Brazilian businessman's initiative creates a chance of cure for a rare type of cancer

After his son was diagnosed with medulloblastoma, Fernando Goldsztein, a businessman from Rio Grande do Sul, Brazil, created the MBI, a consortium that brings together laboratories and medical institutions for research

By Helena Benfica - São Paulo
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"Our desire is for Brazil to be the first country to benefit from the trials," Fernando Goldsztein said — Photo: Ana Paula Paiva/Valor

Finding a cure for a disease can take years of research, especially if it is a rare disease. But what if this period could be considerably reduced? This is the goal of the Medulloblastoma Initiative (MBI), a consortium that brings together laboratories and centers of excellence to discover a cure for medulloblastoma (a rare type of brain cancer that mainly affects children) within two years from mid-2025, which is when clinical trials begin. In the conventional model, this process would take 7 to 15 years.

Created in 2021 by Fernando Goldsztein, a businessman from Rio Grande do Sul, Brazil, MBI is the result of a personal drama. In 2015, his youngest son, Frederico, then 9 years old, was diagnosed with type IV medulloblastoma. He underwent surgery to remove the tumor and dozens of sessions of radiation and chemotherapy in Boston, in the United States.

Four years later, in 2019, the news came that Frederico's tumor had returned. In these cases, the therapies that exist so far are practically ineffective. According to the American Cancer Society, medulloblastoma recurs in about 30% of children, and in these cases, the five-year survival rate is close to zero due to the lack of effective treatments.

It was at this moment that Mr. Goldsztein began to understand the reality of treatments for the disease, which until now had followed protocols established for more than three decades and without scientific advances or innovations on the radar.

"He [Fernando] asked me what we could do if we had resources available," Dr. Roger Packer said, the American physician responsible for Frederico's treatment. He is senior vice president of the Center for Neurosciences and Behavioral Medicine at Children's National Hospital in Washington, D.C., and a world reference in pediatric neuro-oncology. "My promise was that we would do whatever was scientifically sound, but in a slightly less conventional way."

Dr. Packer's proposal consisted of bringing together different institutions to work collaboratively on research focused on type IV medulloblastoma – something that had not been done until then. To be part of the consortium, the central condition was to break down any barrier or competition, ensuring the immediate sharing of data and advances between the laboratories involved.

"The mission was to get a new therapy available to children in two years, which is virtually unheard of, since going from discovery to therapeutic application in people can normally take 15 years," Dr. Packer said. The model was readily accepted by Mr. Goldsztein, who invested his own resources to found the MBI.

Graduated in administration, he made a career in the real estate segment with his family's construction company in Rio Grande do Sul. In 2010, the business was sold to Cyrela, one of the largest construction companies in the country, where he joined the board of directors.

Since the foundation of MBI, most of his time has been dedicated to finding a cure for his son's cancer and learning about the history of other families facing the same problem. The experience with Frederico revealed to him a situation that he was unaware of until then.

"There is no focus on children. In the United States, of all the amount available for research, only four cents of [each] dollar are directed to pediatrics," he said.

Three years later, the institute already collaborates with 16 laboratories and medical institutions from several countries and has raised more than US$ 11 million, with most of the donors being Brazilian. So far, there have been two clinical trials approved by the U.S. Food and Drug Administration (FDA). The first trial, already in the phase of tests in patients to ascertain its safety and efficacy, is an unprecedented immunotherapy.

Unlike traditional therapies, which can also affect healthy cells, this approach seeks to train the patient's own immune system to recognize and fight tumor cells exclusively. Researchers have compared this strategy to a "guided missile", capable of attacking cancer with greater precision and reducing side effects.

Another approved treatment involves cancer vaccines based on RNA, the molecule responsible for protein synthesis. While traditional vaccines are developed to prevent infections caused by viruses common to the entire population, cancer vaccines are formulated in a personalized way, based on the characteristics of the tumor already existing in each patient. The goal is to stimulate a specific and long-lasting immune response against malignant cells, helping the body to eliminate them and and prevent disease recurrence.

A third trial, still pending FDA approval, involves a technology known as CAR-T. In this type of treatment, scientists genetically modify the patient's T cells, responsible for the body's defense, to attack cancer cells. The technique has already proven to be highly effective in hematological tumors, such as leukemia and lymphomas, and is considered one of the main advances in precision oncology. The expectation, according to Dr. Packer, is that this treatment will be released for clinical trials in March.

At this moment Frederico has no sign of an active tumor, for this reason he has not yet benefited from the advances in research. But it is known that cancer can return at any time, hence the urgency of MBI to have an effective treatment as soon as possible.

He currently lives in Brazil and goes to the United States periodically for follow-up examinations. At the age of 19, the young man tries to lead a life as normal as possible. He is currently preparing for college entrance exams, plans to study geography in college and cultivates photography as a hobby.

In addition to research, another commitment of the MBI is to ensure that these discoveries are not restricted to developed countries. In early November, the institute signed a memorandum of understanding with Hospital Israelita Albert Einstein, the institution's first formal collaboration with a Brazilian organization.

The agreement provides for scientific collaboration, knowledge sharing, and priority participation in future clinical trials developed by the consortium. "Depending on the results, our desire is for Brazil to be the first country to benefit from the trials. But this is an intention, because we depend on third parties," Mr. Goldsztein said.

For Dr. Packer, who has been following research in this segment for more than 40 years, the experience with the MBI has represented not only a professional opportunity but also a personal change. He, who for a long time considered himself someone who saw "the glass half empty", says that recent progress has made him more optimistic. "Over the last decade, I've been part of things I never thought I'd see in medicine," he said.

Although cautious, he believes that MBI may become a reference for other treatments. "What we are realizing is that this model works and that, in the near future, it should become a sustainable way to bring new therapies to children with other types of brain tumors."