

Chanin and Zeke Zaragoza

A Family's OMAS Journey

Diagnosed with OMAS at just 36 months, Zeke Zaragoza endured a challenging four-year period marked by aggressive, painful therapies, physical, and occupational treatments. By the age of seven, he achieved remission and had remastered the motor functions lost abruptly as a toddler. With the unwavering support of his family and medical team, he began to engage in sports activities that once seemed impossible. Now 24, Zeke, along with his mother Chanin, advocate for those affected by disease, inspiring others to persevere through their own challenges.



What began as a seemingly normal childhood for Zeke Zaragoza quickly descended into a nightmare of dizziness, uncontrolled movements, and a debilitating loss of motor skills. The first signs of trouble emerged when Zeke was barely 3 years old. "He just started having some strange symptoms where he was dizzy and it was would walk sideways and hit the wall," recalls his mother, Chanin. "He would complain that the wind was moving him if he was outside, or ask 'Why is the room moving?'"

Desperate for answers, Zeke's parents sought medical attention, only to be met with a general diagnosis of vertigo. But a mother's intuition was telling Chanin that something more serious was at play. The search for a proper diagnosis led the family on a journey that would ultimately take them to Cedars-Sinai Medical Center in Los Angeles. There, a team of 25 neurologists finally provided the answer they had been seeking: Opsoclonus Myoclonus [Ataxia] Syndrome (OMAS), a rare and debilitating neurological disorder.

OMAS, a condition characterized by uncontrolled eye movements, muscle spasms, and balance issues, had robbed Zeke of his independence. "He wasn't able to walk, he wasn't able to sit up," Chanin recounts.

The next four years proved to be arduous for Zeke, who underwent a grueling regimen of treatment that included ACTH shots, IVIG therapy, and extensive physical and occupational therapy. "He had to do his IVIG monthly and undergo chemotherapy," Chanin explains. "He had about two and a half years of physical



therapy and occupational therapy." Zeke went from living a normal life to being a child who could no longer feed himself, drink from a cup, or stack one block on top of another. Remastering these most basic tasks was a daunting challenge.

Maintaining Certainty in Uncertain Times

During this four-year period, Zeke's parents worked hard to maintain normalcy. For Zeke, this included allowing his next older brother to come in and play during his therapy sessions. Outside of the care setting, Zeke's parents carved out date days for each of Zeke's brothers and ensured they were able to continue in their activities. "And thankfully," Chanin said, "they have godparents who were able to help out with them, take them to school, and do a couple of things with them." As importantly, the family was determined not to treat Zeke differently or "make excuses for him" as Zeke worked through his recovery, showing their commitment to maintaining high expectations for all their children.

Throughout this time, there was a message that this struggle was an opportunity. "Probably around first grade," Zeke recalls, "more and more my mom just continued to embed, 'God gave you a story, use it', and I love that she continues to say that I have a story, and I can use this story for good."

For the Greater Good

When Zeke was younger, Chanin was the one sharing his story and connecting to other families. As Zeke grew older, Chanin said she handed "him the reins and allowed this to be his story, to really embrace, and tell, and be responsible for." Zeke's story continued to blossom - he excelled in sports, particularly football, eventually playing at Oklahoma State University. The inspiring story of a child, once dependent upon a wheelchair, playing Division I sports, caught the interest of national media. Since that time Zeke has used this attention to raise awareness about OMS and inspire others.

Zeke now leverages social media to connect with and build relationships with other families battling OMAS. In reaching out to children, he provides encouragement but also proof that a brighter future is possible. "And it's awesome because, you know, their parents say that I make their day, but really, you know, they're making mine."

Zeke and Chanin continue connecting with families battling OMAS and advocating for care. They are looking forward to meeting other families and researchers in person when they attend the OMSLife Caregiver's Conference in October of 2025, where they will be Keynote speakers.

Rare Awareness Radio is made possible by support from Meeting You Podcast, OMSLife Foundation, and Principled Research Resources L3C.