For your physician

The Angiosarcoma Project is a research study being launched and funded by the Broad Institute of MIT and Harvard, a non-profit academic research institution whose mission is to dramatically accelerate the understanding and treatment of disease. The study is being conducted in collaboration with Dana-Farber Cancer Institute as well as our advocacy partners. With this project, we are exploring a new approach to genomics research in which we partner directly with patients with angiosarcoma in order to speed important discoveries.

If you have any questions about this study, please reach out to us at info@ASCproject.org or 857-500-6264.

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 angiosarcoma, an orphan disease, remains poorly understood.

The types of questions we strive to answer include:

- What are all the genes and mutations that can lead to angiosarcoma?
- What explains why some patients show extraordinary responses to a particular treatment?
- What explains why some tumors never respond to a particular treatment?
- What genetic changes explain why some tumors initially respond to therapy but later recur and metastasize?
- What are all the genes that can lead to developing angiosarcoma in different sites or origin?
- How can we develop better treatments for angiosarcoma?

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 clinically annotated cancer samples will be required.

Because angiosarcoma is exceedingly rare, obtaining tumor samples for study is a major hurdle that needs to be overcome in order to further our understanding of this disease. To address this, we have launched a nationwide study, The Angiosarcoma Project, which seeks to empower patients to accelerate cancer research through sharing their samples and clinical information. We have developed an outreach program in collaboration with a number of sarcoma advocacy organizations to connect angiosarcoma patients around the country with genomics research performed at the Broad Institute, allowing them to participate regardless of where they live.

Working with angiosarcoma patients and advocates, we designed a website (http://www.ASCproject.org) with an online questionnaire that allows patients with angiosarcoma to provide information about themselves and their cancer. Patients with angiosarcoma are then offered an electronic consent form that explains the risks and benefits of the study and asks for permission to obtain a portion of their stored tumor tissue, a saliva sample, and copies of their medical records. For patients who consent, our clinical research team will contact their physicians to request copies of their medical records, which will be reviewed by our study team to confirm eligibility. Enrolled patients are sent a saliva kit and asked to mail back a saliva sample, which is used to extract germline DNA. The clinical research team also contacts the patient's pathology department and requests a portion of the tumor to be sent to the Broad Institute for genomic analysis. We will ask pathology departments to share only a part of the tumor tissue, and not to share anything with us that might be needed for clinical care. 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 will be shared with the NIH and the cancer research community. Study updates and discoveries are shared at regular intervals with all patients who complete the initial questionnaire.

This direct-to-patient approach should be particularly enabling for patients with angiosarcoma to participate directly in genomics research squarely focused on this disease. This project seeks to establish a patient-researcher partnership to accelerate genomic discoveries and improve outcomes in angiosarcoma, and may ultimately serve as a means to build a new clinical and translational research model for all patients with cancer.