Maura McNamara, *Ellery the Brave Celery*, & OMAS

"I think [Ellery] has an understanding that a lot of kids don't... people are going through things... she understands that there's different paths for people.... but she's happy and bubbly and has friends and loves playing and pretending. And that's beautiful."

Hindsight makes the subtle red flags seem obvious. But during the toddler years—especially when a first child—distinguishing between normal developmental setbacks and something more concerning isn't always clear. A missed milestone or a temporary regression can easily be dismissed as part of the unpredictable journey of early childhood.

That uncertainty was exactly what Maura faced when her daughter, Ellery, began losing abilities she had already gained. Initially, the decline seemed linked to a bad fall—a possible concussion. When the pediatrician was unable to pinpoint any classic concussion symptoms, Maura's worry deepened. Ellery became clumsier, bumping into things more often, struggling with sleep.

Seeking answers, the family took Ellery to Boston Children's Hospital, where she underwent an MRI and a spinal tap. The doctors decided to monitor her over the weekend, with a diagnosis of acute cerebellar ataxia. After three days, she was discharged—no improvement, but no decline either. Maura and her husband were told that within two weeks, Ellery should begin to recover.

But improvement never came. Instead, Ellery's condition deteriorated rapidly. Ellery's hands began to tremble so severely she could no longer use them, and her speech slowed and became increasingly labored. Soon after, she began experiencing prolonged rage episodes—"toddler tantrums times a million," as Maura described them. These were not typical outbursts; they lasted for hours and

were marked by intense physical aggression, obsessive-compulsive behaviors, and extreme emotional volatility. The episodes were both unpredictable and all-consuming, profoundly disrupting daily life for the entire family. Sleep became nearly impossible—not just for Ellery, but for her parents. The only way Ellery could rest was by lying directly on top of her mother.

"We'd descended into chaos at this point," Maura recalled. The family took time off work, unable to leave their apartment, trapped in uncertainty—one of the lowest moments of their parenthood journey.

Despite continued diagnoses of acute cerebellar ataxia, doctors gave them one crucial instruction: if Ellery began exhibiting uncontrolled eye movements—rapid, erratic flickering—they needed to call immediately.

A few weeks after their stay at Boston Children's, Maura lay beside her daughter, trying to offer comfort. That's when she saw it. Ellery's eyes flickered, darting unpredictably, dancing back and forth. At first, Maura questioned whether she was imagining it. She turned to her husband, Brad, asking him to confirm what she was seeing. They captured a video and sent it to the on-call neurologist. The response was immediate: Get to the ER right away. The next morning, they had an answer—opsoclonus myoclonus ataxia syndrome (OMAS).

OMAS presents with symptoms that vary in severity and timing. Though opsoclonus (involuntary erratic eye movements) is key to diagnosis, the most frequently observed initial indicator is ataxia —difficulty with balance and coordination. Because ataxia is also a defining feature of acute cerebellar ataxia (ACA)—a condition 50 times more prevalent than OMAS—many physicians mistakenly diagnose ACA instead. Unlike ACA, which often resolves on its own, OMAS demands prompt & intensive immunosuppressive therapy to mitigate lasting effects on cognitive & motor functions.

The Start of Treatment

Once Dr. Mark Gorman, a specialist at Boston Children's Hospital, confirmed Ellery's OMAS diagnosis, an intensive treatment protocol began immediately, involving steroids and immunoglobulin therapy. The family's life became structured around four-week treatment cycles, with Maura and Brad becoming expert

caregivers. The COVID-19 pandemic added another layer of complexity, forcing them to be even more isolated and cautious due to Ellery's compromised immune system.

As treatment continued through the pandemic, the original two-year estimate expanded to five. Physical, occupational, and behavioral therapies were added. During this time, Maura and her husband sought answers through online resources and the OMAS community. Maura remembers reading books about children undergoing medical journeys, hoping to prepare for what lay ahead. But no books were available specifically on OMAS. That realization sparked an idea: What if she could create something herself?

