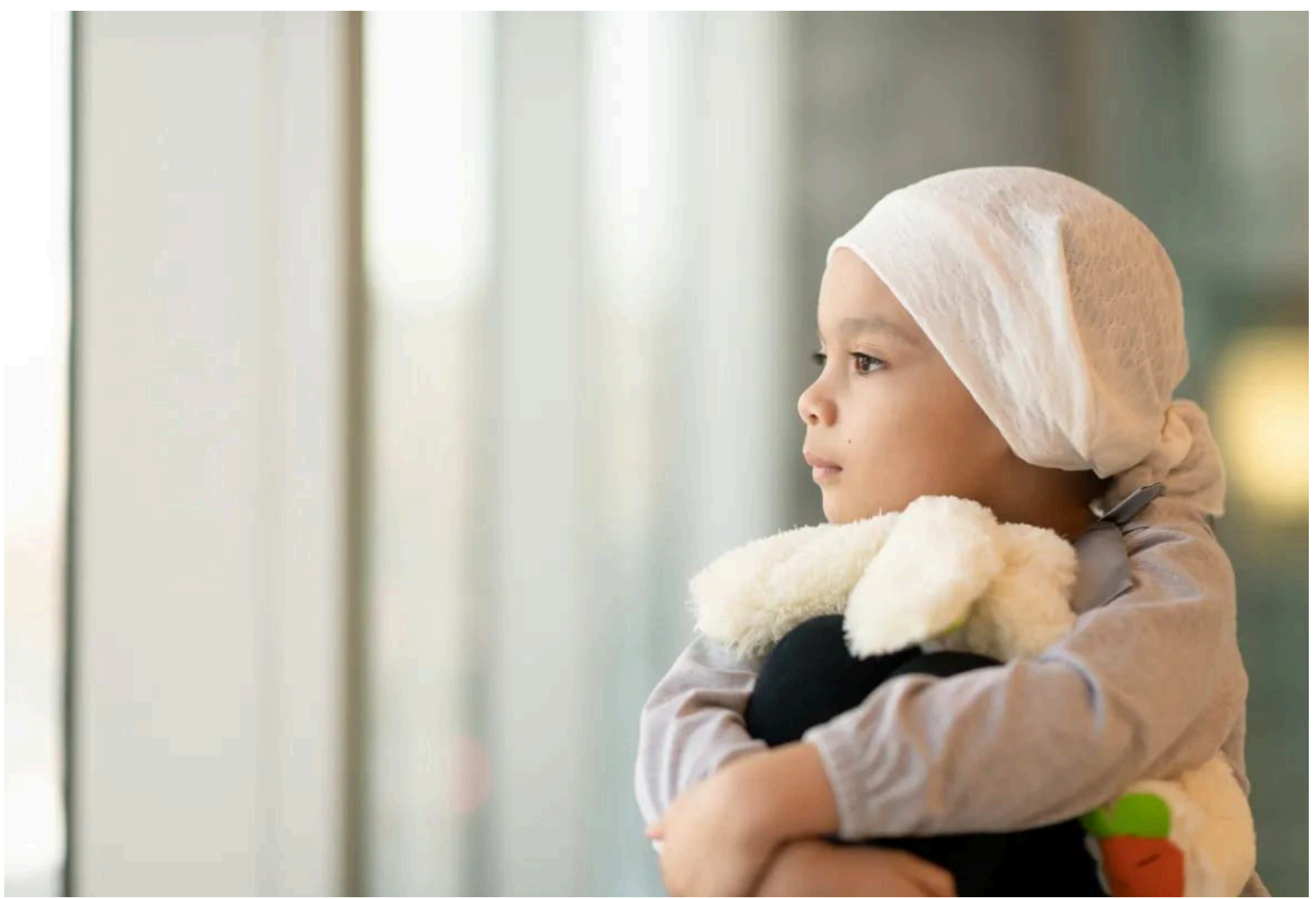


Initiative created by Brazilian accelerates research into childhood cancer

Medulloblastoma Initiative, created by Fernando Goldsztein, funds studies that promise to transform the treatment of a rare type of brain tumor

By Gabriela Maraccini, CNN

Sept. 23, 2025 — 05:00 a.m. | Updated Sept. 23, 2025 — 06:20 a.m.



