**Surviving a Rare Cancer, Teen Helps Study it**

**By Lauren Neergaard, Associated Press on 3.18.14**

WASHINGTON — First the teenager survived a rare cancer. Then she wanted to study it, spurring research that helped scientists find a weird gene flaw that might play a role in how the tumor strikes.

Age 18 is pretty young to be listed as an author of a study in the prestigious journal Science. But the industrious high school student's efforts are bringing new attention to this mysterious disease.

"It's crazy that I've been able to do this," said Elana Simon of New York City, describing her idea to study the extremely rare form of liver cancer. The cancer mostly hits teenagers and young adults.

Making that idea work required a lot of help from scientists, including her father, who runs a cellular biophysics lab at Rockefeller University and her doctor at Memorial SloanKettering Cancer Center. Gene experts at the New York Genome Center also helped. A second person who survived the cancer, who didn't want to be identified, co-authored the study.

**Finding a Gene Flaw**

Together, the team reported Thursday that they uncovered an oddity: A break in genetic material would leave the "head" of one gene fused to the "body" of another, resulting in an unusual protein. It doesn't form in normal liver tissue but it does in tumors, so it might fuel cancer growth, the researchers wrote. They've found the evidence in all 15 of the tumors tested so far.

Yet, it was a small study and more research is needed to see what this gene flaw really does, cautioned Dr. Sanford Simon, the teen's father and the study's senior author.

Scientists at the government's National Institutes of Health (NIH) are advising the Simons on how to set up a patient registry, which will give them a collection of information about people with the disease. NIH's Office of Rare Diseases Research has posted a YouTube video on its website. Elana Simon and another patient who survived the disease explain why teen patients should get involved in the tests.

"Fibrolamellar Hepatocellular Carcinoma. Not easy to pronounce. Not easily understood," the video says about her disease.

Simon was diagnosed at age 12. Getting an operation is the only effective treatment, but her tumor was caught in enough time that it worked. There are few options if the cancer spreads, and Simon knows other patients who weren't so lucky to have caught the disease early.

During her second year in high school, she had an internship at a laboratory studying another type of cancer. She helped researchers sort information about genes that had changed, or mutated, using her computer skills.

**Getting Tumors to Test**

Simon wondered, why not try the same approach with the liver cancer she'd survived?

A hurdle was finding enough tumors to test. Only about 200 people a year worldwide are diagnosed, according to the Fibrolamellar Cancer Foundation, which helped fund the new study. There was no registry that kept tissue samples for testing after an operation.

But Sloan-Kettering's Dr. Michael LaQuaglia, who does operations on children and was Simon's doctor, agreed to help. Simon spread the word to patient groups, and finally, samples trickled in. Sanford Simon said his daughter helped examine what was different in the tumor cells with a computer.

The New York Genome Center mapped the samples and zeroed in on the weird change in the gene, co-author Nicolas Robine said.

Sanford Simon said other researchers showed the unusual protein really is active inside tumor cells.

He calls it "an exciting time for kids to go into science," because there's so much they can research via computer.

As for Elana Simon, she plans to study computer science at Harvard next fall.