

## **Epilogue ~ 10 Years Later...**

Moving to Washington State began a new chapter in Laura and Daniel's lives. They suffered something of a stumble out of the starting gate. As soon as they arrived in Washington, Laura contacted the Department of Developmental Disabilities (the DDD) to get Hannah's services set up. She was mere weeks too late. Just prior to their arrival, the Cap Waiver program had been frozen to new applicants. Worse yet, Hannah was placed on a wait list, but Laura was informed that the "wait list" was more of a "wish list". She was told she should not expect to ever receive services for her daughter--at least not until Hannah reached adulthood. The DDD, instead, offered Laura and Daniel forty hours of emergency respite care.

Laura was in a panic. She had no idea how she was going to manage without any assistance. To her horror, she soon found out that she couldn't even take advantage of the offered emergency respite care. Hannah was apparently not handicapped enough for nursing care (i.e., no tracheotomy/breathing machine), but too handicapped for respite care (i.e., requiring G-tube feeds and seizure protocol).

Laura worried that moving west had been a mistake, but there was no turning back. She needed to get creative and change some plans. Kevin had decided to...be Kevin again. He had quit his job, so child support for the girls had dropped back down to nearly nothing. Laura and Daniel both had college loans in need of being paid back, and Laura still carried some debt from her time living alone with the girls. Laura would definitely need to

work.

She was going to have to work at night, too. Since they had no help with Hannah, either Laura or Daniel would need to be home with her at all times. That limited Laura's options to getting her nursing license and working at a hospital, or working at the local Seven-11. With fresh memories of her dislike for nursing school, Laura told herself that she'd only have to go through the hell of nursing for a few years--just long enough to pay off their debt. She took her nursing exam and applied to work at Seattle Children's Hospital.

Laura didn't hear back from Children's right away. She began to think she was going to have to apply at Seven-11, after all. Then Hannah became ill and was admitted to Children's. While filling out the intake paperwork, Laura mentioned to the nurse that she had filled out an application to work there. The nurse must have passed that information on to her supervisor, because the next day the manager of the Medical Unit asked Laura if she'd mind stepping away from Hannah for an interview.

With Hannah's help getting her foot in the door, Laura got a job on the Medical Unit of Seattle Children's Hospital. She was working within weeks. She learned right away that working in a hospital and studying to work in a hospital in nursing school could not be much more different. She *loved* her job.

Daniel was doing quite well with Nintendo, Laura was doing well at Children's Hospital, and another wonderful life event at that time was when

one of Hannah's doctors at Children's prescribed her a "sleep cocktail". For the first time in years, Laura could put Hannah to bed at a reasonable hour and expect that she would wake the next morning at a reasonable hour. Furthermore, Hannah decided to stop seizing! Within a year of moving west, Hannah was not only seizure-free, but off of all of her seizure meds, too.

Life was calm enough at that point for Laura and Daniel to feel they could finally work on having the children they had always dreamed of having together. Within a year, their son, James Christopher was born. Laura had never felt better while pregnant, the delivery went as smoothly as one can go, and James was a very happy baby.

Within months of James's birth, Daniel left Nintendo for Microsoft's X Box Division, and they bought their first home in Kirkland, Washington. With the adjustment to life with three children and the stress of changing jobs, buying a house, and moving, there were some tense moments in the first months of James's life. Laura and Daniel had survived much worse, however, so they continued on in comparative marital bliss.

Although frenzied, life was rolling along better than Laura ever could have expected. Washington really agreed with them. Almost immediately upon moving west, Laura had fallen in love with the resources available for the children. There was much that the community provided for Emily and Hannah that they never would have had the opportunity to experience in northern New Hampshire. Hannah went to the elementary school every day,

to a special classroom called the “Medically Fragile Room”. It was designed for children just like her, and focused entirely on speech, occupational, and physical therapies. Emily received a complete evaluation and some therapies at the Autism Center at the University of Washington, which proved to be very helpful. Emily was also able to begin riding horses at Little Bit Therapeutic Riding Center. When she had taken riding lesson in New Hampshire, she (and the instructor) had become very frustrated quite quickly because Emily couldn’t keep up with the expectations of the instructor. At Little Bit, Emily had the opportunity to take things at her own pace, and she gained great self-confidence in the process.

