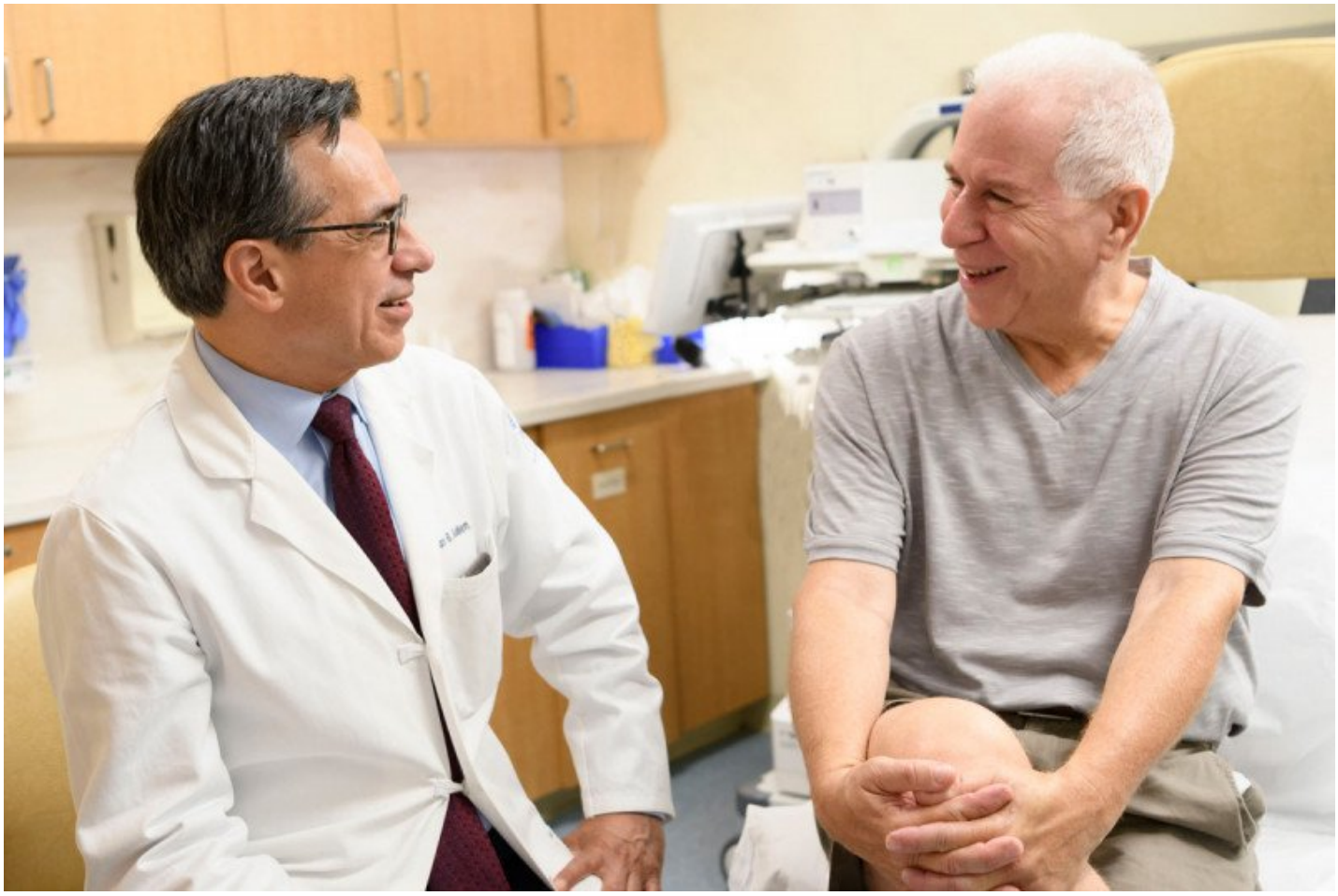
A Family Discovers an Unexpected Cancer Risk in Their Genes

By Julie Grisham, **Thursday, July 19, 2018**



MSK colorectal surgeon José Guillem (left) performed surgery on Elliot Katz after Mr. Katz was found to have a tumor due to Lynch syndrome.

Summary

> One man's cancer diagnosis spurs his brother to undergo more frequent cancer screenings, a decision that may have saved his life.

When his younger brother, Mitchell, was found to have **urothelial cancer** in 2011, Elliot Katz never expected that diagnosis might save his own life.

