

## GENETIC TESTING AND DATA SHARING

Your healthcare provider has ordered a genetic test through ARUP Laboratories as a part of a medical evaluation. This test may identify genetic variants that may cause or increase the risk for various disorders. This information may improve your provider's understanding of your condition and help them make decisions regarding management and treatment. Many genetic variants are common, and their associations with medical problems are well understood. Other variants are rare, making it difficult to know whether they cause medical problems or not.

### **More information is needed to understand the meaning of genetic variants, and you can help!**

ARUP participates in genetic data-sharing efforts in order to improve understanding of genetic variants. Included in this effort, ARUP submits genetic variants and the indication for testing from sequencing and microarray tests to public databases (e.g., ClinVar, a National Institutes of Health-sponsored database of genetic variants). To ensure that privacy and confidentiality are maintained, all personal identifiers are removed so the information cannot be traced back to you.

Rarely, the provider who ordered your genetic test may contact you about participating in research. If you are interested in participating and/or receiving information about research studies, your provider can give you the researcher's contact information. A researcher will not have access to any of your personally identifying information unless you contact them.

Data sharing can only be successful through contribution of genetic results from many patients. With your help, these databases will continue to grow, improving the knowledge of genetic variants, which could provide better understanding of patient results and treatment options. Your participation may help you, members of your family, and others with the same genetic variant or disorder in the future.

### **How do I opt out of sharing with a public database?**

If you do not want ARUP to submit your genetic test results to a public database, you can choose not to participate (opt out). Opting out will not affect your genetic test result or the ability to receive updated information regarding the clinical significance of your genetic findings. To opt out, contact ARUP at (800) 242-2787, ext. 3301, and request that your test result not be shared with public databases. Your test information will not be shared with public databases at any point after the request is made. A separate opt-out request is required for each genetic test.