



A MATTER OF
CONSCIENCE

AT THE HEAD OF THE MEDULLOBLASTOMA INITIATIVE (MBI), FERNANDO GOLDSZTEIN, AN ENTREPRENEUR FROM RIO GRANDE DO SUL, BRAZIL, LEADS A TASK FORCE TO FIND A CURE FOR ONE OF MOST COMMON PEDIATRIC BRAIN CANCERS.

Emanuel NEVES

“Children should never have cancer” – If there was a referendum to vote on changes to the rules of life, Fernando Goldsztein would be the most passionate advocate of this proposal. After all, it is the phrase he repeats the most. A lament transformed into a motto and the purpose of his existence.

An undergraduate in Business Administration from PUCRS, Goldsztein is one of the partners of Cyrela, one of Brazil's main construction companies. However, the role that now best defines him is that of founder of The Medulloblastoma Initiative (MBI). The Initiative is dedicated to raising funds for the treatment of medulloblastoma, the most common pediatric brain cancer. In 2015, at the age of 9, his son Frederico was diagnosed with the disease. It was then that Goldsztein initiated a complicated relationship with Frederico's condition, defined by great resistance and empathy. “Only those who have experienced it firsthand truly understand the severity of the situation. Life is our most precious asset. And the life of a child is even more invaluable,” he says. In fact, cancer was not unfamiliar to him. In 2005, Goldsztein traveled to Houston, US, to treat a bone tumor. The treatment was successful, and the cancer was in complete remission.

However, dealing with medulloblastoma is more challenging. The tumor affects the ce-

rellum, which is responsible for motor coordination. Each year, 25,000 cases are diagnosed – and very rarely in adults. Treatment has barely evolved since the 1980s. It is aggressive and often causes lasting developmental sequelae in children. Approximately 70% of patients are cured, while the remaining 30% often succumb to the disease. “We ended up on the wrong side of the statistics,” says Goldsztein. For these cases, there are no established treatment protocols. The solution is to take a chance with experimental treatments. Goldsztein then reached out to Dr. Roger Packer, one of the leading experts in pediatric brain tumors, of Children's National Hospital in Washington, DC. Goldsztein made an initial donation of US\$3 million of his own money to help advance research. But he knew he had to take things further. In 2021, he created the MBI to expand fundraising efforts and finance a consortium of laboratories dedicated to exploring new pathways for a cure. Currently, Frederico is doing well, and his cancer is under control. The rapid advancement of research gives hope to thousands of other patients.

In this conversation with Revista PUCRS, Fernando Goldsztein sheds light on MBI's journey and discusses the Conexões de Valor project, an event showcasing initiatives by PUCRS alumni, inspired by his experiences at the Massachusetts Institute of Technology (MIT).



“A CANCER DIAGNOSIS IN AN ADULT IS ALREADY DRAMATIC. BUT MANY DEVELOP THE DISEASE DUE TO LIFESTYLE HABITS. IN CHILDREN, IT DOESN'T HAPPEN LIKE THAT. IT'S ONLY THE LOTTERY OF LIFE. IT SHOULD BE PROHIBITED.”

The MBI is the result of your search for treatments for Frederico. How did you navigate such a complex situation?

It was a harrowing moment. We reached an impasse as there were no established protocols for his case. Medulloblastoma affects 30,000 children annually, of whom 10,000 will not survive. I felt compelled to contribute to changing this scenario. So, I reached out to Dr. Packer and made an initial donation. While significant, I knew it wasn't enough. With this money, Dr. Packer was able to assemble a team of some of the most renowned scientists in the world. Today, the project supported by the MBI has a consortium of 13 laboratories in the US, Canada, and Germany. This ecosystem includes three of the top five medulloblastoma experts. Our aim is to develop treatments that could lead to a cure for the disease.

And how does this process work?

The 13 laboratories work online, collaboratively and synergistically, to achieve new discoveries. In under 3 years, we've

already developed four clinical trial protocols – two of which have been submitted to the FDA. This is unprecedented. Typically, such studies take much longer. We anticipate new experimental treatments within the next 2 years. This is all thanks to the structure assembled by Dr Packer. I merely found him.

What makes the treatments being tested unique?

They are all based on immunotherapy, a technique that uses the body's own defense cells. Lymphocytes are trained to attack tumor cells. There are cases of pediatric cancers, such as leukemia, that are being treated with this technique. We want to know if immunotherapy also works for solid cancers. The more clinical trials are conducted, the more chance we have of establishing an effective protocol.

One study revealed that it is possible to detect medulloblastoma in embryos. Could this lead to preventive measures in the future?

This is the work of Dr. Michael

Taylor (University of Toronto), who received support from the MBI. But this is something that goes beyond our Initiative. The idea is that, in the future, there will be a test capable of detecting whether or not a child will have medulloblastoma. The process would be similar to that of a polyp in the intestine. You remove it to prevent the tumor from forming. The project is still very early. It will take decades to develop a vaccine, for example. But this is still an advance.

Medulloblastoma is the most common brain cancer in children. Why was treatment stagnant for so long?

Although the average number of cases seems high, it is insignificant from a statistical point of view. Therefore, the pharmaceutical industry and governments are not interested in funding research in this area. This can only be changed by philanthropy.

Why invest in research abroad?

Research was already more advanced abroad. The laboratories were not chosen at random; all of them had already received funding to study childhood cancer treatments. The difference is that these investments usually occur via grants – a subsidy given to projects that apply to receive it. The MBI model is different. The resources are 100% destined to this ecosystem investigating medulloblastoma. It is such an underserved disease that a Brazilian initiative had to emerge to finance studies in the US, Canada, and Germany. This is also unprecedented.

The MBI helps to shine a light on this topic.

Yes, the focus goes beyond finding a cure. We want to raise awareness on the subject. We want to show that this disease and these children have been

US\$ 10 MILLION

THIS IS HOW MUCH THE MBI HAS ALREADY RAISED. THE GOAL IS TO RAISE US\$15 MILLION UNTIL THE END OF 2024. TO MAKE A DONATION, PLEASE GO TO MBINITIATIVE.ORG.

forgotten by society. The treatment has been the same for 40 years. Since then, technology has changed in different ways and so has medicine. But patients with medulloblastoma remain subjected to a very high-risk approach. Changing this scenario is the essence of the MBI. I believe this exposure could inspire more families to take action, potentially helping to solve other rare diseases.

In 2023, the MBI was one of three projects presented at the Sloan School of Management alumni meeting at MIT. Did the idea for Conexões de Valor originate from there?

Tulio Milman [president of the Friends of the Museum of Science and Technology of PUCRS Association] told Brother Evilázio Teixeira about the MBI. He found the project innovative and reached out to me. From there, the idea for the project emerged to bring the university closer to its alumni. The first edition, held in November, was attended by breast care specialist Maira Caleffi, president of the Rio Grande do Sul Breast Institute (Imama), and professor Jorge Audy, superintendent of Innovation and Development at PUCRS and Tecnopuc. It was undoubtedly the first of many.

How important is this type of event?

It is a great source of stories and connections for PUCRS. Alumni are assets that need to be used. Americans do this very well and serve as a reference.

In this sense, how did your education at PUCRS contribute to your journey?

The Business Administration program is very comprehen-

sive and opened several doors for me. I had exceptional professors. And then, of course, it is up to the student to find focus. I pursued two master's degrees, at the Dom Cabral Foundation and MIT. However, it was the rich cultural and informational environment at PUCRS that provided a solid foundation. This groundwork greatly helped my career and the challenge we're currently facing.