

# The Challenges of Preterm Birth: Beyond the Hospital Doors

## A Vivid Account of One Mother's Journey With Her Son

BY KELLI KELLEY

The first image I had of my son was in a Polaroid picture – the lighting bad, the image fuzzy. My mom taped the picture to the handrail of my hospital bed. I was numb. The pain medication and conflicting emotions flowing through my body made it hard for me to focus on the photo. Could this really be my son?

At 24 week's gestation, my son, Jackson, was born by emergency C-section. He weighed one pound and eight ounces and was 12-and-a-half inches long. His skin was transparent. He wore a tiny sleeping cap that engulfed his head. He had wires and tubes touching almost every part of his body. Nothing could have prepared me for such a sight.

The emotional, physical, financial and psychological impact of having a baby born preterm often blindsides parents. Little can be done to prepare parents for the challenges of having a baby in the neonatal intensive care unit (NICU). But with the support of dedicated neonatologists, caring nurses, social workers, clergy, peer mentors, family and friends, NICU parents slowly adjust to their new reality. And in many cases, that reality is the realization that the challenges of raising a preterm baby do not end at the hospital doors.

### A WHOLE NEW WORLD

We were blessed to qualify for Early Childhood Intervention services that provided weekly physical, occupational and speech therapy for our son after his discharge from the NICU. I embraced the support and worked daily with Jackson to repeat the exercises the therapist had taught me – doing my best to integrate exercises into his daily routine, including diaper changes, bath and tummy time. As he grew, I eagerly engaged in games and activities that our occupational therapist suggested for motor planning. I happily sprayed shaving cream on our kitchen table to allow Jackson to experience different textures. I bought puzzles and toys to challenge his hand-eye coordination and joyfully introduced new food textures to support his oral development.

At the age of three, Jackson graduated from the program. I was ecstatic and incredibly naïve.

I thought my son had “caught up” and would forever be past the challenges of his preterm birth. Imagine my surprise when shortly after enrolling him in preschool, my son's teacher began to point out developmental delays and behavioral issues she suspected were associated with Sensory Integration Dysfunction. I was heartbroken and angry. I was angry that Jackson no longer qualified for social services and questioned whether I had done enough during his infancy. Despite an amazing pediatrician and wonderful therapists, why had I not known about Sensory Integration Dysfunction – a common neurological disorder for many preterm children? How had I not been aware of his low muscle tone and continued fine motor challenges? Looking back, all the signs were there. But as a first-time mom, I did not know how to accurately gauge Jackson's development. And because of his compromised immune system, we had remained isolated at home, declining large playdates for fear of contracting Respiratory Syncytial Virus (RSV), a major cause of respiratory illness in young children. I am sure some part of me did not want to admit that my son (who had come so far) was still behind.

### MAKING PROGRESS, SLOW AND STEADY

Once over the initial shock and disappointment, I took Jackson for a full evaluation at a pediatric therapy center. This is when my blinders were removed and the real work began. I devoured the book *The Out-of-Sync Child*, which helped me understand Jackson's challenges with sensory issues. Our playtime centered around activities in *The Out-of-Sync Child Has Fun*. We scheduled Jackson for weekly occupational, physical and speech therapy, opting to pay the significant out-of-pocket fees our insurance company would not cover rather than saving for college. How could we think about college if our son would not be “kindergarten ready” without therapy.

Jackson's therapists recommended Auditory Integration Therapy (AIT) to assist with auditory processing problems. He was so precious wearing his big earphones and CD fanny pack while he played with his puzzles

and participated in other fine motor skill games. We instituted Therapeutic Brushing and Joint Compression Therapy throughout the day as both had proven effective in decreasing sensory integration issues and often resulted in improved life skills such as tactile responsiveness, focus, alertness, improved coordination and self-regulation.

