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From 'Rylie's Law' to Rylie's Smile

A rare malady led one young girl and her family to push for treatment and to help others in need

By JESSICA GORDON | PHOTOGRAPHS BY CAROLYN WATSON



Because of her health experiences, Rylie Maedler created a foundation to give iPod touch devices to young patients dealing with extended hospital stays and medical procedures.

Shortly after noon every school day, Janie Maedler checks her 10-year-old daughter, Rylie, out of Rehoboth Elementary. Together they walk off the property, where Janie hands her daughter a pill that enables her to live like other kids her age, giving the fourth-grader a reprieve from the devastating side effects of seizures.

After Rylie swallows the capsule filled with cannabis oil, she checks back into school and continues her day. It's a routine the Maedler family — Janie, husband Sean, Rylie, twin brother Gavin and youngest sibling Korban — fought to be able to follow, part of a journey they once never could have imagined taking.

"Without the oil, I get stomach spasms and I hallucinate," says Rylie. "One time I thought there were people in the pillows." She laughs, but admits that at the time, it really frightened her. "With the oil, I'm just normal. Well, pretty much."

The road to semi-normalcy has been a long and painful one. "Mom-gut" is how Janie describes the intuitive sense that something was wrong with Rylie back in the summer of 2013. The Rehoboth-area resident noticed a strange,

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Rylie Maedler, center, is surrounded by her family, from left, twin brother Gavin, dad Sean, mom Janie and younger brother Korban.

Kid Stuff

their home, asking for his help to make medical marijuana a legal option for sick children.

"I'll be honest, I had reservations," admits Lopez. But once he met with Rylie and her family, he decided to try to help her lead a life every child should have: a pain-free one.

In June 2015, Senate Bill 90 — dubbed "Rylie's Law" — was passed unanimously. The House followed suit and the governor signed the measure into law, allowing minors to legally access medical marijuana.

"I think when it comes down to your child being sick and in pain, you're willing to try just about anything."

"There was a lot of crying," Janie says of the moment the bill passed. "To have unanimous votes was so awesome. Even people who just two weeks before were against it changed their minds after meeting Rylie and realizing she wasn't high and was a normal kid who could talk to them about how it makes her feel, and the difference it makes in her life."

For this young lady, the enactment of her namesake law was a chance at relative normalcy. (There is that daily walk off the school property at lunchtime, because cannabis oil is considered a schedule 1 drug under the Controlled Substances Act, which means that the drug-free school zone designation governs where Rylie can ingest her capsule. However, Lopez introduced a bill in January that would allow caregivers to administer such medications on school grounds. That bill must be reviewed by a Senate committee before it can come up for a vote.)

Her mother admits that cannabis use by children, even for medicinal purposes, is hard for some people to accept. "If I thought a pharmaceutical would help, I'd be willing to try it," she says. "Really, it comes down to trying anything that will help. We're not hippie, all-natural people," she adds with a laugh.

"Yeah, we don't hug trees or anything like that," adds Rylie.

The passage of SB 90 was a fight all of the Maedlers took on, but it was the young patient herself who came up with the idea to help comfort sick children through

slight puffiness on her daughter's left cheek and eye area. Rylie also experienced periods of nausea, tooth pain and lethargy. As summer progressed and the child's face became more swollen, family members, friends and doctors offered theories: a sinus infection, a blocked tear duct, allergies, an abscess.

When Rylie woke one October morning and the facial asymmetry and puffiness were more pronounced than ever, Janie loaded her into the car and headed for Nemours/Alfred I. duPont Hospital for Children in search of answers.

After doctors at the Wilmington medical center, known as A.I. for short, discovered a tumor was eating away the tissue and bone in Rylie's face, the family knew they were dealing with an aggressive, invasive mass. But it would be three torturous weeks before they learned if it was benign or malignant.

"Those weeks were absolutely excruciating," recalls Janie. When she and Sean finally received the call from A.I. that Rylie did not have cancer, "it was a huge wave of relief. But at the same time, I had already connected with parents who did not get the call we did. I wondered why we received this miracle and so many others did not. Even though you're happy, it's kind of like survivor's guilt."

