



**THE
MEDULLOBLASTOMA
INITIATIVE**

December/2022

**What is going on at
The Medulloblastoma
Initiative**

www.mbinitiative.org

**EVERY KID
DESERVES
A FUTURE**



Foreword

It's already been 18 months since we started this important project. I remember well the first time I brought the subject up with Dr. Packer. During the many years my son was treated in several institutions in Brazil and the U.S., I met many children affected by relapsed medulloblastoma.

I witnessed and shared the affliction of the kids and the despair of their families. There is nothing sadder than watching a child suffer from an incurable disease. Nothing. We then decided to do something to try to change this heartbreaking scenario. And we are advancing very well. We were able to raise almost 7 million dollars in these initial 18 months. We have engaged 11 laboratories (in the U.S., Canada, and Germany) that bring together some of the main scientists on the planet in this field of medicine.

Progress is being made consistently and synergistically, led by Dr. Packer. Among the main achievements is the publication of a scientific paper about the origins of

medulloblastoma, which acknowledges the important support provided by The Medulloblastoma Initiative, in Nature, perhaps the most important scientific journal in the world. And more than that: we should soon start the first clinical trials with patients.

Our achievements until this point and the amazing support received from our donor partners give us the necessary strength to keep fighting. The challenge now is to raise more resources to begin the clinical trials so that we can move swiftly towards a cure.

Together we can save the lives of thousands of children every year. After all, every kid deserves a future!



Fernando Goldsztein,
The Medulloblastoma
Initiative founder

 [linkedin.com/in/fernando-goldsztein](https://www.linkedin.com/in/fernando-goldsztein)





The link between health and management

In 2002, Fernando Goldsztein joined the MIT Sloan Fellows MBA program "to broaden his understanding of management, learn new leadership skills, and expose himself to different experiences, environments, and cultures." The lessons he learned during his time as Sloan Fellow provided an essential contribution to his ability to successfully establish The Medulloblastoma Initiative.

“That year changed my perspective on life. We’re not only talking about management. We’re talking about life [...] new perceptions of and approaches to different challenges. It was very transformational.”

This story was told by Andrew Husband at the [MIT Sloan School website](#). 



Research and philanthropy by Dr. Roger Packer



Dr. Roger Packer is Senior Vice President of Neuroscience and Behavioral Medicine at Children's National, as well as Director of the Brain Tumor Institute and the Gilbert Family Neurofibromatosis Institute at Children's National in Washington, DC, USA. He also leads the [Cure Group 4 Consortium](#), a group of labs working synergistically to find a cure for relapsed medulloblastoma.

"We know we have to develop new therapies. [...] We know the hard way, that doing [research] in adults doesn't give us the pediatric answers. These techniques, these approaches are extraordinarily expensive and there is no way to do this without great philanthropic partners [...] government funding alone can't be used for this [...] And that's why

philanthropy is so critical for us. Without it, we wouldn't be able to move as innovatively and we wouldn't be able to move as quickly."

"My goal is to put the patient at the center of all of this, the family, the child, and remember, that's why we're doing this and to recruit cohorts of physicians and researchers and physician researchers, and nurses, and all the other support people we need to make those steps. We never can do enough, but we've got to take the next step. We've got to keep pushing the frontier. And I'm just proud to be part of that effort."





Research and care, hand in hand

If you are looking for an expert to help you solve a medical problem, Expertscape is a well-recognized source — the platform identifies and objectively ranks medical expertise by specific topics. Expertscape primary users are patients, consumers, and referring physicians who are looking for a knowledgeable specialist for a serious medical issue.

So if you search Expertscape for "Medulloblastoma," guess what: three Cure Group 4 Consortium researchers — Drs. Vijay Ramaswamy, Michael Taylor, and Stefan Pfister — are ranked among the 5 top in 2022.



