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## San Marcos Songwriter with Rare Disorder Wins 2025 Rare Artist Award

San Marcos, CA – November 11, 2025 – Alex Yiu, a young songwriter from San Marcos living with IRF2BPL Related Disorder, has been named a 2025 Rare Artist Awardee for his original country song “Tennessee.” The Rare Artist Program is a national initiative powered by the EveryLife Foundation for Rare Diseases (“the EveryLife Foundation”) that honors individuals with rare diseases who use art to share their stories and inspire hope.

Alex was diagnosed with IRF2BPL-Related Disorder, also known as NEDAMSS (Neurodevelopmental Disorder with Regression, Abnormal Movements, Loss of Speech and Seizures) is an extremely rare condition that took over a decade to identify. The disorder has gradually taken away many of his physical abilities—he can no longer eat or drink, speak, walk, or breathe independently, and he experiences seizures. Despite these challenges, Alex’s passion for music remains unstoppable.

Alex began writing songs in 2020 with the support of his music therapist. He now composes and performs using an EyeGaze tablet and the EyeHarp app, which allow him to play instruments such as bass guitar and flute through eye movement. He discovered his love for music through therapy sessions and continued learning with the United Sound program in high school and the School of Music at College of Adaptive Arts.

“Alex has an incredible spirit and inspires me every day with his resilience and drive to create his music,” said Lindsay Zehren, Alex’s music therapist. “Music gives him a voice, and he uses it to tell stories that move people.”

His award-winning song “Tennessee” is part of his dream to record a full country album in Nashville. “It has been an especially challenging year of hospitalizations. Being recognized by the Rare Artist Program has brought Alex joy during long weeks in hospital,” says his mother, Caroline Yiu. “Through his music, he wants to raise awareness for his ultra-rare disorder, help other patients feel understood, and remind them to never give up.”

The Rare Artist Program, established in 2010 by the EveryLife Foundation, celebrates the talents of individuals impacted by rare diseases through visual art, poetry, and, for the first time in 2025, music. Alex was one of 10 awardees selected by public vote after judges narrowed the field to 20 finalists from 235 entries. Awardees receive coaching to strengthen their advocacy skills and are invited to speak at Rare Disease Week, February 24–26, 2026, on Capitol Hill in Washington, D.C. where their artwork will be showcased at biopharmaceutical and patient conferences throughout the year.

Alex hopes this recognition will spark collaborations with musicians, technology innovators, and scientists to create new music, improve adaptive instruments, and advance research for IRF2BPL-Related Disorder.

To learn more about Alex's journey and listen to his music, visit [www.alexsodyssey.com](http://www.alexsodyssey.com).

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