Research Groups Participating in the Study

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The Saban Research Institute



ChildrensHospitalLosAngeles

International Leader in Pediatrics

The Genetics of Ewing's Sarcoma Study

Your Participation Counts!

Childrens Hospital Los Angeles Division of Hematology-Oncology

The Genetics of Ewings Sarcoma Study

What is the Genetics of Ewings Sarcoma Study?

Ewings Sarcoma is a rare form of bone cancer in children and adults. Doctors have made a lot of progress in treatment but very little is known about the causes of this disease. Childrens Hospital Los Angeles and the University of Southern California are uniting to learn more about the genetic causes of Ewing's Sarcoma and to improve prevention and treatment.

Who is asked to participate?

- Individuals of all ages who have been diagnosed with Ewing's Sarcoma.
- Parents with children who have Ewing's Sarcoma.
- Siblings of individuals with Ewing's Sarcoma.

Is my privacy protected?

We are required by law to protect your confidentiality. Your contact information is available only to study staff, and the information you give us is identified by an identification number only. Personal information will not be published in any study reports or given to any person or agency not involved in this study.

What are we asking families to do?

- Provide a blood sample.
- Give consent to researchers to process their blood sample.

Why do we need a blood sample?

By collecting blood samples from Ewing's Sarcoma patients and their family members we can look at inherited changes in the DNA that can be found in all cells in the body, and that are passed on from generation to generation.

Why is my participation important?

In order to learn about the causes of Ewing's Sarcoma and how it can be prevented, we need help from the individuals who have the disease. Scientists believe that there are many factors that increase the risk of Ewing's Sarcoma, so it is important to study as many people with Ewing's Sarcoma as possible.

Will participants be informed of study results?

The final study results will be available upon request.

Will participants be compensated?

Childrens Hospital Los Angeles will pay for blood collection and shipping costs.

Can I change my mind?

Your participation is completely voluntary. Your relationship with Childrens Hospital Los Angeles or the medical institution where you were diagnosed and/or treated will not be affected in any way if you decide not to participate. You may change your mind about participating at any time.

How do I get more information?

For questions about this study, please contact Dr. Shahab Asgharzadeh at (323) 361-6371 or send an email to <u>Shahab@chla.usc.edu</u>. You may also call Melissa Warden at (323) 361-5642 or email to <u>mwarden@chla.usc.edu</u>. Thank you for taking the time to read this and considering the possibility of participating in this study. Your participation will be a great help to the success of this project!

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