Expertise in Medulloblastoma Worldwide



1

Vijay Ramaswamy

Toronto - CANADA 



2


Michael D. Taylor

Toronto - CANADA 



4

Stefan Pfister

Heidelberg, DE 

[Check this out at the Expertscape website.](#) 



Groundbreaking research published in NATURE

Three Cure Group 4 Consortium researchers, Dr. Robert J. Wechsler-Reya, Dr. Michael Taylor, and Dr. Vijay Ramaswamy are co-authors in a [groundbreaking article recently published in Nature](#), one of the most important scientific journals in the world. The article appeared in the September 29, 2022 issue, and reflects research developed at least in part with support from The Medulloblastoma Initiative.

In an interview to News Medical – Life Sciences, Dr. Taylor explained: “We wanted to see how we could speed up the development of more effective therapies, but what we discovered may be even better than what we imagined. Preventing cancer from happening in the first place instead of treating it after it happens is the best possible outcome for children. This paper makes great strides for children with medulloblastoma and could only have been possible through a remarkable international collaboration that involved 46 different hospitals across 17 countries.”



Cure Group 4 Consortium Biannual Workshop

The all-day Cure Group Four Consortium Biannual Workshop took place on May 23rd, 2022, hosted by Children's National. The workshop gathered hand-picked renowned researchers and physician scientists from several countries who are looking to discover new therapeutic approaches to treat medulloblastoma – the most common of childhood malignant brain tumors – and especially the Group 4 subtype.

The consortium, led by Dr. Packer and launched in the spring of 2021 through the visionary support and leadership of philanthropist [Fernando Goldsztein](#), Founder of the Medulloblastoma Initiative (www.mbinitiative.org), has engaged the expertise of international institutions including [Children's National Hospital](#), [The Hospital for Sick Children](#), [Sanford Burnham Prebys](#), [Hopp Children's Cancer Center Heidelberg](#), [UFHealth University of Florida](#), [McMaster University](#), [Michigan Medicine](#) and [Emory University](#).



Cure Group 4 Consortium Biannual Workshop

The Consortium is looking for novel ways of treating the disease within a 12 to 18-month period by combining expertise to understand tumor biology and develop novel therapies (such as molecular based therapy and immunotherapy). Together, they share data, work synergistically, and expedite the development of ways for treatment.

During the meeting, Drs. Roger J. Packer, Conrad Cruz, Eugene Hwang, Lena Kutscher, Tobey MacDonald, Duane A. Mitchell, Yanxin Pei, Vijay Ramaswamy, Brian Rood, Sheila Singh, Michael D. Taylor, and Robert Wechsler-Reya led the discussion on the Consortium's main work fronts, including immunotherapy, molecular-based therapy, and a combination of these modalities as an initial treatment protocol. Next steps and timelines were also covered. Input was also provided by members of the External Advisory Board, represented by Drs. Scott Pomeroy and William A. Weiss. Dr. Andre Fay, Medulloblastoma Initiative advisor, was also present.

The workshop was held at the [Children's National Research & Innovation Campus](#), an amazing facility in Northwest Washington, D.C., which brings together the strengths of public and private partners, including industry, universities, federal agencies, start-up companies and academic medical centers.



Sparking passion: The Medulloblastoma Initiative-Cyrela Library



A great reader inspires others: “He is a very smart guy... He is a very heavy reader,” says Fernando Goldsztein of his son Frederico’s, who has inspired the creation of The Medulloblastoma Initiative. Now, Frederico’s love for books has also inspired the creation of a library at Cyrela, a major real estate company in Brazil, where his father is a partner and member of the Board of Directors. Book pick-up and return is simple, making reading a pleasure that everyone can enjoy.



CYRELA

Follow The Medulloblastoma Initiative on social media

In addition to the website (www.mbinitiative.org), The Medulloblastoma Initiative can now be accessed through Instagram, Facebook, and LinkedIn, where we provide briefs and news about our research and other medulloblastoma-related topics — we look forward to seeing you!



