Bhavna Sivanand Dias, OMAS, & A Call to Action

"What I hope the most is that [Amara] can soar with wings as if nothing ever happened to her, but also that she knows what happened and is confident in the resilience that created in her."

Bhavna Sivanand Dias is the Executive Director of the UCLA Center for Social Impact, rare disease advocate, and mother to a child with OMAS. In a recent interview with Rare Awareness Radio, Bhavna shared her family's personal journey and her efforts to use her public health and policy expertise to advocate for others navigating the complexities of rare diseases.

Bhavna's connection to Opsoclonus Myoclonus Ataxia Syndrome (OMAS) began when her daughter, Amara, just shy of 18 months old, began exhibiting a tremor in her leg. What followed was a frustrating and emotionally draining journey through emergency rooms and neurology departments. Initial tests came back negative, and despite Amara's rapid deterioration – the tremor spreading, her ability to walk vanishing, and her sleep becoming a nightmare – the catch-all diagnosis of acute cerebellar ataxia offered no real answers, just a directive to "wait and see."

A week of EEGs, blood draws, MRIs, lumbar punctures, and numerous other tests as an in-patient at the hospital failed to provide insight. A day after release, Amara developed a new troublesome symptom of erratic eye movements. Convinced this was an indicator of a more serious condition, Bhavna immediately called the hospital only to be told that these symptoms did not change the diagnosis. Undeterred, Bhavna and her husband relentlessly pursued answers online, finally stumbling upon another family's story of a child with similar symptoms, including opsoclonus, the hallmark random eye movement of OMAS.

The possibility of OMAS brought a new concern, as this rare autoimmune disorder is often associated with a tumor. With this new information, and an informed neurologist, the official diagnosis of OMAS was made. The search for a tumor began, albeit unsuccessfully with no indication of a mass via ultrasound and MRI. A subsequent test involving a radioactive tracer detected a tumor behind her liver. An odd and brief sense of relief washed over Bhavna and her husband, "We've identified the cause... now we [are] parents of a child with cancer."

Upon tumor detection, preparations for surgery began immediately, as the tumor's location required a complex procedure involving a liver transplant specialist. By the time surgery day arrived, Amara's condition had deteriorated to a critical state—she was unable to communicate or even lift her head.

55%
of patients with OMAS have evidence of a tumor.

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After the successful surgery, the journey shifted to recovery with ongoing treatment for OMAS – a regimen of immune suppression including donor antibodies, steroids, and rituximab. For 20 long months, Bhavna and her husband dedicated themselves to Amara's care. It wasn't until her second birthday that Amara began to walk again, followed by the arduous process of relearning everything – crawling, climbing, talking.

"When we were in the trenches with Amara, I just felt completely alone... we had a great network of friends that showed up for us, but we also felt completely isolated because we didn't have anybody that understood what we were going [through]."

Finding community

During this most challenging period of Amara's illness, Bhavna discovered the OMAS community on Facebook and connected with other parents who truly understood her journey. These initial connections provided crucial emotional support during a time when she felt isolated and overwhelmed.

Bhavna's background in public health and evidence-based decision making also proved invaluable, as she meticulously researched treatment options and advocated for her daughter's care. Now in remission, Amara's resilience and recovery have inspired Bhavna to become a passionate advocate for the OMAS community. Witnessing the delays, the lack of awareness, and the sheer rarity of OMAS ignited a desire to help others navigate this challenging terrain. "We feel like we are one of the lucky ones," she explains, acknowledging that many families face even longer and more difficult treatment journeys.

"You never really know why things happen the way they do to anybody. But after she got better, we realized, okay, it's because we need to help. We need to stay involved... she got better, so now we have the capacity to help others."

Heeding the call

Bhavna and her husband are unwavering in their commitment to supporting families affected by OMAS. As an integral member of the OMSLife Foundation's International Steering Committee, Bhavna collaborates closely with founder Mike Michaelis to advance research initiatives and create resources tailored for OMAS families. She actively stays informed on the latest developments in OMAS treatment by attending specialist conferences in England and plays a pivotal role in organizing caregiver conferences in Los Angeles.

Drawing on her extensive background in public health—rooted in evidence-informed decision-making and policy work—Bhavna has honed the skills necessary to curate research and champion systemic change.

She assisted in successfully advocating for the establishment of California's Rare Disease Advisory Council (RDAC), a vital step toward amplifying the voices of the rare disease community at the state level. Beyond this achievement, Bhavna is spearheading efforts to develop comprehensive resources for families, including a curated list of OMAS-experienced providers and advocacy for increased research funding.

Bhavna deeply understands the challenges OMAS families endure—such as the ever-present fear of relapse and the intricate maze of navigating healthcare systems for ultra-rare conditions. She often highlights how parents are forced to become custodians of crucial, nuanced information, as standardized protocols frequently fall short. By sharing Amara's journey, Bhavna hopes to inspire other parents to join her in transforming personal struggles into a powerful collective voice, driving meaningful change for OMAS families worldwide.

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