

{ A LIGHT IN THE
DARKNESS }

I

remember that I went up to my dad, and I was like, ‘Dad, my stomach really hurts.’” A hint of a smile plays across senior Amanda Pelletier’s face as she looks toward her father, Mike Pelletier. It is a knowing smile, one that harbors seven months worth of memories, of pain, of telling stories just like this one.

story by
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photo by kelbi davis

Facing endoscopic brain surgery in 13 days, senior Amanda Pelletier relies upon her faith and the comfort and aid provided to her by her family and friends. "I think it's just an opportunity for me to grow, and I see it as that and not as, like, some tragic thing that sucks. Even though sometimes it does," Amanda said.



Since Amanda began showing symptoms related to the cyst on the pineal gland in her brain, she has visited 26 different doctors, in what became a frustrating quest for answers for the Pelletier family. "You know, when we're going to the doctor's offices, we're all sitting there and ... you want that doctor visit ... to be able to tell you what's wrong with your child," Janet Pelletier, her mother, said. "There's been 25 of them. You know, we're chatting and listening to music the whole way down, but it's coming home after they tell you that they have no idea what to do, it's silent. It's silent."

photo by kelai oavis

"I think you felt [my stomach] - didn't you feel it?" Amanda prompts.

"Yeah, we looked at it," says Mr. Pelletier. "There were no bruises, nothing."

The two share an easy banter. They remember the night together, carefully piecing the details together word by word.

"Yeah, there was nothing there," Amanda says.

A twinkle has crept into her eyes.

"And [my dad] was like, 'Oh, just go to bed. You'll be fine in the morning.'"

The idea is just too funny. Amanda is laughing before she can finish her thought. The room warms as her contagious chuckle rises up to the ceiling and everyone joins in, if just for a moment.

The mood cools as Amanda picks up her story where she left off: how she went to school the next day. How she found herself in math class, texting her mom – here, another chuckle – the words that would prove to ring true for months to come:

"Mom, I feel bad."

The day was April 15. Janet Pelletier, Amanda's mother, remembers it distinctly.

"It was tax day," she says.

Peals of laughter ring out into the room again. It was the day everything changed for Amanda and her family, one they will remember forever.

As the laughter dies down, silence settles over the room once more.

Amanda's fingers move steadily across the keyboard as she types in the web address for the Skull Base Institute of Los Angeles. Recurring blurred vision makes this type of thing difficult, but it's clear she's been here before. When the site pops up – a sleek, blue-and-grey page that calls to mind the files of a high-tech lab – she navigates to the side of the screen with finesse.

She clicks once on a tab that reads 'Pineal Tumor.'

To be accurate, Amanda does not have a true pineal tumor. What she does have is a cyst in her pineal gland – a small, pine cone-shaped node tucked away deep inside the brain. At 1.2 cm, it is roughly the size of a marble. It is benign – non-cancerous – but this does not mean that it has not outgrown its welcome; the pressure the cyst exerts on its surroundings is causing a plethora of unpleasant symptoms for Amanda, including blurred vision, severe headaches, dizziness, nausea and coughing fits.

Still, the treatment for an obstructively large pineal cyst is generally the same as that of a tumor: brain surgery. It is a daunting solution, but one the Pelletier family welcomes after months of searching for answers in a maze of misdiagnoses, false hopes, and doctors' heartbreaking shrugs of defeat.

When Amanda began having severe abdominal pain in mid-April, a 21-hour trip to the emergency room and a string of medical tests fell short of solving the mystery behind her symptoms. Finally, a test revealed Amanda's gallbladder was functioning at around 11 percent efficiency.

"It was working," Mr. Pelletier says. "It wasn't working optimally."

The pain persisted, and Amanda was wheeled into surgery in late April for a cholecystectomy, or gallbladder removal.

"When I went into [surgery], I was not mentally thinking that it was anything," Amanda says. "I was thinking, 'Oh, this is going to be a breeze.' And then I got out of it, and obviously it was not easy."

