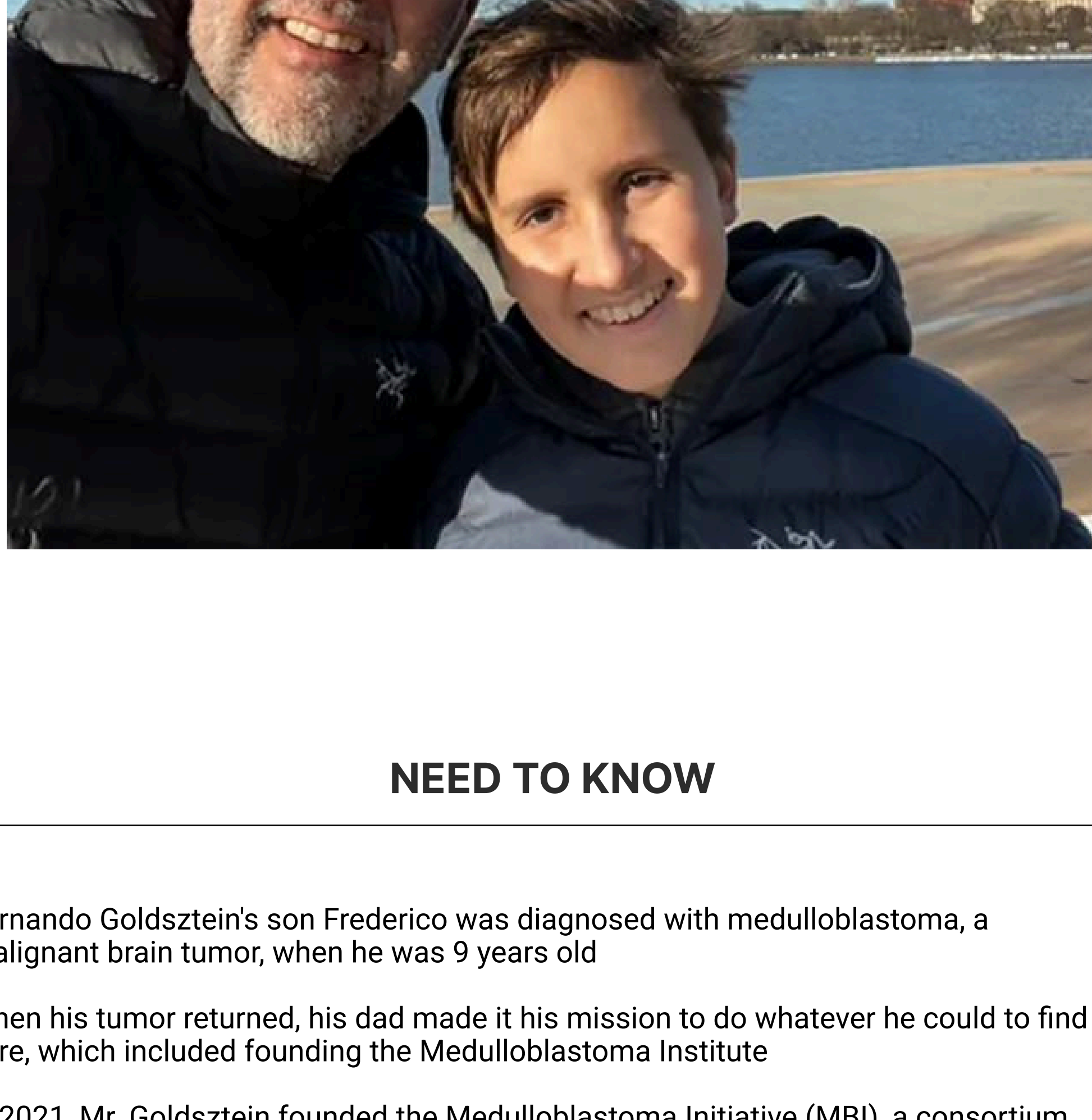


Exclusive

# Dad Is in Race Against Time to Save Teen Son and Thousands of Other Kids with Same Rare Brain Tumor (Exclusive)

Fernando Goldsztein founded the Medulloblastoma Initiative in 2021 to find a cure for his son and others living with the same diagnosis

By **David Chiu** Updated on January 20, 2026 11:28AM EST



## NEED TO KNOW

Fernando Goldsztein's son Frederico was diagnosed with medulloblastoma, a malignant brain tumor, when he was 9 years old

When his tumor returned, his dad made it his mission to do whatever he could to find a cure, which included founding the Medulloblastoma Institute

In 2021, Mr. Goldsztein founded the Medulloblastoma Initiative (MBI), a consortium that brings together scientists around the world with the goal of raising funds for clinical trials of new therapies against medulloblastoma.

