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. Count Me In's Osteosarcoma (OS) Project is supported by a grant from the National Cancer Institute's Cancer Moonshot program and is part of the Participant Engagement and Cancer Genome Sequencing (PE-CGS) Network of research centers. By partnering directly with patients, we can accelerate discoveries in osteosarcoma, leading to the development of new therapies and treatment strategies.

What is the goal of the Osteosarcoma Project?
The goal of the OSproject is to transform cancer care by enabling all patients who have ever been diagnosed with osteosarcoma to accelerate biomedical research through sharing their cancer samples, clinical information, and their experiences. In order to achieve these goals, datasets containing linked clinical, genomic, molecular, and patient-reported data (without including any personal information) will be regularly shared with the biomedical research community through scientific repositories such as cBioPortal for Cancer Genomics and the National Cancer Institute (NCI) Genomic Data Commons.

What steps are involved for participants?
Participants 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. If desired, the participant may also opt-in to providing an additional saliva sample to learn more about their germline (or “normal”) DNA, described in further detail later on this page.

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 participants receive individual results back from this study?
If a participant elects to share archive tissue samples with the project, we may be able to share information about what we learned from the genomic sequencing of the tumor sample back with the participant. This information is intended to highlight how participant sample(s) are contributing to research and will not have implications for their treatment or prognosis. Because of regulatory restrictions, we are unable to share results with participants in New York and Canada.

The project is also partnering with Invitae in order to sequence and share information on germline DNA (or “normal” DNA) from saliva samples. During the project, participants may be able to decide if they would like to provide an additional saliva sample to learn more about their normal DNA and speak with a genetic counselor to understand these results. If a participant does not participate

in this process, their data will not be shared with Invitae. This process is not available for participants in Canada, as Invitae is not licensed to provide genetic counseling services there.

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.

How is the genomic and clinical data shared with the research community?
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.

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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