The operation did not appear to eliminate any of Amanda's symptoms. In retrospect, the family believes the true root of the pain to have been a rib that had become separated from the cartilage of her chest.

"[I've] seen GI specialists, cardiothoracic surgeons, orthopedics, general surgeons, neurologists, neurosurgeons, pain teams, [and] diagnostic teams," says Amanda. She looks at her mother quizzically.

"That's it, right?"

The pain persisted, and Amanda struggled to finish her junior year in the midst of prom, AP exams, and finals. She entered the summer with a host of afflictions, including the newly appearing symptoms of headaches, fatigue, dizziness, and blurred vision.

"Summer was really hard," Amanda says simply.

The tipping point arrived one murky night in late July. After spending two days in Columbia, Mo. helping her sister, Caitlin Pelletier, move into her apartment at the University of Missouri, Amanda drove home solo.

"I tried to just go back to my normal life," Amanda says with a sage shake of her head. "And I drove both ways ... probably not the best idea, but I did. I remember I got home and my face was green."

Amanda sits, tranquil and poised, in one of the blue plastic chairs that huddle in flocks in the classrooms of school. The sun has fallen below the skyline, and the pale moon is beginning its ascent to the top of the sky as she continues recounting the story of that night at the end of the summer. As always, she is impeccably dressed, in a crisp, khaki jacket, tall boots, and a gold locket, with hair falling down

to her shoulders to reveal elegant pearl earrings. Nevertheless, there is a flicker of weariness in her eyes as she describes the moment she knew her life was changing.

"The world was just spinning," she says. "I knew then ... I was really sick."

Amanda sat on the porch, dizzy and breathless, as her friends Jack Rodell and Danielle Lorenscheit called Mrs. Pelletier to alert her to Amanda's worsened condition. She had tried to push through the pain up until that evening.

"And then I couldn't," Amanda says, smiling faintly.

The Pelletiers stumbled across what would prove to be the home stretch of their journey after scores of doctors' appointments, diagnostic tests, and hospital visits. Amanda has been admitted to the hospital three times; she

child that has ever complained if there ever wasn't something wrong."

"There's been 25 [doctors]; you drive down there, and we're chatting and listening to music the whole way down. But it's coming home after they tell you that they have no idea what to do ... it's silent."

The silence ended with three neurologists standing in front of Amanda at Children's Hospital in St. Louis. After examining her for the umpteenth time, they ordered an MRI of her brain.

There, in the center of the scan, they found the cyst.

The Pelletiers immediately began searching for experts on pineal cysts. They found the Skull Base Institute site online; after securing a referral from Amanda's primary care physician, they arranged for a videoconference with the director of the clinic, Dr. Hraryr Shahinian.

Dr. Shahinian boasts an impressive background in the field of endoscopic skull base surgery, a discipline that differs from traditionally invasive brain surgery. He has been a guest on television programs such as "Oprah" and "The Doctors" and holds several patents for minimally invasive surgical techniques.

Amanda and her parents exchange reserved smiles as they remember their first meeting with him.

"It was just instant," Mrs. Pelletier says. "He knew exactly what was going on."

"[Dr. Shahinian] has helped patients who have exhibited the same symptoms that Amanda has had," says Mr. Pelletier.

They are grinning now, in a cautiously optimistic state of excitement. In the weeks since their first consultation, Dr. Shahinian has outlined a course of treatment for Amanda that aims to alleviate all of her symptoms and have her back to her normal life by February.