Jackson loved therapy and never complained. It was just a part of life and our regular routine. I think on some intrinsic level he knew that it helped him cope with everyday life. His behavior drastically improved and he gained new skills quickly. But most milestones were considerably delayed – from writing his name to riding a bike. I fondly remember a friend reassuring me that Jackson would know how to properly use a fork by the time he was in college – but by college most boys prefer pizza anyway.

Jackson graduated from private therapy prior to beginning kindergarten, but his very wise and dedicated therapist cautioned me that Jackson might need to come in for a “tune up” from time to time. She was right. Jackson is now 11, and has benefited from short occupational therapy sessions many times over the years. With age and maturity, he has learned to compensate for certain challenges and has integrated coping skills for sensory integration dysfunction into his daily life. For instance, we found that wearing a heavy backpack and chewing gum greatly reduced anxiety and sensory overload during our summer trip to Disney World.

Jackson was officially diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) last year and began taking medication and seeing a child psychologist to help him learn to manage frustrations related to the disorder.

An outgoing fifth grader, Jackson is an avid reader and performs on grade level. He enjoys sports even though he still struggles with coordination and motor planning. And he has found his strengths in acting and never shies away from the stage.

Therapy has been and will most likely continue to be an important part of

Jackson's life. I am so grateful to all the therapists who loved and cared for him and contributed to his success. As the founder of Hand to Hold, a nonprofit that provides support to parents of preemies and babies born with special healthcare needs, I have had the opportunity to meet thousands of children born preterm and provide information and ongoing education to their parents. I am a strong proponent for early intervention. Hand to Hold strives to educate parents about the challenges their children might face and prepare them to meet those needs. I frequently advise parents to contin-

ue regular developmental screenings and to supplement services provided through state and federal programs with private therapy.

The journey of prematurity does not end at the hospital doors. In many cases, it is just the beginning. Children born preterm may need ongoing medical care and therapy for many years to overcome the challenges presented by their early births. One thing I have learned about preemies, they are fighters. And with the right resources and support, they can lead full, active and healthy lives.

Jackson still struggles with a knife and fork...but that does not worry me too

much these days. The skill will come in time. And I will cheer the loudest when it does. Who knows, I may even take him out for pizza to celebrate. 



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the Ministry of Health and Social Welfare, has established programs to minimize the impact of HIV and AIDS by providing HIV and TB prevention and care for apparel employees and their spouses or partners.

### **State of Rhode Island, Office of Employee Benefits, Rewards for Wellness**

This program was established by the Rhode Island state government to encourage long-term employee lifestyle changes and improved health and wellbeing through wellness programs and screenings. The program ties beneficial lifestyle choices made through the program to financial savings, awarding participating employees with health insurance premium co-share credits.

### **Universidade Federal de Minas Gerais, Telecare to Remote Areas (Brazil)**

Telehealth supports remote municipalities in Brazil, allowing access to specialized medical services by low-income populations located in remote areas. The program allows health professionals in geographically isolated areas, with little access to other specialized professionals and without technological resources, to keep abreast with current techniques and diagnose and treat certain diseases or urgent cases. 

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### **How can case management departments enhance their collaboration with physicians to better the organization as a whole?**

Care management leaders can enhance their collaboration with physicians by identifying a physician champion for care management initiatives. The approach to identifying the right physician champion must be strategic. In the past, senior leadership assigned a traditional doctor or seasoned physician who could no longer do clinical practice to this position. This approach is archaic. The individual in this position must be willing to challenge the "status quo" and drive change. Through the leadership of this physician champion the opportuni-

ties for improvement that care management identifies can be recognized. This recognition will lead to collaboration and development of innovative solutions. These improvements will bring necessary change that will enhance the overall operations and performance of the organization. 



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particularly in care coordination. Through facilitation of communication and sharing of information, technology tools become invaluable to helping case managers coordinate care across multiple providers all along the healthcare spectrum. Through technology to gather and share information, case managers are able to address the needs of the whole patient to achieve positive outcomes. 

### **References**

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