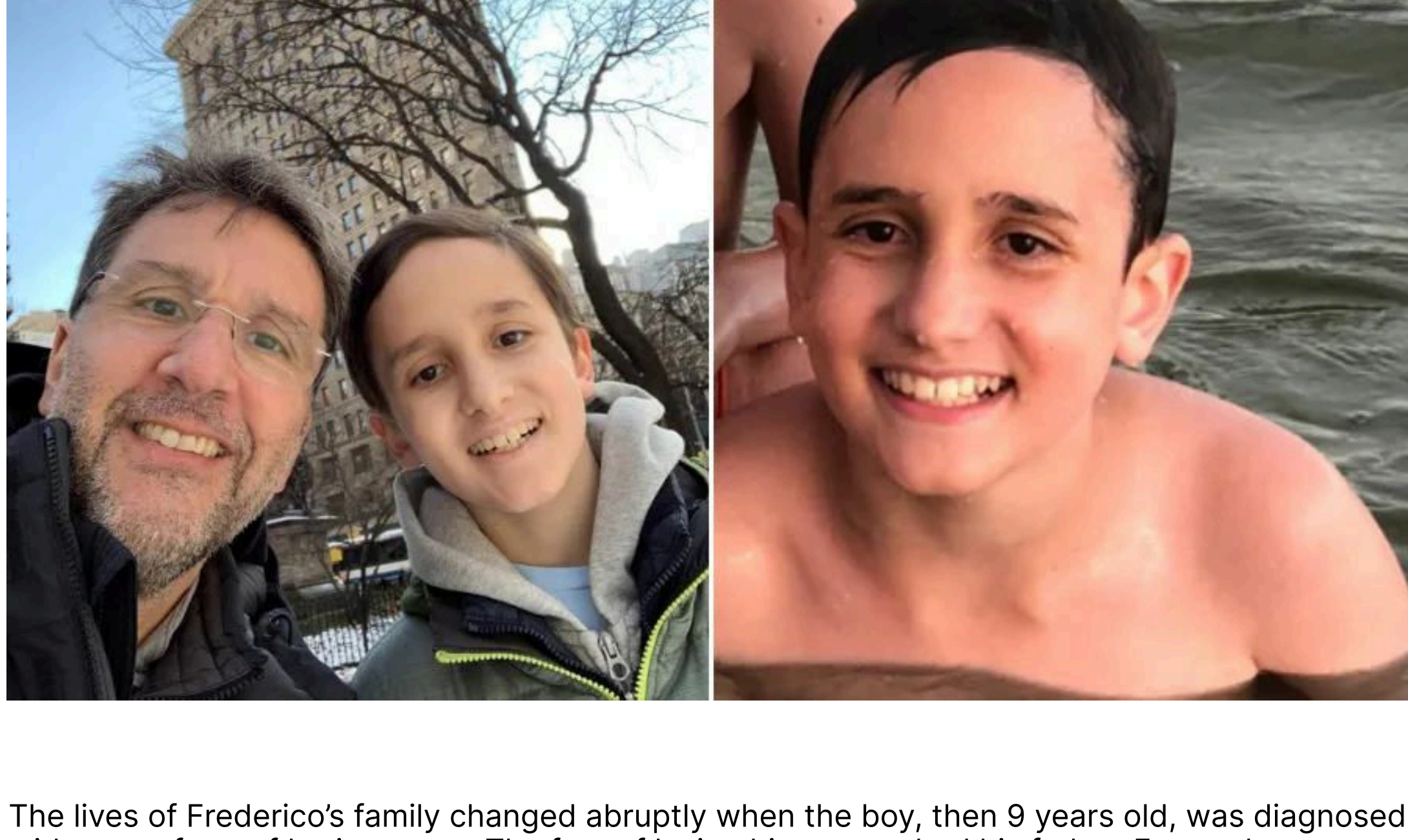


'I'm going to save my son': father launches initiative to study brain cancer

By Giovanna Arruda - VivaBem

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The lives of Frederico's family changed abruptly when the boy, then 9 years old, was diagnosed with a rare form of brain cancer. The fear of losing his son pushed his father, Fernando Goldshtein, to create an initiative that now seeks new treatments against medulloblastoma.

Frederico received his first cancer diagnosis in 2015. Medulloblastoma is the most common malignant brain tumor in children and develops from embryonic cells.

"The disease originates specifically in the cerebellum, the area of the brain that governs, among other functions, balance," explained Dr. Andrea Cappellano, a pediatric oncologist and head of neuro-oncology at GRAACC Hospital in São Paulo (the Support Group for Adolescents and Children with Cancer).

The tumor disrupts the flow of cerebrospinal fluid — the liquid that circulates throughout the brain and spinal cord — causing a buildup in the brain's internal cavities, known as ventricles. This accumulation increases pressure inside the skull and triggers symptoms.

