

From Hope to Joy

A Memoir of a Mother's Determination and Her Micro Preemie's Struggle to Beat the Odds

February 2, 2016

The Honorable Charles Schumer
United States Senate
322 Hart Senate Office Building
Washington, D.C. 20510

Dear Senator Schumer,

As a mother of a preemie and an author who has chronicled the struggles and triumphs that can accompany the arrival of premature baby, I am writing to urge you to co-sponsor S. 2041, the Promoting Life Saving New Therapies for Neonates Act of 2015. There is no one cause—and no one cure—for an early delivery, but in those critical days and weeks after birth, doctors and nurses need innovative treatments that are specifically tailored for their smallest, and most fragile, patients. This bill makes the development of such treatments possible, giving renewed hope to the mothers and fathers of premature infants seeking therapies for the newest members of their families.

In 2012, my entire world was turned upside down after my daughter, Joy, was born 17 weeks early, and I have dedicated my professional life to sharing her story in the hope of helping other families with premature infants through their own. At just one pound and four ounces, Joy needed treatments that were carefully designed to both fight her unique conditions of prematurity and be effective on her small body. With the help of our outstanding doctors and nurses, Joy endured 121 days in a neonatal intensive care unit (NICU) and is now a healthy and vibrant young girl.

Joy's survival is nothing short of a miracle, and yet she is just one of the nearly 200,000 newborns who are admitted to a NICU every year. For too long, there has been an undeniable shortage in novel therapies for the newborn population – the FDA has not approved a single drug designed for neonatal health since 1999. Where past legislative efforts have failed, this bill marks a promising step forward by incentivizing research through the provision of a transferrable “exclusivity voucher” for drug manufacturers who successfully develop products in critical areas of neonatal health. It rightly encourages the scientific breakthrough that has revolutionized the treatment of so many other conditions, and it's far past time that we work to provide a boost to new investment in research for our nation's most precious group of citizens.

I hope that my story serves as an inspiration to what we can achieve for New York families and those across the country struggling with the challenges of prematurity. Please lend your support to the Promoting Life-Saving for New Therapies for Neonates Act of 2015.

Sincerely,

Jennifer Degl

Author, *From Hope to Joy: A Memoir of a Mother's Determination and Her Micro Preemie's Struggle to Beat the Odds*