## RARE VIEWS Advocating for NICU Support



## **Corin Nava**

Executive Director of Project Sweet Peas, a national non-profit organization providing support to families and caregivers of premature or sick infants and families impacted by pregnancy and infant loss.

- Q.
- What inspired you to get involved with your organization?
- A. In 2006, my first son, Gabriel, was diagnosed with Congenital Diaphragmatic Hernia (CDH) shortly after birth. He spent 55 days in the Neonatal ICU at three different hospitals, undergoing numerous surgeries and procedures. Sadly, Gabriel passed away from complications related to his condition. Following this devastating loss, I turned to the internet to find support and connected with two women, Kate Crawford and Stephanie Olivarez. Both had children born around the same time with the same birth defect. Kate's daughter, Shannon, had passed away from a combination of CDH and HLHS, while Stephanie's daughter, Shelby, is a CDH survivor. We found comfort and support in sharing our NICU experiences and decided to help support other families going through similar challenges. We wanted to provide families with the necessary materials, knowledge, and support that we wished we had during our NICU stays and let them know they are not alone. This led us to start assembling care packages for local hospitals, and from those efforts, Project Sweet Peas was established in 2009.
- **Q.** In your view, what is the biggest unmet need for your caregivers and families?
- One of the biggest unmet needs for our NICU families is financial assistance. Annually, over 350,000 babies are born in the United States and admitted to the NICU. A survey showed that 9 out of 10 of these families reported significant financial burdens due to medical expenses, loss of income, and additional unforeseen expenses such as travel costs, parking fees, and meals away from home. These financial burdens add to the extreme stress and emotional strain these families are already enduring.
- Q. Are there any new resources that you'd like people to know about?
  - We offer most of our core services for NICU families nationwide on our website. Families can access these services by visiting our website (<a href="www.projectsweetpeas.com">www.projectsweetpeas.com</a>) and browsing through the dropdown menu under the NICU Support tab.
- How can the public help raise awareness and support your community?
- Project Sweet Peas founded and established Neonatal Intensive Care Awareness Month in September to honor NICU patients, their families, and the dedicated NICU professionals who care for them. This special month is aimed at creating a supportive and empowering community for families during their most challenging times. It's also a time to show appreciation for those who dedicate their lives to helping these families.

## Ways to raise awareness in September:

- 1. Wear green and encourage others to do the same!
- 2. Share your story on social media using the hashtag #NICUAwareness.
- 3. **Do some good! Volunteer for a NICU organization**, donate to your local NICU, or perform an act of kindness for a current NICU family in need.
- 4. Participate in our 5K Your Way event: <u>5K Your Way | Doliggy</u>

Rare Views is an ongoing spotlight series brought to you by Mallinckrodt's Patient Engagement & Advocacy Team.

