

Beyond Isolation: The Power of Advocacy

Cristal Grogan

The National Perinatal Association (NPA) is an interdisciplinary organization that strives to be a leading voice for perinatal care in the United States. Our diverse membership is comprised of healthcare providers, parents & caregivers, educators, and service providers, all driven by their desire to give voice to and support babies and families at risk across the country.

Members of the NPA write a regular peer-reviewed column in Neonatology Today.



In the heart of May, as spring begins to blossom and the world seems to awaken, a powerful call to action can be heard throughout the pages of Neonatology Today.

"It is NEC Awareness Month."

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As a parent who has walked the heartbreaking path of watching her child battle Necrotizing Enterocolitis (NEC), there have been so many moments where I have felt like I am entirely alone. All odds are stacked against us; I sometimes feel as if I am fighting some invisible enemy—an enemy that seems impossible to beat.

At the beginning of our journey, I vividly remember the feeling of isolation and the weight of uncertainty I carried with me every step I took. Nevertheless, as the years passed, I discovered a community of fellow warriors, each carrying their burdens and fears yet bound together by a common purpose. Within their stories, I

found solace and strength, realizing that I was not alone in this world that often seemed to be collapsing in on me.

Together, we created a bond that transcended the boundaries of isolation, uniting us in our shared determination to overcome the challenges of NEC and to advocate for those still navigating its treacherous waters. Moreover, as we stand shoulder to shoulder, our voices raised in solidarity, we embody the resilience and hope that define our collective journey. I no longer stand alone. I am a proud member of a resilient tribe united in our collective mission to raise awareness and offer unwavering support. Furthermore, as we grow in numbers to fight this battle, we continue to weave the diverse narratives of our journeys into a tapestry of unity, strength, and advocacy.

However, the journey to raising awareness for NEC is not a solitary one. It requires the collective strength and unwavering commitment of parents, healthcare providers, researchers, and advocates to illuminate this often overlooked but devastating disease. Together, we stand as a beacon of hope for families navigating the treacherous waters of NEC, offering solace, guidance, and a steadfast presence in their darkest hours.

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Within our close-knit community, we acknowledge the profound toll that NEC takes on the mental health of both parents and infants. The relentless stress, anxiety, and grief that accompany an NEC diagnosis can be overwhelming, threatening to crush even the most resilient souls. This is why we must not only raise awareness of NEC itself but also advocate for comprehensive support services that address the mental

health needs of families. From counseling to peer support groups and respite care to financial assistance, every resource that is offered strengthens the core of our existence: empowering parents to navigate the emotional challenges and complexities of NEC with courage and resilience.

Yet, as we raise our voices in solidarity, we cannot ignore the stark realities of inequity that persist within our healthcare system. For far too many families, access to quality care remains elusive, hindered by systemic barriers of race, socioeconomic status, and geographic location. Our small but mighty community recognizes that **AWARENESS WITHOUT ACTION IS MEANINGLESS.** We must confront these

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In the face of adversity, our community is a testament to the transformative power of unity and resilience. We are mothers and fathers, nurses and doctors, teachers and caregivers, advocates and allies—all bound together by a common purpose: to raise awareness, uplift families, and build a future where NEC no longer exists. Our rallying cry is heard in the halls of hospitals and in the hearts of communities across the globe, echoing the unwavering determination of parents to fight for their children's happiness and healthy long-term outcomes.

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As we continue to bring light to NEC Awareness Month, let us do so with the bravery and strength of our tribe behind us, knowing that together, we are an unstoppable force for change. Let us raise our voices, share our stories, and stand in solidarity with all those affected by NEC. Because in our unity lies our greatest strength, and in our resilience, our brightest hope for a better tomorrow.

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