Over the years, Emily’s most pressing challenges were identified and specific therapies were offered to help her. IQ testing revealed mild developmental delay, but Emily’s biggest challenge, by far, was that she had no concept for the passage of time. She could generally tell time (as long as the clock didn’t have Roman numerals), but the numbers had little to no meaning for her. If, for instance, she misread a digital clock to say “8:74” as opposed to “8:47”, she wasn’t able to deduct that she must have made a mistake. If she felt hungry she would prepare a snack. The fact that the clock read 6 PM and Laura was in the kitchen finishing preparations for dinner meant nothing to her. One time Laura told Emily to do her nightly reading.

Emily asked, “May I just read for fifteen minutes tonight instead of a half hour? I’m really tired.”

“Sure,” Laura said. Then Laura proceeded to get busy with Hannah and James and forgot to tell Emily that her reading time was complete. Emily ended up reading for about two hours before Laura got back to her. Later that night, Emily’s Thankful Thought at dinner was that she had only had to read for fifteen minutes.

Laura was continually amazed at the pervasive nature of the lack of understanding of time, especially when coupled with developmental delay that hindered compensation. If one doesn’t understand time, one can’t understand hurry, late, or time management. Laura was astonished at how easy it is to take for granted the ability to manage one’s time. It is necessary for everything from planning to set the alarm before going to bed to planning to use the restroom before getting in the car for a long trip.

Despite the workload of a toddler’s care, Hannah’s care, and attempting to help Emily with her struggles, Laura and Daniel felt they could handle one more child. In no time at all, Laura was expecting child number four. This pregnancy was much more taxing than when she had carried James. Only three years separated the pregnancies, but she really *felt* those years. She was much more tired and uncomfortable. In the meantime, she was beginning to struggle with James. His toddlerhood included a level of activity and intensity Laura had never experienced before. She knew boys tended to be more boisterous than girls, but this felt *way over the top* to her. With each passing day, James seemed to lose more

and more control. There was zero impulse control, zero ability to sit and play an age-appropriate game (like Candyland). If Laura didn't want him to do something she learned quickly that she couldn't tell him, because saying, for instance, "James, don't touch the stove," would result in him *absolutely* touching the stove. Laura didn't know what she was going to do, but she didn't feel comfortable sharing her fears and frustrations with the pediatrician. She already had two children with diagnoses. She wondered what kind of mother she would look like if she were to say, "Okay, now there's something wrong with number three."

Meanwhile, the family welcomed Madeline Gail. She was a beautiful baby, but Laura found her infancy just as challenging and tiring as the pregnancy. In stark contrast to her brother as an infant, Madeline was very demanding and "picky". She wanted to be held only by Laura and, furthermore, only in Laura's left arm. It was especially difficult for Daniel, who was hurt and frustrated that Madeline apparently wanted no more to do with him than with anyone else.

Adding a baby sister to the mix seemed to do nothing but intensify whatever was going on with James, too. At times, Laura truly felt that she simply didn't have what it would take to raise her son. She felt she had proven herself a patient woman, having gone through the many obstacles Emily and Hannah had thrown at her, but James required a level of patience that didn't feel humanly possible to her.

Then Laura took James in for his four-year, well child check-up. Within

two minutes of the visit the doctor said, gesturing to James, “What is this? What is going on here?”

Laura sighed. “Sorry...this is my every day,” she said.

“*Something* is going on here; you need to get him evaluated,” he told her.

Within a week James had an appointment with Emily’s child psychiatrist. He diagnosed James with ADHD. Laura had suspected ADHD all along, but she didn’t want to believe it. She had written a term paper in college about ADHD, arguing that if parents would only discipline their kids they wouldn’t have to throw drugs at them to get them to behave. She hated the bitter taste of eating her own words.

Not only was James’s ADHD one of the most challenging obstacles she had ever faced, but she didn’t even feel her struggles earned any respect. Even if people didn’t always understand what she was going through with Emily and Hannah, they at least seemed to have an understanding of the level of challenge associated with autism and a rare genetic disorder. When Laura attempted to share some of her frustrations about James’s behavior (like darting out into traffic during a family walk or running over the top of a table instead of sitting down to it when Laura was trying to go over his ABC’s with him), the response was often, “Eh, he’s a boy! Boys are just more active!” Laura particularly disliked the chuckle that often accompanied those words.

Laura and Daniel were faced with the decision to medicate James.