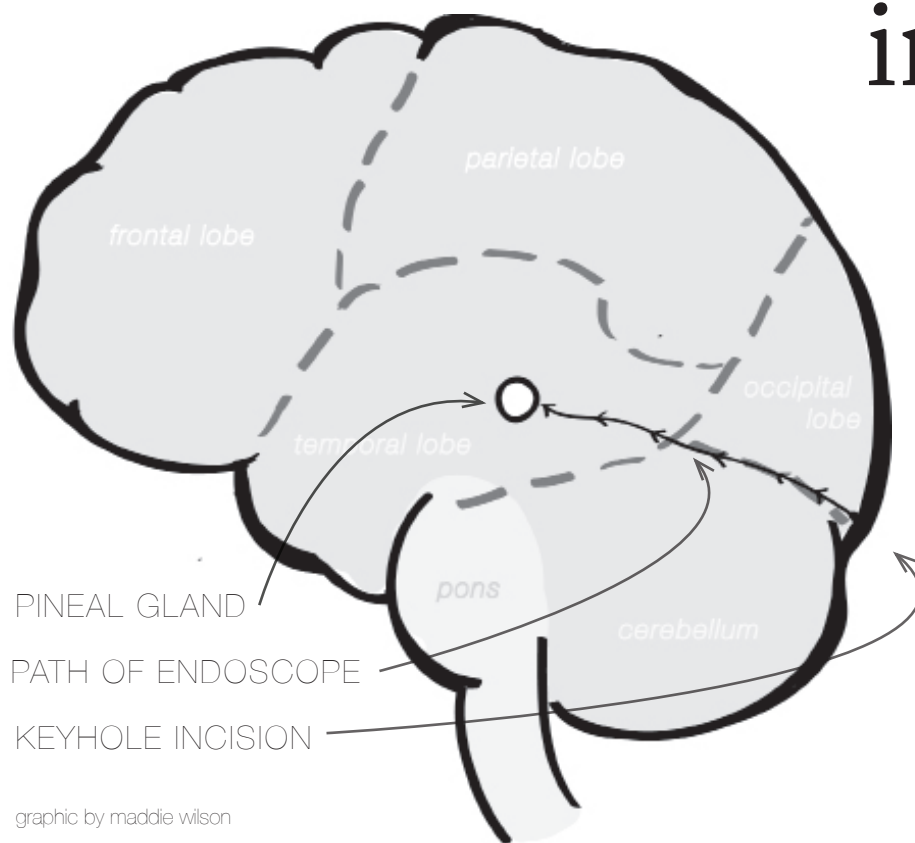
In one 15-minute meeting, Dr. Shahinian was able to do what two dozen doctors weren't able to accomplish in two dozen weeks.

According to the Skull Base Institute, Amanda's cyst is relatively large, but by no means record-breaking in size. It is a small comfort as the family prepares for the most dramatic step in the process to Amanda's recovery: brain surgery.

Amanda has no qualms about clicking play on the video that shows, in detail, the exact procedure the Skull Base Institute team will perform on her 13 days from now. The short video, which uses footage from an actual pineal tumor removal done by Dr. Shahinian, does not shy away from up-close shots of blood, bone or brain. Watching it is not for the faint of heart; envisioning it being done on your own

inside the surgery

The Central Focus spoke to Dr. Hrayr Shahinian, who will be performing Amanda's surgery, about pineal cysts and the procedure to remove it from Amanda's brain.



ON THE NATURE OF PINEAL CYSTS

"In the case of [a] pineal cyst, most of the time, you are born with them ... Some of them stay that way for the rest of life; some progress. [Once removed], these cysts do not come back."

ON THE PROCEDURE

"What we do is a minimally invasive alternative using fiber optic technology [endoscopes]...which allows us to peek inside the brain in hi-def. It's literally like playing a video game. We do [surgery] while watching an LCD screen."

ON WORKING WITH YOUNG PATIENTS

"We love working with younger people. They're much more resilient than older people. They take it much better than older folks. In that context, it's nice. On the other hand, there is an innate feeling [that] you don't want to operate on younger people. Once you make the decision, it is much more pleasant and much more rewarding in younger people."

brain is an entirely different matter that most would avoid altogether.

Amanda not only watches the video, she watches with a keen interest. She has said that she wants to become a surgeon herself one day, and with her widened eyes and body shifted slightly forward, it's convincing. She is ready.

