



‘He Wants To Be Remembered’: Tiny Desk Contestant Finds His Voice While Fighting ALS

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A couple of years ago, Bernie Dalton was a strong, physically fit, 40-something-year-old surfer. Every morning, he would get up at 4 A.M. to watch the sunrise in Santa Cruz, Calif. Bernie wasn't a musician at the time, but he was passionate about music. His lifelong dream was to record an album.

Bernie had just started voice lessons with his teacher, Essence Goldman, when he received the diagnosis that he had bulbar-onset ALS, an aggressive form of Lou Gehrig's disease. Doctors told him he had maybe a few years to live, and that he would lose most of his bodily functions well before that.

"It was time to get my butt in gear," he says through an Eye Gaze Device at the beginning of his Tiny Desk Contest entry video, complete with an ultra-tiny desk and a copy of Stephen Hawking's *A Brief History of Time* on it. "I could no longer speak or sing, so I asked my singing teacher, Essence, to become my voice."

Bernie formed the band Bernie And The Believers with friends. Together, along with Essence, they recorded an album called *Connection*. The songs were written by Bernie and sung by Essence and the band. Essence, who appears in the Tiny Desk entry video, was working on her own album when Bernie asked her to sing on his.

"I wanted to help him, but you know, I didn't quite know how this would manifest," Essence says. She said yes because, as she explains, Bernie's music and his story have a rare urgency. "What could be more important than this man's mission to convey his values and his advice for living for future generations when he doesn't have much time left?"

They sat down in Essence's living room one evening and within a few minutes, they had a song. "It just poured right out," she says. The track, "Simon's Hero," is what Essence calls a kind of sermon due to



its lack of pop-mold rhyme. She says she had to step outside of herself to inhabit the words meant for Bernie's grandchildren.

"The song talks about taking a step back and resonating with what really matters: each moment and the people who you care about," Essence explains. "That faster is not always better. More is not the answer."

Bernie's lyrics reach a hopeful conclusion: "Know every situation / and all probable outcomes / hold love at the center of it all," he writes.

"Bernie is the eternal optimist," Essence laughs. "I have never met somebody who has more hope than Bernie Dalton. He is laying in a bed. He can only move his eyes. And he's planning his next move."

For his next immediate move, Bernie wants to move from the nursing home he's in now, where he doesn't receive the proper ALS-specific care, to his home. And he wants to be remembered.

"He wants to be remembered as a creative person and an artist, not as a sick guy," Essence says, "He just wants people to hear the music."