They didn't want to. They already had a mini pharmacy in the house for his older sisters; they didn't like the thought of medicating three out of four of their children. That being said, James's quality of life was severely affected by his ADHD. He had no friends; his hyperactivity and lack of social skills prevented that. He had no academic life; he just couldn't focus in on anything. And he had no home life; he was constantly being reprimanded for his poor behavior. Even at his young age, he was frustrated and depressed; he couldn't control himself and every time he was yelled at or turned down by a peer, his self esteem plummeted. Laura and Daniel decided to give the meds a try--just for a day or two--to see if there was a noticeable difference.

Within hours of the first dose on the first day, James looked up at Laura, and with the brightest, most excited smile said, "Mommy! I'm being *good* today!"

It was a drastic difference that James felt and saw just as much as anyone else. He continued taking the meds, and various weekly therapies were added to help him, as well. Laura and Daniel felt unfairly judged by many people for medicating their son, but they were confident they had done what was in James's best interest.

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Ten years flew by for Laura and Daniel. Emily was in her senior year in high school, and still very active with Little Bit Stables. She looked forward to attending Bellevue College after graduation. Located in the neighboring city of Bellevue, the school offered a one-of-a-kind program,

called the Occupational Life Skills program. It was designed specifically for people like Emily, and worked to prepare students to become self-determined, responsible citizens. Laura was, again, very thankful that such a program was available to them, and in such close proximity.

Hannah remained relatively healthy. Seizures had returned, but they weren't out of control like they had been when she was young. She remained non-verbal and non-ambulatory, continued with G-tube feedings, and remained at the cognitive developmental level of about a nine to twelve-month old. Laura was very relieved when it became obvious that Hannah was enjoying many more happy years than she had suffered difficult years earlier in her life. Laura didn't know if it made all of the difficult times "worth it", but it definitely helped to set her mind at ease.

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Daniel ended up doing *very* well at Microsoft, becoming Art Content Director for a popular car racing game. Laura adored nursing at Children's Hospital. Unfortunately, she was faced with the very difficult decision to give up her career after about ten years. Due to Daniel's great success at Microsoft, they no longer needed the second income, and it had become too difficult (and dangerous) for Laura to try to keep up with the needs of her four children on no sleep (as she exclusively worked the 11 PM to 7 AM shift for those ten years). She left Children's and missed it very much, but she felt confident in her decision to stay home with the kids.

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As Laura's father had predicted, Kevin did seem to mature some with age. He went to Iraq and Afghanistan with the Army Reserves and sent considerably more child support when he was receiving active-duty pay. He insisted on having Emily visit him for a full summer soon after their move to Washington, but Emily returned home such an emotional mess that the decision was made to limit her visits with Kevin to no more than two weeks at a time. Over the years there were also some skirmishes over medical costs/coverage and who "deserved" to claim the girls on income taxes, but after ten years and with three thousand miles between them, Laura no longer felt it completely unpleasant to talk to Kevin.

The hard work Laura and Daniel put into helping James with his ADHD really paid off. They discovered that he was dyslexic, as well. In fact, both his kindergarten and first grade teachers described James as "the absolute most dyslexic child they had ever worked with in their careers." After working with an occupational therapist and receiving some social skills training, he settled into a routine of tutoring twice a week, martial arts, and chess. James developed some close friends, school was going very well, and he constantly charmed everyone with his fabulous sense of humor. Madeline made a 180-degree turn-around from an infant who wanted nothing to do with anyone but Laura, to an absolute social butterfly and a shameless flirt. She enjoyed an active life, including gymnastics, dance, piano, and chess. Ironically, Laura feared that of all of her children, Madeline would prove to be the one who would end up challenging her the

most in future years. Her dating years promised to be particularly stressful.

Laura and Daniel continued to beat all the odds, as they were just as much in love after ten years of marriage as they were on their wedding day. They celebrated their tenth wedding anniversary with a one-week trip to Mexico for *just* the two of them. Laura knew that, with Emily and Hannah, it was unlikely she and Daniel would ever truly experience an empty nest, but she made it a very high priority to ensure they find ways to spend time alone together with at least some regularity.

Laura never would have guessed at the beginning of this journey that it would ever be possible to lead such a comfortable, pleasant life as she found herself enjoying with Daniel and their children. Laura and Daniel know they have “made it”. They live the life that Laura didn’t ever dare to dream for. They live a life that everyone deserves.









