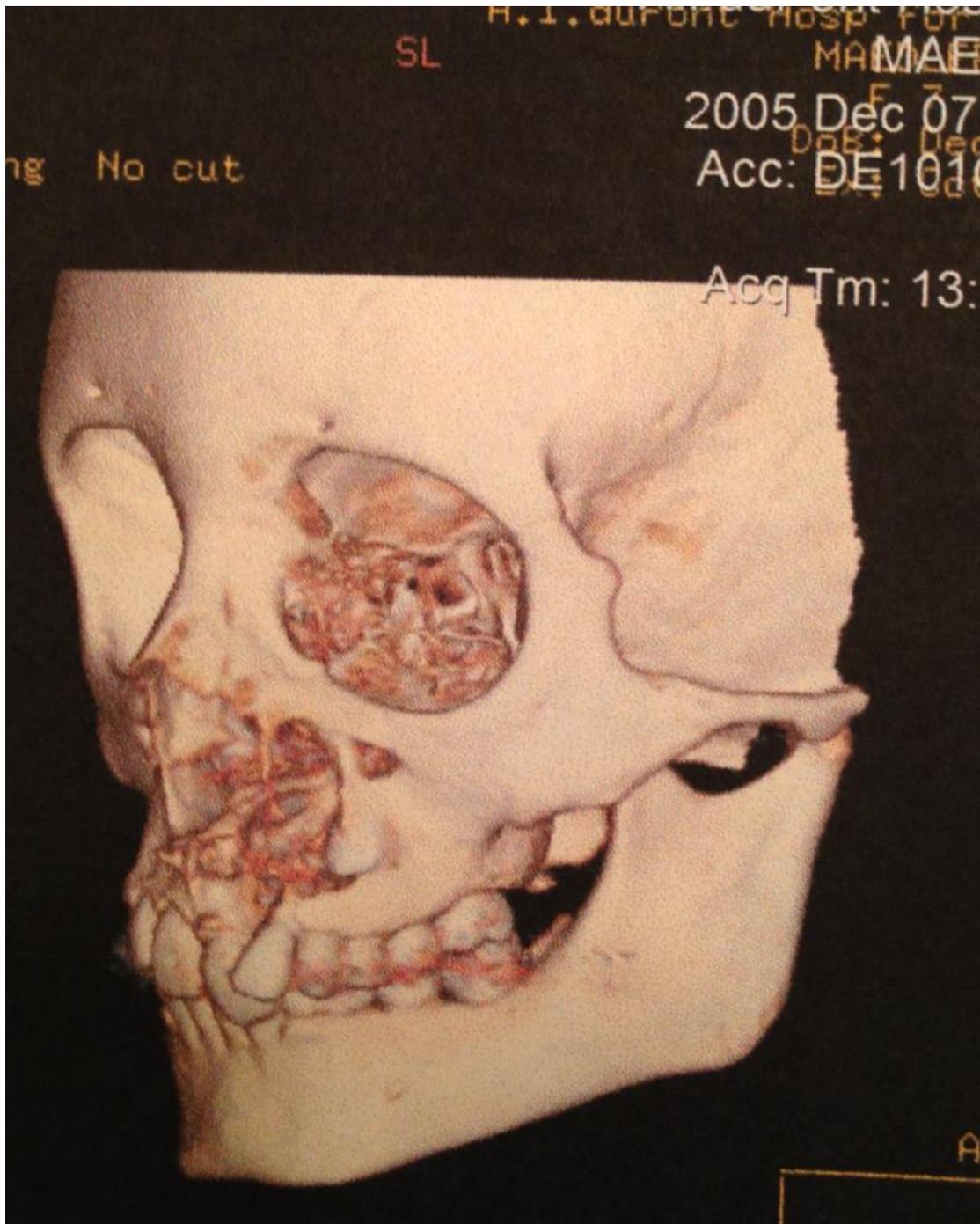


For a parent, few things are scarier than when their child is diagnosed with a serious illness: the fear, the anxiety, questions that begin with “what if” and “why us?”

For Sean and Janie Maedler, of Rehoboth, Delaware, their nightmare began in 2013, when their daughter, Rylie, was just 7 years old. Her face began growing in a malformed way, and, says Rylie, “The pain was indescribable.” In addition to developing very puffy, red blotchy skin, she felt a hollowness in her cheeks that none of the other kids—her twin brother included—appeared to have. Most of her teeth — she was already starting on her adult set — were either severely crooked or falling out.



