

# EXCLUSIVE

By MEREDITH ENGEL  
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FOR A TEEN battling an extremely rare brain disorder, Taylor Swift is just what the doctor ordered.

Johanna Benthal, one of Swift's biggest fans, can often be heard belting out "Love Story" and "Shake It Off" with the help of her music therapist at NYU Langone Medical Center.

Benthal, of Jamesport, L.I., was born with the CCM3 genetic mutation, which has been documented about 100 times around the globe. It causes blood vessels in her brain to develop abnormally and leak blood. The disorder has landed the 18-year-old in the operating room a staggering 91 times.

But the power of music helps the brave teen feel her best.

"It gives me a sense of purpose but also an opportunity to show what I have to offer to the world," she told the Daily News.

Benthal's music therapist, Joseph Lee, meets with her and other patients up to five times a week to teach them singing, performance and how to play instruments. On a larger scale, he provides a sense of comfort and distraction during what can be a difficult time for families and patients.

"(Music) is normalizing and (makes) the hospital less scary," he told The News.

The physical benefits of music therapy have been documented: It lowers blood pressure and heart rate, helps oxygenate the blood, stimulates the brain and regulates gait, for example.

But its cognitive effects are even more astounding.

Kids with illnesses undergo a tremendous amount of loss and change. Not only do they deal with the physical effects of being sick, they're also often pulled out of school and forbidden from visiting with friends. It can become quite isolating, Lee said. But learning music is socializing and connects patients to a greater purpose.

"Now they can see themselves being a musician," Lee said.

Music has always been a crucial piece of Benthal's care plan. Her mother, Eileen, would sing lullabies to her as a baby when she was wheeled into the operating room. During one particularly bad bleeding episode, she was not able to speak, but miraculously could sing along while her father played guitar, as music and speech are stored in different parts of the brain.

The first time Lee met Benthal, they bonded over a shared love for Taylor Swift. Lee has since taught her to sing three Swift hits: "Shake It Off," "We Are Never Ever Getting Back Together," and "Love Story." Benthal loves to belt out the tunes wherever she is, whether at home with her family or in the intensive care unit.

Tragically, there's no cure — or even treatment — for the teenager's condition. Her care so far has just been to manage the neurological complications that her mutation causes. Research is scant because her disorder is so rare, though NYU Langone did hold a fund-raiser Thursday to raise money for new studies as well as its music therapy and other complementary health programs.

Because the brain loses function every time it bleeds, Benthal's cognitive abilities are severely impaired, and her life expectancy is shorter than average, though doctors don't know what it is yet.

For now, Benthal loves the challenge of learning new songs.

"It's not easy, but I always end up nailing them," she beamed.



PHOTOS BY BRYAN R. SMITH

# A SONG OF HOPE

**Music serves as therapy for L.I. teen with a rare illness**



Johanna Benthal belts out a tune with her music therapist, Joseph Lee.