Rylie was diagnosed with aggressive giant cell granuloma, a rare benign tumor that mimics cancer. "It's baffling," admits the young girl's mother, who has spent countless hours studying the condition. "From my research, it seems these tumors are usually somewhat small, but Rylie's took up almost her entire face." To demonstrate, she points to an area on her daughter's MRI: It's a picture of her skull with a large hole on the left side of her face. "The doctors at A.I. told me they had never seen a case of it before."

Surgery to remove the tumor and undergo facial reconstruction in November of that year went well. But just two weeks later, Rylie started experiencing what the Maedlers now know were seizures.

Nearly a year and numerous prescriptions later, Janie realized the one medication that eased her child's symptoms more than any other — and didn't cause debilitating side effects — came with a catch: Cannabis oil was illegal for medicinal use by anyone under 18. How one obtains it is not something the Maedlers wish to discuss.

"I think when it comes down to your child being sick and in pain, you're willing to try just about anything," states Janie, who originally heard about the oil's benefits from other mothers of sick children. Studies suggested it could help with bone regeneration, protect nerves, reduce inflammation and slow tumor growth, all of which Rylie could benefit from.

While the family's original plan was to use cannabis oil for a short duration, once they weened Rylie off of it the seizures came roaring back. The pharmaceuticals that doctors prescribed either didn't work or left the young girl exhausted, irritable, and with so much pain in her jaw and teeth that she couldn't eat.

But they knew it would be an uphill battle to keep her on the cannabis oil given Delaware's laws governing its use. Someone suggested the Maedlers contact a local legislator to see if they could get an exception for Rylie, "but that wasn't good enough," insists Janie. "I thought about all of the other children who could benefit from it. I knew a bunch of other kids that were secretly on it and seeing good results."

So the family invited Republican state Sen. Ernie Lopez to

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Rylie's Smile, a foundation she formed. With assistance from her parents and brother Gavin, it became an official 501(c)(3) in February 2015.

The genesis for it came during one of Rylie's initial visits at A.I., when she became scared and angry after being poked and prodded and scanned. Hospital staff gave her a mini iPad to play on, and Janie and Sean noticed Rylie relax almost immediately as she focused on something other than needles and big, noisy machines. Seeing how much that escape mattered, her grandmother bought her an iPod Touch.

"She would listen to her favorite songs and take pictures and videos of the things she was going through," says Janie. "It became a tool that helped relieve so much anxiety."

Rylie, her family, and a small board now accept applications from families of hospitalized children ages 3 to 17 and distribute iPods to those who fit their criteria.

"We're not going to give you an iPod if you're not sick, or if we don't think you

“She would listen to her favorite songs and take pictures and videos of the things she was going through. [The iPod] became a tool that helped relieve so much anxiety.”

need it," Rylie explains. "Like if you have a cold, you're not going to get an iPod."

Funds for the initiative come from grants and fundraisers the family holds. Donations can be made by visiting Ryliessmilefoundation.org.

Janie believes the undertaking helps give her daughter perspective: "She realizes how fortunate she is, but we don't ever want her to forget it. I know we never will."

Janie, who owned Inner Reflections day spa near Rehoboth until last year, decided to dedicate time to an issue closer

to her heart. "One day I was sitting at the spa and realized it just wasn't important after what we'd been through," she explains. "I wanted to be more of an advocate for parents concerning cannabis oil, and continue to build Rylie's Smile, and just be with my family."

And Rylie, despite the roller coaster of health issues she's experienced, is still like any other 10-year-old. She plays the piano, loves to ride horses and likes to draw ("even if I'm not that good at it," she laments). She also enjoys jazz and classical music, and hopes to be able to play Duke Ellington's songs one day.

"She's an old soul," her mother says with a smile.

An old soul with a lot of living left to do. ■

JESSICA GORDON is a freelance writer who lives in Lewes. She is a frequent contributor to *Delaware Beach Life* and has written for *The News Journal*, *Delaware State News* and *Delaware Today* magazine.