

Decisions to make if you decide to have genetic testing

Whether you want secondary findings to be a part of your medical record:

There are laws to prevent employment and health insurance discrimination based on the results from sequencing tests. However, there are currently no laws that prevent life insurance eligibility, disability insurance, or long-term care insurance discrimination based on the sequencing tests.

Whether you want to have left over tissue samples stored for future testing:

You can decide whether you want the tumor biopsy to be stored for future clinical testing and/ or for future research testing. As sequencing improves, future tests may provide more accurate and meaningful information.

Whether you want to be contacted in the future in case new information becomes available:

Currently, doctors and researchers do not entirely understand how changes in every gene affect a child's health. Over time, they might learn more about how the changes your child has can affect his or her health. When your child undergoes testing, you can decide whether you would like to be contacted if new information becomes available, and whether you would like to be contacted about participating in future research.

Whether you want to participate in research that may help other children in the future:

You have the option to decide whether you want to share your child's genetic information with doctors and researchers in the field. This information could help doctors understand cancer and affect how other children will be treated in the future.

All of these decisions can be discussed in greater detail when you meet with your doctor.

What is the Sohn-PIPseq Initiative?

The Precision in Pediatric Sequencing (PIPseq) Program at Columbia University Medical Center with support from the Sohn Conference Foundation is offering clinical cancer genomic testing for all children in need within the Tristate area **free of charge**.

Where is the testing done?

The Columbia University Laboratory of Personalized Genomic Medicine at Columbia University Medical Center (CUMC) uses the latest genetic sequencing technologies for the diagnosis and treatment of children with cancer and blood disorders.

After you have signed consent, tumor tissue along with blood or saliva will be sent to the laboratory at CUMC for testing.

Your doctor or a member of his or her staff will work with the Sohn-PIPseq project coordinator at CUMC for testing.

To Learn More, Visit Our Website

PIPseq Program

<http://columbiapedscancer.org/care/specialprograms/precision-in-pediatric-sequencing-pipseq-program/>

Discover. Educate. Care. Lead.

Sohn-PIPseq

Precision in Pediatric Sequencing Initiative

Sponsored by the Sohn Conference Foundation



Bringing clinical cancer genomic testing to all children in need within the Tristate region

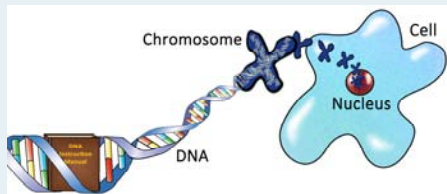
This brochure will explain new types of clinical genetic tests called whole genome sequencing and whole exome sequencing



**COLUMBIA UNIVERSITY
MEDICAL CENTER**

What is DNA and how does it relate to cancer?

The body is made up of many cell types. In order to develop, your cells must read a complex instruction manual, known as your genome, made up of DNA. Specific genes contain information for specific functions, such as your height or heart beat. You can think of these genes as pages in the manual. Often, only a subset of the entire DNA, known as the exome, is necessary for cells to understand their instructions.



Cells constantly divide to replace old or damaged cells. This continuous growth requires the cells to copy DNA from your genome. Occasionally, a change occurs when the genome is copied. This change is also known as a mutation. Some of these changes are not fixed and may cause the cell to grow out of control, causing cancer. Using sequencing, we may be able to identify the changes that are driving cancer.

How does genetic sequencing work?

To find changes, we compare the DNA sequence in normal cells to that of cancer cells. The cancer cells are taken from tumor tissue that was removed during a biopsy or surgical procedure, while normal cells are usually taken from the blood or a cheek swab.



Three different types of genetic sequencing can be performed:

Whole Genome Sequencing (WGS) is used to analyze the entire DNA sequence, also known as the genome.

Whole Exome Sequencing (WES) is used to analyze portions of the DNA sequence that contain direct instructions for cell function and development, also known as your exome.

Gene-expression-profiling is used to analyze the transcriptome, or instructions specific to a given cell, to more accurately classify cancers and predict clinical outcome.

What kind of information can I learn from genetic sequencing?

No changes: Usually sequencing results do not show any differences. This outcome can occur if there are no changes in the DNA of the cancer cells, or if the test was not advanced enough to identify them.

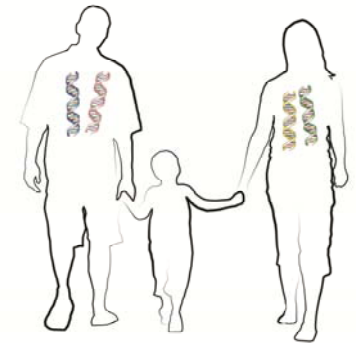
Changes that cause cancer, predict its behavior, or affect treatment options: Occasionally, sequencing results show changes in the DNA of the cancer cells. These changes may be causing the cancer or they may affect the behavior of the cancer, such as its growth or the likelihood that it spreads to other parts of the body.

It is unusual for sequencing results to alter the initial cancer treatment plan. However, this information may be useful if the cancer does not respond to the original treatment or if it returns.

Changes with uncertain significance: It is possible that the sequencing results show changes that may affect the cancer, but are not completely understood. If there is evidence strongly suggesting that it is related to the cancer then it will be reported as a change or variant of uncertain significance.

What are secondary findings?

Secondary findings are changes that are found during sequencing that may not be related to the cancer being studied. These include changes that may increase the risk for developing other diseases or reactions to certain medications. Because these changes are inherited, other family members may have the same changes and health concerns. It is important to remember that an increased risk does not always mean that the disease will develop.



There are advantages and disadvantages to learning about secondary findings. Depending on the results of the tests, other family members may want to get tested as well. The severity of certain diseases can be prevented or decrease through lifestyle changes and regular screening. Knowing about secondary findings can also increase anxiety. Ultimately, it is your choice whether you want to be informed about secondary findings.