Mitchell, now 64, initially had surgery with then-MSK urologic surgeon Raul Parra to remove a tumor in his kidney. A short time later, the cancer came back, and he had genetic testing with **MSK-IMPACT™**. In addition to looking for 468 mutations that are known to drive tumor growth, the test can reveal cancer-related mutations in the normal tissue that someone with cancer may have inherited.

Mitchell's test results showed that he had a hereditary condition called **Lynch syndrome**. Lynch syndrome is associated with a genetic predisposition to a number of different cancer types. It's most commonly linked to **colon** and **rectal cancers** but is also known to increase the risk of developing **uterine**, urothelial, **ovarian**, and other gastrointestinal cancers.

A Cancer Risk That Runs in Families

Families that carry one of the genes for Lynch syndrome usually have many members, spanning several generations, who have had cancer, especially colorectal cancer. Elliot and Mitchell's father died of **lymphoma** when he was in his early 40s, but their family didn't have a cancer history otherwise. Their mother lived to her 90s.

Learn more about Lynch syndrome and MSK's **research on its link to cancer risk**.

After Mitchell learned he had Lynch syndrome in 2015, he met with MSK genetic counselor **Meg Sheehan**, who explained the risks to him and recommended that other family members get tested. "I was very surprised to find out I had this condition," he says. "Once I knew, it was important to me that my family have testing too, just in case they had the same thing."

Elliot, now 66, met with Janice Berliner, a genetic counselor who works at **MSK Basking Ridge**, to get tested. Elliot was found to share his brother's mutation for Lynch syndrome.

Focusing on More-Frequent Cancer Screenings

Because he was over age 50, Elliot had already begun undergoing screening colonoscopies, but only one polyp — a sign of possible precancer — had ever been found. Once he learned he had Lynch, he began undergoing **colonoscopies** every two years. The standard recommendation for the general population is every ten years. In October 2017, a few small polyps were found in Elliot's colon. "Because I knew about Lynch, I decided not to wait," he says. "I went back in six months."

At that next exam, Elliot was found to have an early-stage colorectal cancer. "I'm lucky," he says. "If I hadn't known about Lynch, I would have waited much longer to have my next colonoscopy. I probably would have missed the boat."

In April 2018, MSK surgeon José Guillem performed laparoscopic surgery to remove the tumor and a portion of Elliot's colon. Dr. Guillem also removed a number of lymph nodes to determine whether the cancer had spread. They were all clear, which indicated that Elliot would not need any follow-up chemotherapy or radiation.

In addition to being a surgeon, Dr. Guillem is Director of MSK's **Hereditary Colorectal Cancer Family Registry**. This registry allows researchers to learn more about the genetic causes of colorectal cancer and to develop new ways to prevent, diagnose, and treat cancers of the colon and rectum. It also makes it easier for people who have inherited this risk to undergo more regular monitoring.

Elliot (left) and Mitchell Katz in the 1950s

Lynch mutations are autosomal dominant, which means a person with Lynch has a 50% chance of passing it down to a child. Elliot and his wife don't have any children, but Mitchell's two daughters, ages 29 and 34, were also found to carry a mutation for Lynch syndrome. Despite their young age, they began undergoing annual colonoscopy screenings to check for polyps or other signs of colorectal cancer. This is an action they never would have known to take otherwise.

"Very few centers provide patients with information about inherited risk at the same time their tumors are genetically screened," comments geneticist **Kenneth Offit,** who directs MSK's **Niehaus Center for Inherited Cancer Genomics.** "The experience of the

Katz family shows the potential benefit of genomic sequencing, not only to offer targeted therapy but also to empower prevention and early detection."

Mitchell is receiving an immunotherapy drug called atezolizumab (Tecentriq®) for his urothelial cancer. This drug has been found to work well for many people with Lynch syndrome. He continues to see MSK medical oncologist **Gopa Iyer** for his treatment and has had no evidence of disease in the four years since he started receiving the drug.

Elliot is recovering from his surgery and doing very well. He's walking for exercise almost every day and has resumed most of his other daily activities. He says he has lost weight, and his blood pressure is better than it's been in years. He now plans to follow up with colonoscopies every year.

Hereditary Colorectal Cancer Family Registry

If you or someone in your family has a hereditary colorectal cancer, joining our registry will help to improve understanding and treatment of the disease.

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