for microarray tests, contributed by individual patients. With your help and as the ISCA database grows over time, laboratories will be able to use this information to determine the meaning of rare results. Patients with rare or uncertain results may then learn the true meaning of their results and optimize their medical care.

To Opt Out of the ISCA Database

To learn more about the ISCA Consortium, log onto www.iscaconsortium.org. If you do not want your results to be submitted to the ISCA Consortium database, you can choose not to participate (to opt out). If you opt out, your microarray test and test results will not be affected. To opt out, call ARUP Laboratories Client Services at (800) 522-2787 to request that your test results not be sent to the ISCA Consortium.