

Natural History Study of Rare Solid Tumors

What is the Natural History Study of Rare Solid Tumors?

The Natural History Study of Rare Solid Tumors studies people with rare tumors over time. The goal of this study is to collect information from rare tumor patients to learn how the tumor grows and develops. This helps researchers understand these rare tumors better so that they can develop new treatments.

How do I participate in the study?

First, you will provide a saliva sample and medical records from your doctor. We will collect any samples of your tumor that may be available from a past biopsy or surgery. You will fill out questionnaires about your medical history, your family's medical history, and how having a rare tumor impacts your life. You may be invited to NIH to see doctors here and while you are here, we will collect blood and other samples, such as stool. You may also be invited to participate in focus groups about how living with a rare tumor affects your life, but you do not have to participate in these groups. Once a year, we will send you a follow-up form to record any changes in your health.

What do you do with my samples?

Your saliva and tumor samples will be used to perform genetic testing. We will combine your data with data from other people with the same tumor. If we collect blood, we will look at what kinds of cells and molecules are in your blood stream that might affect your tumor. We will look at how your immune system and digestive system work. Your samples may also be stored for future research. We will share the information we learn with other scientists while protecting your privacy. This way many scientists can work on new treatments for your kind of tumor.

What are the risks of participating in this study?

The Natural History Study of Rare Solid Tumors is not a treatment trial, so we are not testing whether an experimental treatment will work or if it is safe. Because you are not exposed to an experimental treatment, natural history studies are considered very safe and have very minimal risks.

Do I have to travel to the NIH Clinical Center to participate?

No. You can provide your saliva sample and other information from home. However, based on a review of your medical records, you may be invited to the NIH Clinical Center to meet with experts who will perform additional tests and answer any questions you have.

Can I receive treatment for my rare tumor?

Yes. You can receive treatment for your cancer while participating in the natural history study. The natural history study is not a treatment trial. Therefore, you can continue to receive the recommended care for your cancer or participate in a treatment trial. If we know of a treatment trial that we think could help you, we will let you know.

Will my genetic testing results be returned to me?

Some of the results will be returned, but some will not. Your tumor will be tested for common cancer mutations and results may suggest drugs that could treat your tumor. If we suspect that cancer may run in your family, we may test your blood or saliva for mutations, too. These results will be shared with you and your doctor. Some of the genetic testing we perform is to find new mutations and this is not the same as having genetic testing ordered by a doctor. We will share with you the combined results from many people with your tumor, but we will not tell you the results from your tumor alone. We do not charge you or your insurance company for the genetic testing that we do.

How can I learn more about the study?

You can contact us at NCICRRareTumorClinic@mail.nih.gov. Visit us online at cancer.gov/mypart. Follow us on Twitter [@NCI_CCR_PedOnc](https://twitter.com/NCI_CCR_PedOnc).