"Just knowing that [Dr. Shahinian] is the best is reassuring," she says later. "There are risks... with him, I'll have the best chance." Her voice barely wavers.

The location of Amanda's cyst in her pineal gland makes any surgical operation difficult. The gland is located in almost the exact center of the cerebrum, the wrinkled grey matter that constitutes the majority of our brain. To see the pineal gland is almost impossible; attempting to do so is fraught with risks. It is the brain, after all – the organ in which every neuron is important and too much manipulation could be detrimental.

This is where endoscopic skull base surgery comes into play. Dr. Shahinian will make a two-centimeter incision at the back of Amanda's head. Through that small opening, he will thread an endoscope (a long, flexible tube-like device that allows surgeons to see deep inside the body) through the natural passageways of her brain, locate the cyst, and then remove it piece by piece.

It is the medical equivalent of a secret agent penetrating a villain's lair, hopping from toe to toe to avoid the perilous laser beams shining from wall to wall, and quickly making off with the target.

Amanda knows this. Her sisters know this. Her parents know this. But this operation is about bringing back the energetic Amanda they knew, the Amanda that plays volleyball with a passion, goes to church every weekend, and works around the clock to balance schoolwork and Student Council duties.

How will Amanda prepare for such a big moment?

"I'll probably do a lot of praying," she says with a laugh.

Although the number of days until her surgery is now finite, Amanda continues to soldier on just as she has before. She continues to laugh just as loud, smile just as wide, and see her friends just as much as she has been for the past year. She is adamant about not letting her predicament become steeped in negativity.

School is a part of Amanda's day from about 10 a.m. to 1:30 p.m., when she sits in AP Calculus AB, AP Literature, AP Biology, and lunch.

Armed with an elevator key and an

iPad from the district (to assist her with reading assignments when her vision is compromised), Amanda considers her time at school to be normal. When she goes home, much of her time is consumed by homework – something she grudgingly admits as her parents look on with sly smiles.

Sometimes, it can be overwhelming.

"[When it is,] I talk to my friends ... I go hang out with them, drop what I'm doing," Amanda says. "Or I'll listen to music or read my Bible ..."

"[You] do some calculus," Mr. Pelletier finishes for her. The room rings with laughter as Amanda rolls her eyes at her dad.

There is some playful repartee as Amanda and her parents talk back and forth. They remember doctor visits as a unit and fill in the gaps in each other's memories. They reminisce over car rides and family vacations.

"That's really been kind of a blessing, because we've gotten to talk a lot in the car," says Mrs. Pelletier. "Wherever Amanda wants to go, I will take her."

"With the [blurred] vision and nausea and dizziness, the car keys disappear," Mr. Pelletier explains. "It's probably one of the hardest things."

Mrs. Pelletier shuttles Amanda to and

from school, hospitals, friends' houses, and piano lessons. Music, the Pelletiers say, is not something they will do without.

"We listen to that – what's that, Mumford? Every day," Mrs. Pelletier says with a good-natured sigh.

"Mumford and Sons," Amanda corrects her. It's one of her favorite bands, along with Coldplay and Muse. For listening, that is.

On her piano, Amanda prefers classical. Every Monday that she can, she meets with her piano teacher – a family friend whom the Pelletiers affectionately refer to as Ms. Jackie – for a lesson.

"Playing piano helps me a lot," Amanda says.

"I think it's a big relaxation tool right now," Mrs. Pelletier says. "I called [Ms. Jackie, when they got the diagnosis]... she opened her schedule. She will adjust to whatever Amanda needs."

Some days are better; some days are worse. Mrs. Pelletier says that Amanda's sisters, Caitlin and Meagan, often send Amanda quick texts during the day to check in and cheer her up if she's feeling down.

Amanda smiles, for the hundredth time that night.

"When it's really hard, I just know that it will get better. So I just focus on that."