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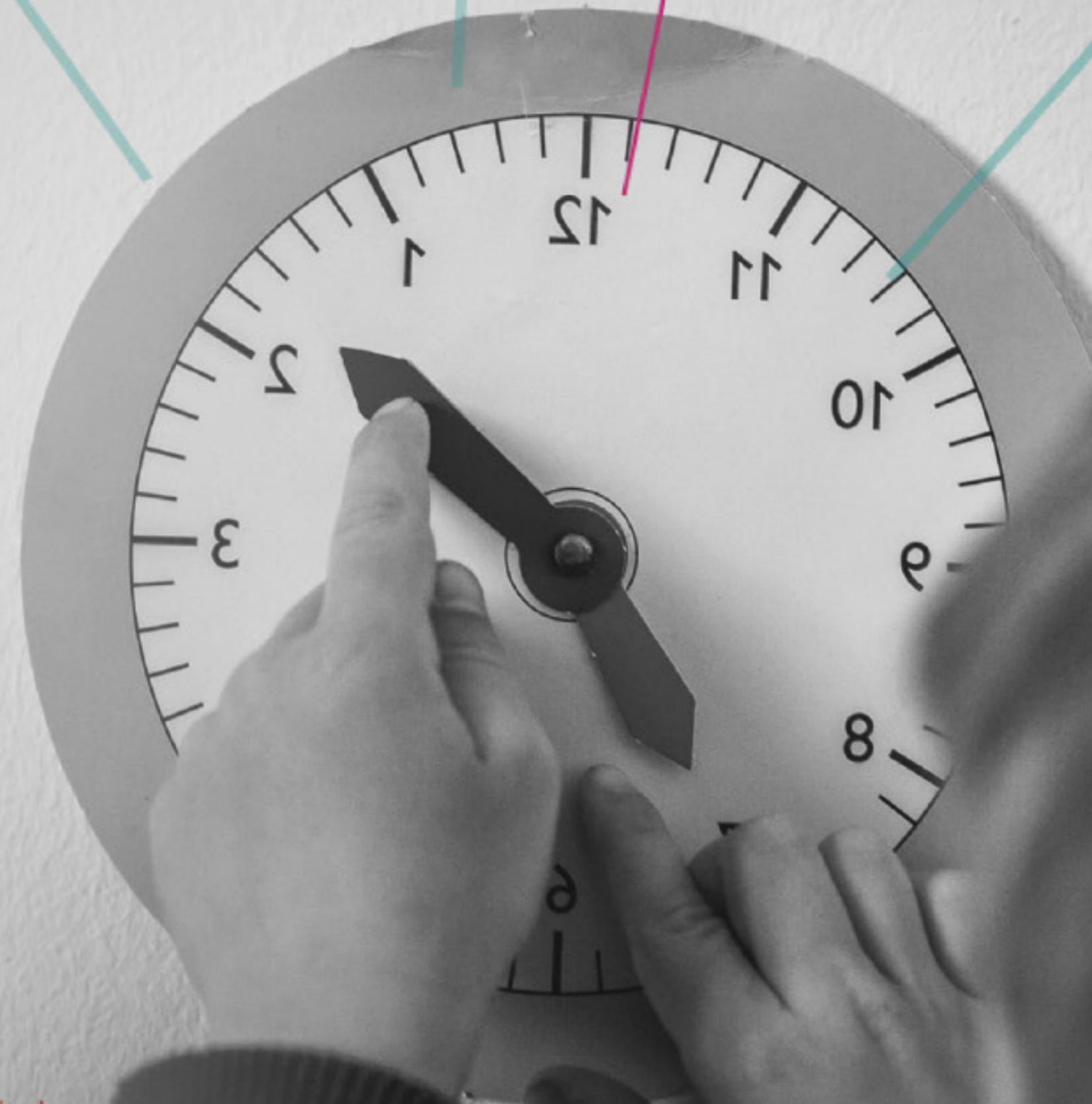
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Our children cannot wait.

Help us to find a cure for Medulloblastoma.

[Donate Now](#)



**"Whoever saves one life
saves the world entire."**

– The Talmud



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