



EO Media Group photos/Natalie St. John

Casey Harrell helps her daughter eat a bowl of chicken soup. The loss of muscle control caused by her cancer sometimes make it hard for Dylan to eat. The sock on her left arm covers a port that allows doctors to give her IV medications and draw blood without giving her constant injections.

# TINY WARRIOR

## SMALL TOWN UNITES FOR PRESCHOOLER IN THE FIGHT OF HER LIFE

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There is a tiny walker in Casey and Jeff Harrell's living room. It's an unwanted but constant presence in their lives, which makes it a pretty good metaphor for their daughter's illness.

In August, 4-year-old Dylan Harrell received a crushing diagnosis: diffuse intrinsic pontine glioma, or DIPG, a type of childhood brain cancer. To date, the disease has had a 100 percent fatality rate. The Harrells of Seaview, Washington, are devastated, but not without hope. Bolstered by support from family and community, Jeff, Casey, Dylan and her big brother Mason are fighting the disease every way they know how.

Over the summer, Dylan's day care teacher noticed that her left eye was turning in. Their doctor told them to put an eye patch on her stronger eye, but it kept getting worse. Soon, her other eye was turning in too. She started having problems with balance. In July, she started throwing up.

"It became very clear that something's going on here," Casey recalled. A family friend helped fast-track an appointment at the Casey Eye Institute in Portland.

"We went in for an eye appointment and had the biggest bomb dropped on us," Casey said.

"I can remember the doctor going, 'Let's chat.'"

The eye doctor sent them to the emergency room at Doernbecher Children's Hospital for a basic brain scan. Doctors said they could see something on the pons — a small, but essential, part of the brain stem.

"We still had no clue what that meant," Casey said.

Dylan was admitted to the hospital and scheduled for a full MRI the following day. The Harrells knew they were about to receive terrible news when a doctor called them into



a room to talk. The neuro-oncologist cried while telling them Dylan's diagnosis, but no amount of empathy could soften the blow.

"For lack of better words, I feel like they put you on the death march," Casey said.

"They told us to just go home and enjoy our time," Jeff added.

The Harrells were dumbstruck at first. How could their sassy, rambunctious, smart, athletic daughter be so sick? At the time, Dylan was learning to ride a bike. She had strong opinions on fashion, and on how her big brother should behave. She thought burps and farts were hilarious. How could a child with so much life-force just fade away?

Further tests and her worsening symptoms quickly forced them to come to terms with DIPG. Dylan may have a less aggressive form of the disease. She has already had more time than many DIPG patients get, but in September, she began having difficulty walking. By October, she couldn't

walk unassisted, and she had developed hydrocephalus — a buildup of fluid in the brain. When doctors treated the hydrocephalus, they also took a biopsy. The results showed that Dylan had a type of tumor known as an anaplastic astrocytoma. It was a "grade three" on a scale of one to four. The battle started in earnest.

### 'A horrific few days'

Dylan underwent the first of 30 radiation treatments on Oct. 18. The treatment caused severe inflammation and vomiting and landed Dylan in the intensive care unit. After a second night in the general ward, doctors sent her home with a new prescription for a steroid drug that controls inflammation but causes severe side effects.

"It was a horrific few days," Casey said. Dylan's bad reaction had major implications, because radiation is the only treatment proven to alleviate DIPG symptoms. Fortunately, Dylan did much better when they restarted treatment a few



LEFT Jeff Harrell jokes around with Dylan on a too-rare lazy Sunday afternoon.

ABOVE There is currently no cure for DIPG, a rare type of childhood brain cancer. However, the Harrells are trying a variety of traditional and alternative treatments. Dylan has to take dozens of pills a day.

days later. In fact, she is the youngest Doernbecher patient to ever undergo radiation without sedation. Her ability to lie still inside the MRI-like machine means treatments take 15 minutes instead of a couple of hours. It also means Dylan doesn't have to go through the stress and risk of being sedated five times a week.

For Jeff and Casey, both pharmacists, the limitations of western medicine have become very personal. Jeff reads research papers, consults with other DIPG parents and calls experts all over the world. He recently attended the first-ever summit on DIPG in Washington, D.C. But help is hard to come by. There are treatments being tested in other countries that haven't made it through the United States' byzantine approval process. There are promising procedures doctors won't try and insurance companies won't approve because they don't want to be sued if things go awry, and experimental drug trials for which Dylan doesn't qualify. One

of the most promising cancer-fighters — cannabis — is still illegal under federal law.

Jeff respects and appreciates Dylan's medical team, but finds it maddening to be told again and again that radiation is the only option. To him, it feels like doctors are floating every single DIPG child down the same river, knowing it leads to a giant waterfall.

"If you failed in any other field like that, you would be fired," Jeff said. "They don't have that answer for us. That's the thing we talk about every time we go into the doctor's offices. They look at us, and they cannot give us an answer."

The Harrells are frank about the fact that, as the part-owners of a successful chain of pharmacies, they have some advantages in the fight against DIPG. Their business partners and employees have taken on most of the day-to-day work, making it possible for them to work part time, mostly from home. An employee got a friend to

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