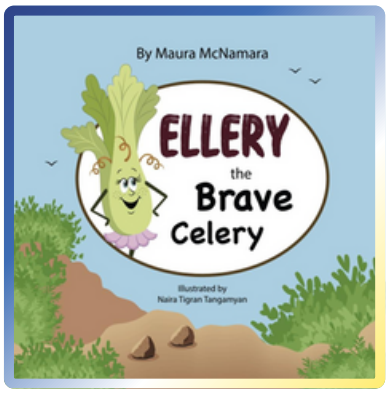
Ellery the Brave Celery

Maura wanted a way to capture both the complexity and resilience of a child's journey with OMAS—something kid-friendly and meaningful for adults. What began as a personal story about Ellery evolved into a whimsical world where "Ellery the Brave Celery" navigates Veggieland, meeting vibrant characters who reflect the reality of her

> *"You hear there's a treatment, and [you think] this is so great. But getting, like, 20 milliliters of oral liquid steroids into a 2 1/2 year old?*
>
> *I mean, if you've ever smelled liquid steroids, it's disgusting.*
>
> *So, we mixed it with yogurt, you know, all of these things... getting one dose of steroids in her would take three hours.*
>
> *And the IVs -- it would take the IV team a half day just to just get the IV in. We were so thankful that there was a treatment, but, but just the logistics of that were not easy.*
>
> *And, you know, that's a part of the journey that's been really, surprising, because it's like, oh, great, there is a treatment, but, getting it into a raging child is not [easy]."*

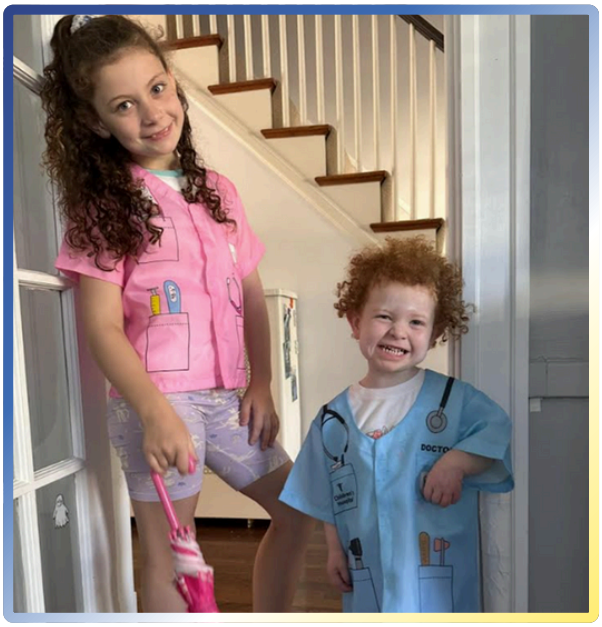
experience in a way children can understand. The book blends a serious medical condition with playful storytelling—helping newly diagnosed families process the experience while keeping the heart of the journey accessible.

Ellery herself played a key role in shaping the book, contributing original artwork and ensuring her little sister was included in the world she created. With the support of the OMSLife Foundation, the book will be distributed to newly diagnosed families as part of an essential resource packet—offering not just medical insight, but a story that connects, informs, and reassures.



The Next Chapter

Now in third grade, Ellery has made remarkable progress. She thrives in a neurodiverse classroom with an extensive Individualized Education Plan (IEP), navigating academic challenges while building meaningful friendships. Though learning delays and the lasting effects of her diagnosis require careful planning, her family remains steadfast in ensuring she has the support to succeed.



Though risk of relapse is an ever-present concern, Ellery approaches life with resilience and embraces her role as a caring big sister.

When reflecting on challenges faced, Maura shared, "I think [Ellery] has an understanding that a lot of kids don't... people are going through things... she understands that there's different paths for people.... but she's happy and bubbly and has friends and loves playing and pretending. And that's beautiful."

To Learn More

Maura's book, Ellery the Brave Celery, is available on Amazon.

Visit OMSLife Foundation for resources and support for families, researchers, clinicians, advocates, and other healthcare stakeholders.

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