EXAMPLE STORIES OF PATIENT EXPERIENCES

It is hard to think about what might happen if you choose to participate in the MI-ONCOSEQ DNA sequencing study. To make this easier, below are several stories based on the experiences of real patients who have been part of the study. We have changed some details, but the basic story in each case is real. If you have questions or concerns after reading these, please discuss with study team members or your doctor.

An example of the most likely outcome, no personally useful information: "Joe"

"Joe" really hoped that they would find something that could cure his cancer. Even so, Joe accepted the fact that that it was not very likely that study would find something that would affect his treatment. He still hoped that he could provide information to his family that would help them make health-related decisions for themselves.

After several months "Joe" had a scheduled appointment with his doctor. His doctor told him that she had received the genome sequencing results which did not identify anything that would impact his treatment. "Joe" was disappointed, however, to find out that there were no significant results about his cancer or any information he could pass on to help his family. He was not particularly surprised by these results, and he still felt okay about having participated.

An example of one possible discouraging outcome: "Mary"

When going through the informed consent process for the gene sequencing study, "Mary" made the choice not to receive any results that did not improve her chances of treating her cancer. She said at that time that she didn't want the burden of knowing information she couldn't do anything about.

After her biopsy, "Mary" learned that she has two specific mutations in her cancer. One of these mutations is the subject of an ongoing clinical trial of a new drug. However, when she and her doctor went to try to enroll her in the trial, they learned that an unrelated condition, high blood pressure, made her ineligible to participate in the trial.

Having had her hopes raised by the test results, "Mary" found the news that she could not participate in the clinical trial to be very disappointing and hard to deal with, especially because the reason seemed, in her opinion, silly. It was also frustrating because she had said that she didn't want to know about results that she couldn't do anything about.

An example of one possible outcome that might be beneficial: "Maya"

"Maya" decided to do the genome sequencing study because she wanted to help future patients with cancer. After undergoing the biopsy, she didn't think any more about the study and went about her daily life and current treatment plan.

A few weeks later she got a call from her oncologist and was surprised to find out that the study had found a mutation that could affect her treatment. A chemotherapy that is usually used for a different type of cancer might also work on her cancer. They scheduled an appointment for her to come in two weeks later to check if her current treatment is working. If not, her doctor told her that they could consider the new medicine suggested by her genome sequencing results. "Maya" felt hopeful to have another treatment option, one that might be able to help her.