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We are researchers studying the causes of craniosynostosis and our ultimate goal is to identify genes and environmental factors causing this condition. The goals of this project are achieved through the effort of the International Craniosynostosis Consortium which includes collaborators from many craniofacial centers listed on the study web site (https://genetics.ucdmc.ucdavis.edu).

We are recruiting families with at least one child with craniosynostosis. If they agree to participate each family member will need to sign a consent form. We will arrange for a clinical examination and blood sample collection from the child and his or her biological parents. These samples will be prepared so that we will not need another sample in the future. The families will not benefit directly, but we hope by learning about the cause for craniosynostosis that someday we will be able to provide better care to craniosynostosis patients. The results of our study will be published, but the participants will be coded by identification number and will remain anonymous.

These families will also be asked to participate in a survey, designed to identify environmental factors that may be causing craniosynostosis. All responses to the questionnaire will be kept confidential and shared only with the craniosynostosis collaborators (researchers) that are in the International Craniosynostosis Consortium (https://genetics.ucdmc.ucdavis.edu/icc.cfm). There will be no charges to participants in the study.

You can register for the study and complete the consent forms and the epidemiologic questionnaire online through our research web site: https://genetics.ucdmc.ucdavis.edu.

Please contact <u>Dr. Araceli Cuellar (acuellar@ucdavis.edu)</u> at 916-703-0454 or <u>Dr. Simeon Boyd, M.D. (sboyd@ucdavis.edu)</u> to inquire about our study, or to make arrangements for participation.

Sincerely,

Simeon Boyd, MD

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