At age 9, Frederico, the son of Brazilian businessman Fernando Goldsztein, began experiencing unexplained headaches and vomiting. After weeks of medical consultations and diagnostic tests, the boy was diagnosed with medulloblastoma, a malignant brain tumor.

Reaching that diagnosis in 2015, however, was far from straightforward. “It is not the general rule, but sometimes doctors hesitate to order imaging right away to rule out a brain tumor because it is considered a rare disease,” Mr. Goldsztein said in an interview with CNN. “But unfortunately, it affected my son, and he was diagnosed only after some time.”

Standard treatment for medulloblastoma includes surgery to remove the tumor, followed by chemotherapy and radiotherapy. However, after multiple attempts to cure the disease, doctors told Mr. Goldsztein there were no effective options left for his son. “They told us there was nothing left to do because my son had fallen into the 20% to 30% of patients who do not respond to treatment. The tumor had returned and there was no cure,” he recalled. “But giving up on my son was never an option.”

Refusing to accept the grim prognosis, Mr. Goldsztein embarked on a personal mission — not only to find a cure for his son, but to help thousands of other children facing the same diagnosis. Out of that determination came a new research model built on cutting-edge science, direct funding, and international collaboration. The result was the creation, in 2021, of the Medulloblastoma Initiative (MBI).

In just 30 months, the MBI raised US\$ 11 million and formed partnerships with 17 leading institutions in the United States, Canada, and Germany, accelerating scientific discoveries that once took more than a decade to reach patients. The key driver of this acceleration was the Cure Group 4 Consortium, created with Dr. Roger Packer, a pediatric neurosurgeon in the United States.

“The institutions operate collaboratively and in complete synergy. Each one contributes a piece of the puzzle,” Mr. Goldsztein said. “There are no [information] silos, no duplicated efforts. This synergy allows our research to move faster than it ever could if each laboratory were acting alone.”

The initiative has been recognized by the Massachusetts Institute of Technology (MIT) as a funding model for rare-disease research that could be applied beyond medulloblastoma.

“One major difference with the MBI is the sense of urgency,” Mr. Goldsztein said. “Family-led initiatives like ours are not uncommon in the United States, but many of them are created in memory of children who have already passed away. In my case, I created the MBI to save my son and other children. That gives it a unique sense of urgency, where every day and every week count in conducting studies focused on finding a cure for this disease.”

In the coming months, the MBI will launch its first clinical trial involving advanced immunotherapy, approved by the U.S. Food and Drug Administration (FDA). The treatment aims to stimulate the body’s own immune response against tumor cells.

Another study underway is developing an RNA-based vaccine against medulloblastoma, using messenger RNA technology similar to that employed in COVID-19 vaccines, with potential for global distribution.

“It is not a question of ‘if’ we will find a cure, it is a question of ‘when,’” Mr. Goldsztein said.

Understanding medulloblastoma

Medulloblastoma is an aggressive tumor that develops in the cerebellum, the region of the brain responsible for balance and motor coordination. Although rare in the general population, it is the most common malignant brain cancer in children, accounting for roughly 20% of pediatric brain tumors.

“Most diagnoses occur between ages 5 and 9, with a slight predominance in boys. While it can occur in adults, those cases are far less frequent,” explained Dr. Cláudio Galvão de Castro Junior, a hematologist and pediatric oncologist who advises the MBI.

Symptoms may include persistent morning headaches, unexplained vomiting, balance problems, vision changes and, in infants, unusually rapid head growth. “Parents and health care providers must stay alert,” Dr. Galvão said. “The early signs may seem nonspecific, but early detection makes all the difference in prognosis.”

Standard treatment combines surgery, radiotherapy, and chemotherapy, but the side effects can be severe, including cognitive deficits, hormonal changes, and hearing loss. “Medicine is moving toward more targeted therapies,” Dr. Galvão added. “Current research aims to reduce radiation doses for low-risk children and to explore immunotherapies and new targeted drugs that may improve survival and, most importantly, quality of life.”