"I want to save Frederico, but now, it's much bigger than him," Fernando tells PEOPLE. "We are talking about thousands of kids, and this is the purpose of my life"

Fernando Goldsztein, an entrepreneur based in Brazil, remembers a time when he, his wife, Barbara, and their two young sons, Frederico and Henrique, were living a normal life. But that changed in 2015, when Frederico began having headaches and vomiting spells at the age of 9.

Doctors initially didn't find anything seriously wrong with him until a new symptom, double vision, led him to be diagnosed with a malignant brain tumor known as [medulloblastoma](#).

"It's very hard to put in words," Fernando tells PEOPLE. "We were terrified with the diagnosis. It's kind of like the watch stopped and our lives froze, and then everything started from there."

About 500 children are diagnosed with medulloblastoma each year, according to estimates published in the [Journal of Clinical Neuroscience](#) — and it accounts for approximately 20% of all childhood brain tumors.

Determined to help his son and other kids around the world living with the same rare cancer, in 2021, he started the Medulloblastoma Initiative to raise money and awareness — and to find a cure.

"This is my purpose," he says. "This is my motivation. That's how I spend my time nowadays."



Following his initial diagnosis, Frederico underwent surgery, later traveling to Boston for months of radiation treatments.

"My parents told me that I had a little ball in my head and it would have to have it removed," says Frederico, now 19. "After that, there were 30 sessions of radiation and nine rounds of chemo. There were side effects. Nausea, vomit — and I could not feel the taste of the food. It was really tough."

Although his dad was terrified by the course of treatment, he said his son's bravery never wavered. "He faced everything with lots of courage," Fernando says.



The family later returned to Brazil where Frederico had medical follow-ups every three months. However, in 2019, the family learned that Frederico's tumor had come back, which led to more radiation and chemo treatments.

According to the [American Cancer Society](#), medulloblastoma recurs for about 30% of children, but their 5-year survival rate is "close to zero" as "with recurrence, there aren't any other effective treatment options."

"A relapsed medulloblastoma is equal to a death sentence," the boy's dad says. "The doctors in the U.S. told us that there might be something to do like a clinical trial, but the best option would be to go back to Brazil and for Frederico to be with the people that he likes."



But Fernando wasn't ready to give up hope.

He started talking with more people, which brought him in contact with [Dr. Roger Packer](#), a pediatric neurologist with the Children's National Research Institute. From that meeting, Fernando discovered that the current treatments for medulloblastoma were outdated and had seen little innovation over the years.

A donation from Fernando to Packer led to the formation of a group of the best scientists in the field. Impressed, Fernando then started MBI "to create something bigger and faster" and "to find the cure as fast as possible."

Since then, the organization has raised \$13 million to date and oversees 16 laboratories working together on their shared goal.

Additionally, Fernando says that they have [two clinical trials that were recently approved](#) by the FDA — one that attacks the tumor by allowing the patient's own cells "to identify and destroy the cancer cells," and the other that tests an mRNA vaccine that "generates a targeted immune response to destroy tumors."



Although Frederico is not a part of the new trials — as his dad explains, Frederico's health has stabilized to the point where no tumors show up on MRI, which makes him ineligible to participate — he knows that they're still in a race against time.

"He does not need this trial so far, but we know that his tumor will come back because it always does," he says.

Still, for the moment his health is stable — and Frederico, who graduated from high school last year, is about to start his freshman year of college.



Since starting MBI, Fernando has maintained contact with other families all over the world affected by medulloblastoma. "They see us maybe as their only hope," he says of the families he communicates with through Zoom and WhatsApp. "It's very hard, but that gives me strength to work even harder."

"I want to save Frederico, but now, it's much bigger than him," he adds. "We are talking about thousands of kids, and this is the purpose of my life."