

Seattle Architect Was Shocked When Diagnosed With a Rare Lung Cancer at 31

A second opinion and proton therapy were key to eradicating a neuroendocrine tumor.

June 15, 2026 By Fred Hutch News Service

Originally from Cairo, Egypt, Amal Moussa came to the U.S. to study architecture at the University of Washington and now lives and works in Seattle.

Last year, she began to experience unusual fatigue and after feeling particularly tired one night, she awoke to a strange burning sensation while breathing. She went to urgent care, worried it might be pneumonia.

There, they ordered a chest X-ray and doctors concluded she didn't have pneumonia, but she might have the flu. She picked up some medications but by the time she got home, the doctors had already reached out.

"They had further reviewed the X-rays and were worried about a tumor," Moussa said. "They said they wanted me to promise to go to the ER right way. They'd be awaiting me. It was shocking."

At the ER, they did a CT scan and gave her medication to help her breathe more easily. They also told her she had a tumor in her right lung, and it had spread to several lymph nodes as well.

"I was crying. It was not what I expected to hear," Moussa said. "I was exercising, I was a non-smoker, I thought I was healthy.... Luckily, my friend was there to later remind me of what the doctors had said, because I was in too much shock to take anything in."

The ER doctors referred her to Fred Hutch Cancer Center, and she had an appointment within a few days, meeting with the pulmonology team and [Keith Eaton, MD, PhD, a](#) medical oncologist and thoracic cancer specialist.

After a biopsy, Eaton informed her that she had a Stage 3 [lung neuroendocrine tumor](#) (NET), a very rare type of lung cancer.

These tumors can be harder to treat than other lung cancer subtypes because of the lack of

targeted therapies and the aggressiveness of the tumor.

“Due to the rarity of this disease, treatment protocols are not as established compared to typical non-small-cell lung cancer,” Eaton said.

Lung NETs arise from neuroendocrine cells in the lung (they help with blood flow) and usually grow slowly. Moussa’s tumor had likely been growing for a long time.

Getting a second opinion

Moussa and her care team, including thoracic radiation oncologist [Jing Zeng, MD](#), talked through several treatment options.

Her surgery team was worried they would have to remove the entire right lung and — given her young age and the consequences to her long-term wellness — recommended chemotherapy and radiation.

Moussa was having a hard time accepting her diagnosis and such an intense treatment plan, she said, so she decided to get a second opinion. Her Fred Hutch doctors, Eaton and Zeng, encouraged her to do it so Moussa flew out to the Mayo Clinic in Minnesota.

“They recommended surgery followed by proton therapy,” Moussa said. “I was on the phone a lot consulting with Dr. Eaton during this. They ended up performing the surgery there and removed two of the three lobes in my right lung as well as a number of lymph nodes.”

Moussa didn’t tell her family back in Egypt about her diagnosis until she had a treatment plan in place. They were so far away and she didn’t want to worry them, she said. But her mother and siblings flew out to be with her during surgery, and her mother stayed with her for the entire treatment course.

“I felt so grateful to have all this support, both from my family and my local friends,” she said.

Proton therapy for Lung NETs

When Moussa returned to Seattle and met with Zeng, she opted to have proton therapy for post-operative radiation to the surgical area and lymph nodes to ensure all microscopic cancer cells had been killed.

Protons, Zeng explained, would reduce the long-term side effects to her healthy organs. Because Moussa was so young, they wanted to make sure exposure of radiation to her heart, left lung and liver would be minimal.

“I really loved my radiation therapists,” Moussa said. “They were all so sweet and kind and

accommodating. And Dr. Zeng was very responsive and attentive to my symptoms and gave me helpful suggestions on navigating treatment. The people were just great.”

Moussa went through six weeks of proton therapy. She often felt tired, but her care team encouraged her to walk, so she and her friends took her corgi, Martini, for walks around the neighborhood. Early on, she began to have trouble swallowing, and it got progressively worse over time. She also developed intense pain from inflammation towards the end of her treatment. She met with the integrative medicine team and started physical therapy and acupuncture, which she continued after treatment.

“The pain came on quickly about four and a half weeks in, but it also went away quickly once I was done, and the swallowing quickly improved as well,” she said.

Moussa finished treatment the day before her 32nd birthday.

“A lot of people came for my last day, including friends and family and my favorite radiation therapist,” she said. “It felt like a big milestone. Forget 31. This was going to be a new year, new beginnings.”

Life after cancer treatment

Moussa continues to recover today. She will have to be monitored for the rest of her life, but her most recent scan was clear, leaving her hopeful.

“Dr. Zeng said she considers me cured, but that time will tell,” she said.

Moussa gets out of breath very easily — she only has one and a third lungs now. And she still occasionally experiences lingering pain in her ribs. She said she’s learned to listen to her body and prioritize rest.

“I’m just glad to be here,” she said. Her energy is improving; she’s back at work full-time and she’ll soon be leaving for a two-week visit to Cairo to see family and friends. She’s also doing pottery, spending time with her friends and Martini and hopes to be able to spend time outside with her loved ones this summer.

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