Rylie’s parents took her to their pediatrician, who ordered MRIs of Rylie’s face, head and neck. A week later they had some answers but not enough for a diagnosis. The MRIs showed a series of bone tumors in Rylie’s face that had eaten away at her [palate maxillary sinus](#), her [sphenoid sinus](#), her left cheek, and the bottom of her eye orbits.



Following more tests, the Maedler family got their diagnosis: [central giant cell granuloma](#) (CGCG), which came with grim news. Although benign — meaning, despite the condition's destructive nature, Rylie would not succumb to CGCG — [CGCG is very aggressive](#). Because of Rylie's age at onset and the fact that her bones weren't finished forming, damage to the facial structure would likely be, as it is more often than not in such cases, permanent.



Given how aggressively Rylie’s tumors were growing and the rate at which they were consuming her bones, her team of doctors had her in the operating room in a matter of days to perform [debulking surgery](#). As Rylie’s mother, Janie, explained, “They go in and they try to remove as much tumor as they can. They try to take as much of the margins around a bone — leaving an even greater hollowness than Rylie had before. So literally, when she came out of surgery, the whole left side of her face was like a potato sack because they had to take the margins, and what was left behind had no structure.

“Prior to surgery, the doctors prepared us that they would probably need to remove all of her teeth, leaving her to get implants when she was older. But they decided to stitch her teeth into the gums, one by one, and hope that they would live ... they left like a crust. The way they described it was just like when you bake a cake and you have that crust on the top — that’s kind of how they described what they left behind around the teeth — was that crust of cake was left behind and they hoped that it was enough to hold in, and some bone over a long period of time would start to form or maybe thicken a little bit.

“Unable to chew, Rylie was on a liquid diet for many, many months, just hoping that they would live. But [the doctors] had warned us—don’t expect any of these teeth to live—but...” Janie paused. “They all lived!”

Side Effects Include...

With debulking surgery behind them, the Maedler family's thousand-mile journey was just beginning. Recurrence of giant cell granuloma is somewhere between 34 and 70 percent in young adults whose bones are not finished forming. Janie explained what the next few months were like for the family: "Although they did the debulking, they said that they would give us a watch-and-wait period, but they were totally expecting to have to throw her on something [[like biologics that stop the progression of disease](#)]. So, we had a follow-up scan."

As was anticipated, the doctors told Janie that they had been unsuccessful in removing all the tumors. A tiny bit was left behind, which is very common with CGCG. The doctors discussed treatment options with Janie and her husband.

The medical team recommended Rylie be put on two biologics, [Denosumab](#) and [Interferon](#), plus the peptide hormone [Calcitonin](#). Janie and her husband discussed the side effects, both the likely and common as well as the rare and possibly dangerous.

Combining the three drugs, Rylie could reasonably expect to develop serious side effects including a compromised immune system, muscle pain, vertigo, early menopause, liver damage, loss of taste, and other debilitating complications.

Adding insult to an already injurious situation, Rylie had developed seizures as a result of the surgery. Janie and her husband had a long talk about their now 8-year-old daughter's future and decided that Big Pharma's treatment could prove more dangerous than living with the tumors.

"I had begun doing research on my own and seeing incredible outcomes of patients who [consumed cannabis to treat both symptoms and grave illness](#)," Janie explained. "That the National Institutes of Health was funding so much research into cannabis, I believed we had to at least consider it for Rylie. We had one huge problem: Cannabis wasn't legal in Delaware."

The Lengths a Mother Will Go to for Her Child

Janie admits to copping cannabis before she could obtain it legally. For obvious reasons, she didn't disclose details about how and from whom she received it. She did report that because she had zero interest in compromising her daughter's already fragile health, she didn't get it off the street from strangers. Beyond that, she didn't go into details. Indeed, even her husband didn't know all the details. "I wanted him to have plausible deniability," she explained. "We needed his salary and health insurance to survive, so we couldn't do anything that could jeopardize that."

Three months after Janie started her daughter on cannabis to see if they could ease the symptoms of CGCG and slow its progression, the family received the first set of scans since the surgery. Not only was Rylie no longer feeling any discomfort or pain, the tumors had shrunk. An unintended but very welcome side effect of the cannabis was that the seizures Rylie developed after the surgery had also stopped. Several months later, they got new scans: Her face was actually filling out. In other words, the cannabis wasn't just stopping the progression of the

tumors caused by giant cell granuloma—absent any other explanation (because Rylie wasn't on any other treatment) [the cannabis was actually reversing the condition](#).

