Osteosarcoma Project

For your physician

The Osteosarcoma Project (OSproject) is part of *Count Me In*, a nonprofit organization that brings together patients and researchers as partners to accelerate discoveries in cancer research. *Count Me In* is stewarded by the Broad Institute of MIT and Harvard, a leading nonprofit biomedical research institution; the Dana-Farber Cancer Institute, a leading cancer hospital; and Emerson Collective, a California-based social change organization. By partnering directly with patients, we can accelerate discoveries in metastatic breast cancer, leading to the development of new therapies and treatment strategies.

What is the goal of the Osteosarcoma project?
The overarching goal of the project is to create a publically available clinico-genomic database on osteosarcoma, comprised of clinical elements from medical records, patient-reported data from surveys, and whole exome sequencing data from patient samples.

What steps are involved for patients?
Patients register for the study online at osproject.org. By consenting to the study, patients allow us to request and obtain copies of their medical records, archived tumor samples (if available), and a saliva and optional blood sample.

What steps are involved for the physician's offices of enrolled participants?
When they enroll, participants provide information about where they have received care for their osteosarcoma. The study team works directly with medical record and pathology departments to obtain copies of medical records and portions of archived tumor samples. We will ask pathology departments to share only a part of tumor tissue, and not to share anything with us that might be needed for clinical care.

Do patients receive individual results back from this study?
Because our sequencing tests are performed in a research lab and not a clinical lab, we are not currently permitted to return personal genetic data to patients. However, we will regularly update patients with key discoveries, overall results, and progress made through this research.

What makes this project different from existing studies?
The Osteosarcoma Project seeks to empower patients and families to accelerate cancer research by sharing their samples, clinical information, and experiences with the research community. Most patients are cared for in community settings where genomic studies are not typically conducted, so this study connects osteosarcoma patients around the country with genomics research performed at the Broad Institute, allowing them to participate regardless of where they live. The study was designed in partnership with osteosarcoma patients, families, advocates, and advocacy groups, who continue to provide input on future directions.

If you have any questions about this study, please reach out to us at **info@osproject.org or 651-602-2020.**

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How is the genomic and clinical data shared?
Next generation sequencing (whole exome and transcriptome sequencing) is performed on tumor and germline DNA. Sequencing data are linked to de-identified clinical information, and the resulting data are used to identify drivers of tumorigenesis, mechanisms of response and resistance to therapies, and diagnostic, prognostic, and therapeutic biomarkers. The database of clinically annotated genomic information is shared on publicly available platforms such as cBioPortal and the NIH.

What kinds of questions is this project aiming to address?
Over the past decade, genomic characterization of tumors has shed enormous light on the molecular underpinnings of cancer. These discoveries have led to the development of novel therapies and preventive measures that have already revolutionized cancer care. Despite this progress, the genomics of osteosarcoma remains poorly understood.

The types of questions we strive to answer include:

- What are all the genes and mutations that can lead to osteosarcoma?
- What explains why some patients show extraordinary responses to a particular treatment?
- What explains why some tumors never respond to a particular treatment?
- How can we develop better treatments for osteosarcoma?

Despite the progress that has been made to begin to answer these questions, we remain far from the goal. To get there, the detailed genomic characterization of many thousands of clinically annotated cancer samples will be required.

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