Because the tumor is located in the cerebellum, patients may struggle with movement, losing their ability to walk normally due to impaired balance. "The child begins having frequent vomiting, sometimes waking up at night to vomit forcefully, along with persistent and worsening headaches," Dr. Cappellano said. "There may also be eye misalignment, such as strabismus."

These were the symptoms Frederico experienced. "At first, nothing seemed serious. The symptoms could have been easily mistaken for emotional issues or something minor," Mr. Goldshtein said. "That ended up delaying the diagnosis, which only arrived after he developed double vision."

"If symptoms persist, imaging can make all the difference between an early diagnosis and a tragedy"
— Fernando Goldshtein

Frederico began the so-called "gold standard" treatment for medulloblastoma. According to Dr. Cappellano, treatment begins with surgery to remove the tumor. Subsequent treatment depends on the patient's risk category, which considers age, the extent of tumor removal and whether metastasis is present.

After surgery, Frederico received radiotherapy and chemotherapy. To combat medulloblastoma, treatment is quite aggressive and can cause immediate side effects (those that occur at the time the medication is being administered) and long-term side effects (those that occur over time, after the end of treatment).



Radiation, for example, may increase the risk of secondary brain tumors later in life.

"Radiotherapy can affect different areas of the brain, causing attention and learning problems or hormonal changes due to radiation in the hypothalamus," Dr. Cappellano said. Treatment may also impair hearing, motor function, and growth, since radiation is also directed at the spine.

According to Mr. Goldshtein, Frederico did not experience side effects. "Even so, he suffered a great deal during the treatment," Mr. Goldshtein said. By 2016, Frederico entered remission — when the signs of cancer disappear.

Recurrence of the disease motivates the creation of an international initiative

The cancer returned in 2019, reigniting the family's fear of losing Frederico. According to Dr. Cappellano, recurrence in medulloblastoma is especially challenging to treat. "Saving patients with recurrence is extremely difficult," she noted.



"In the United States, some of the leading specialists told us there was nothing left to do. That was the moment I decided I would not accept that fate. I told myself: I will fight. I will find alternatives. I will save my son."
— Fernando Goldshtein

The parents' fear turned into determination. "I began searching for alternatives across the world until I connected with Dr. Roger Packer at Children's National Hospital in Washington, D.C.," Mr. Goldshtein said.

"I was deeply impressed by his work and his ability to unite the best scientists globally. I made a personal donation to help launch a new collaborative project among laboratories, and from that, the Medulloblastoma Initiative (MBI) was born."

Created in 2021, the MBI seeks new forms of treatment, since the standard treatment protocol used today was developed by Dr. Packer in the 1980s.

Dr. Cappellano stresses that current treatment offers survival rates considered "excellent" for many patients. "We must be extremely careful before changing a protocol that works, especially for low-risk patients," she noted. Still, Dr. Cappellano considers the studies supported by the MBI essential.

"[The results] are crucial for classifying patients according to the molecular groups of medulloblastoma, identifying which patients are likely to experience recurrence and developing alternative treatments — we need to reduce long-term effects," she said.

According to Mr. Goldshtein, in just 4 years, the MBI has raised more than US\$ 10.5 million through families, companies, and foundations. "But more notable than the amount is the pace with which the resources have translated into concrete scientific results."

The initiative has already secured Food and Drug Administration (FDA) approval for two clinical trials.

"The first children have begun receiving these new experimental therapies," Mr. Goldshtein said. "It is still too early to talk about a cure, but progress has been remarkably fast. Getting two FDA approvals in such a short period shows that we are moving in the right direction."

The MBI now collaborates with 16 laboratories in 12 institutions across the United States, Canada, and Germany. "At our last scientific meeting in July, nearly 30 scientists gathered in person to share data and results in real time," Mr. Goldshtein said. "This shows that science can advance much faster when there is true collaboration."

Dr. Cappellano hopes eventual breakthroughs will be available to Brazilian children as well. Researchers in Brazil, including at GRAACC, also study medulloblastoma.

According to Mr. Goldshtein, Brazil is expected to join MBI's studies through a partnership with the Einstein Hospital Israelita in São Paulo. The hospital told VivaBem it expects to begin receiving research results next year.

Hope amid the uncertainty of diagnosis

Today, Frederico has no evidence of new tumors. He does, however, live with lasting effects from treatment, particularly balance issues and growth challenges. "He is extremely resilient, brave, and full of life. He faces everything with remarkable strength," Mr. Goldshtein said. "Not every family has the financial or emotional ability to do what we did, but I hope our story and our initiative inspire others to push for cures for other rare diseases."

"I share every discovery and every advance with him. He is very proud of the work we are doing and sees enormous hope in this journey. He understands that this is not just for him, but for thousands of other children."
— Fernando Goldshtein



Today, at 19, Frederico is preparing for college entrance exams and spends his free time reading and taking photographs. [On Instagram](#), he shares images from his travels around the world.