Instructions not Included

Unlike the highly regulated drugs that come from Big Pharma, there are no written instructions with cannabis — regardless where you're sourcing it from. How did Janie know how much, in what form and how often to give her daughter cannabis?

After Rylie's surgery, Janie went to work. She joined groups on social media and talked with adults and parents of kids who have all sorts of cancer—both those with decent cure rates and those with poor outcomes, such as [multiforme glioblastoma](#), as well as CGCG. Many reported incredible results when they went off the Big Pharma drugs and switched to cannabis or used cannabis to complement the standard of care. Although nobody felt comfortable suggesting doses and frequency of use, Janie knew she was on the right track.

Next Janie spent countless hours doing research: articles about cannabis and studies into the safety and efficacy of using cannabis for illnesses, particularly [breast cancer](#) and [bone regeneration](#). Janie explains how she arrived at dosing and frequency. “A lot of how I did it was based on the recommended dosage of [dronabinol](#), which comes in 5mg doses. By knowing the mg per ml I figured out how to dilute it with [carrier oil](#) so that I could dose it at only 5-10 mg at a time in the beginning.

“Because cannabis doesn't come with instructions, figuring this was like an Algebra equation. Once I confirmed the research showed promise, with my own understanding about how cannabis works, how it metabolizes in a young body and what receptors I was aiming for, I could work out a dose. I purposely started low and increased in tiny increments.

“My goal was to give her as much as I could three times a day but minimize the “high” to keep her functional. I needed for her to be OK in school. Especially since it was illegal. Only twice did I mess up and give her too much before school. We also gave her [citicoline powder](#) to help counteract the high so that we could increase the doses.

“We also took Rylie to pain management doctors (because they usually have cannabinoid training) and called ‘cannabis doctors’ hoping they would help with dosing, but once I'd contact them either they'd say they wouldn't change anything I was doing, which was great, or offer to help (by repeating the same treatment plan) for hundreds of dollars.”

Even with doctors' endorsement of Janie's treatment plan for Rylie, confirmation wouldn't come until Rylie had future MRIs. At the time of this writing, Rylie has had 17 MRIs and all have been excellent with no return of CGCG.

From Copping Illicit Cannabis to Raising the Cannabis Industry's Youngest CEO

Much of the criticism about cannabis comes from those who cite outdated information. In 1971, then President Richard Nixon declared the War on Drugs, adding the [cannabis plant to the Schedule 1 list](#), joining actually dangerous drugs like heroin. No distinction was made between hemp and cannabis, as both were considered controlled substances. This one act altered the course of cannabis, which hitherto had been [touted for its medicinal benefits for thousands of years](#).

In their criticism of cannabis, most who oppose it talk about it killing brain cells, turning people into spaced-out zombies, being a gateway drug to more dangerous substances such as heroin, cocaine and meth, and exposing consumers to a life of crime.

At 15 years old, Rylie Maedler is a normal teenager. She has gotten straight As since she started consuming cannabis at the age of 8, to fight the tumors associated with giant cell granuloma.

But there are a few things about Rylie that are pretty atypical for a teenager.

As the founder of [Rylie's Smile](#) and [Rylie's Sunshine](#), Rylie is the youngest CEO in the cannabis industry. She travels to cannabis conferences all over the world, including to South Africa and Australia, to share her story and explain why she feels cannabis saved her life. Rylie has addressed Congress, [appealed to then U.S. Attorney General Jeff Sessions](#), and explained [why legislation around cannabis has to relax](#). And in 2015, Delaware passed [Rylie's Law](#), which permits children under the age of 18 suffering from seizures and other debilitating and grave illness to consume cannabis.

In the past year, Rylie learned a tough lesson about access. As she explains things, “We’ve had people contact our foundation, saying that they want to get a medical card, but they can’t because they live on government property—called Section 8 housing. And who lives in Section 8 housing, right? So, from hearing stories like that—we didn’t know about this before—my foundation wrote a law that’s in Congress for consideration that will allow those in Section 8 housing to receive the same medical marijuana card I got without hesitation. Because of the pandemic, I was told Congress has put it on hold but will revisit when things calm down.”

Access to Big Pharma’s medicines is limited to those who can afford them and those with excellent insurance. And given how drastically many in power want to reduce or eliminate access to affordable healthcare, how will we treat all that harms? With [two-thirds of Americans favoring cannabis legalization](#), and stories like Rylie’s, will cannabis emerge as the standard of care for much of what ails our society?

Rylie's story was originally published by the [Village Voice](#) and [LA Weekly](#) and is republished with permission.