

Chromosomal Microarray Testing and the ISCA Consortium Database

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

The chromosomal microarray is a way for the laboratory to look at all of a person's genetic material in order to find missing (loss) or extra (gain) pieces of the chromosomes. Many of the losses and gains found by microarray are common and have well understood patterns of associated medical concerns. However, some microarray results are rare and have not been seen before. In some of these cases, it is not possible to know if a particular microarray result will cause a problem or not, or what medical problems may be expected. Parental testing can sometimes help to clarify this type of uncertain result.

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

Mayo Clinic Cytogenetics is a member of the International Standards for Cytogenomic Arrays (ISCA) Consortium, an organization of more than 160 laboratories working together to gather the information needed to understand the meaning of rare chromosomal microarray results. Mayo Clinic Cytogenetics contributes the microarray test result, along with the reason for testing (such as autism or heart defect), to the central ISCA Consortium database for every microarray test performed.

Privacy is of the utmost importance to us, therefore all patient identity information is removed (de-identified) before results are submitted.

The ISCA Consortium database is only possible through the contribution of individual patient results. With your help, as the ISCA database grows over time, laboratories will be able to use this information to improve the reporting of rare results and new research may be sparked. Patients with an uncertain result may then learn the true meaning of their microarray result and optimize their medical care.

To Opt-Out of the ISCA Database

If you do not want your results to be submitted to the ISCA Consortium database, you can "opt-out" of participation. If you opt-out, you can still have microarray testing and it will not affect your results.

There are three ways to opt-out:

1. Ask your doctor to check the opt-out box on the test requisition form or patient information sheet.
2. Call the laboratory and ask to speak with a laboratory genetic counselor: 507-538-2952 (800-533-1710, extension 8-2952).
3. Check the opt-out box on your final microarray report and fax to 877-749-3332, Attn: Cytogenetics laboratory genetic counselors.

Please call if you have questions about the use of your information.

To learn more about the ISCA Consortium visit:

www.iscaconsortium.org

or call 800-533-1710 extension 8-2952