

Funding a new hope for research into rare tumors

By Rachel Kirkpatrick
Editor

When Mikey Czech was diagnosed in January 2008 with a diffuse intrinsic pontine glioma (DIPG), a rare pediatric brain tumor, his parents Steve and Jennifer were told there was little that could be done. Up until that point, doctors in the United States were hesitant, if not unwilling, to biopsy these brain tumors due to their locations in the brainstem and the perceived risks.

Children with DIPGs were often diagnosed, went through intense, experimental chemotherapy or radiation, and they died, as Mikey did exactly nine months later at age 11.

Through the creation of The Mikey Czech Foundation, the Czechs set out to tell Mikey's story and to be a resource for people like themselves, who struggled with the lack of information available on DIPGs. And now, their hard work and perseverance, and that of their supporters, has begun to pay off.

At the foundation's fourth annual "Soaring Towards a Cure" gala on November 19, the Czechs announced that a major clinical trial is being launched in the U.S. that could provide more information than ever on the molecular makeup of these DIPG tumors and, in turn, the best way to treat them.

"This just goes to show you that when people get together, when you focus on something and are relentless in its pursuit, you can change anything," Steve told the Advertiser.

On a mission

DIPG is one of the most aggressive and deadliest forms of brain tumors diagnosed in children between the ages of three and 16, according to the foundation. DIPGs are inoperable, incurable and — until recently — unable to be biopsied.

Approximately 80% of patients diagnosed with DIPGs die within one year of diagnosis;

nearly 100% die within five years of diagnosis.

"Conventional treatment consists of general radiation and chemotherapy," according to the foundation. "Alternative treatments include various clinical trials (approximately 250 over the past 30 years) which, to date, have proven no more effective than conventional treatment."

Following Mikey's death, the Czechs identified the foremost expert in the world on DIPG, Dr. Mark W. Kieran of Harvard Medical School/Dana-Farber Cancer Institute — one of the five doctors they consulted following Mikey's diagnosis.

"We were very impressed with him," Czech said. "We went back to him and said, 'Look, everyone but you said this tumor was not biopsiable, why?'"

The Czechs learned that while neurosurgeons in the U.S. were not willing to do these biopsies, Parisian neurosurgeons are — and have, successfully.

In fact, at that time the Czechs met with Kieran, the doctor told them there had been 20 biopsies taken of these tumors by French neurosurgeons and not one of them had a single complication.

With backing from the foundation, Kieran set out to convince 20 U.S. hospitals that this procedure was not as dangerous as had been believed.

"He convinced the neurosurgeons from 20 U.S. hospitals here with the Parisian neurosurgeons and said, look, here's the technique," Czech said. "And once they saw that technique, they said, 'You're right — we can do this.'" (A list of the participating U.S. hospitals is available at NCAdvertiser.com.)

Now, The Mikey Czech Foundation, in conjunction with six other foundations, is funding a new clinical trial which was approved on November 11, allowing these tumors to be biopsied in the United States for the first time.

Participating foundations

include: The Zach Carson DIPG Fund, The Ellie Kavalieros DIPG Fund, The Prayers From Maria Foundation, Children's Hospital of Los Angeles Imaging Center, The Pediatric Brain Tumor Research & Clinical Fund at Dana-Farber Cancer Institute, and Stop & Shop Pediatric Brain Tumor Research Fund.

A new laboratory

A second goal of the foundation is to establish a dedicated translational research laboratory where these tumors can be studied and remedies can be developed.

With the support of the aforementioned foundations, Kieran obtained the live tissue samples of the 20 biopsies from children in Paris and took them to the Broad Institute of Boston (a joint venture between Harvard Medical School and the Massachusetts Institute of Technology), where the tumor cells can be deciphered to identify their molecular makeup using the "latest and greatest" in nanotechnology and biomedical engineering, Czech said.

The Broad Institute has already identified 2,000-plus different mutations that cause cancers in general.

"We're going to launch this next phase, the U.S. phase of this," Czech said. "What's going to happen at these 20 centers where the kids get diagnosed is, the day they get diagnosed, they are going to get biopsied. Those live tissues will be flown to Broad and they're going to identify what the molecular markers are, what the mutations are, and compare them to the 'encyclopedia' of mutations that are already known in an effort to identify existing remedies that can be used to treat these DIPG tumors.

"The idea being that each one of these kids now, for the time, is going to have his or her own custom-made treatment, as opposed to just throwing everything at the wall and seeing what sticks," Czech said.

Just \$700,000

In the two and a half years The Mikey Czech Foundation has been in existence it has raised more than \$1.5 million in funding. As Czech points out, this has been accomplished at the grassroots level, with no corporate or government involvement.

"The extent to which people have reached out has been incredible," Czech said. "I always refer to New Canaan as my 18,000-person family, because of the way the community has embraced us. We'll always be grateful."

It has taken 10 years for researchers to get to this point and it was done, notably, with \$700,000. Czech knows that with consistent funding and support, the possibilities are endless.

There are no pharmaceutical companies willing to write a big check for research — nor is the federal government — at least for now, because this cancer is so rare. So when Czech, a hedge-fund manager, raised his second fund, the \$1.1 billion Czech Asset Management, LP, last year, he made a contractual commitment to donate a fixed percentage of his personal profit from the hedge-fund to The Mikey Czech Foundation.

"For the first time, there is a meaningful, sustainable source of funding for efforts solely directed toward pediatric brain tumors," Czech said.

"And that's what it is going to take — there has to be a sustainable source to keep these people interested in researching it, but also to attract other researchers into the field."

Nearly four years since the loss of his only son, Czech is finding a comfortable balance in life.

"It's very simple: it's family, faith, foundation and the fund, and the fact of the matter is, the fund and foundation's success are very much aligned," Czech said.