

## Our Janie

When I first visited Stepping Stones in late Oct. 2002 it wasn't to enroll my then 2 month old daughter, Jane, in Early Intervention (EI). You see, I was going there to prove to myself that my little girl was absolutely fine and didn't need the program.

Yes, as I nurse I knew the physical signs of Down syndrome and saw some of these in my daughter—the low muscle tone, the almond-shaped eyes, the low set ears, the tiny, snub nose—but found myself excusing away these characteristics. Well, I had low-set ears as a kid, I told myself as I examined her from head to toe; look at my mom's baby pics, doesn't she have exactly the same eyes? And several of Jim's brothers and sisters have the same pug noses. Even the black and white reality of the DNA test didn't put a stop to my rationalizing. Sure, the karyotype test says 47 chromosomes, but look—they only tested a few cells and probably missed all the 'normal' ones in the sample.

So when Judy Bellina greeted me and my daughter on that blustery day, I planned to take 'the tour', politely show my interest by asking the requisite number of questions and then tell my husband Jim over dinner that night that *our* daughter didn't need Stepping Stones (or any *other* program) for special needs kids.

Judy showed me an EI session going on in the lounge, where moms just like me sat on the floor with their babies, having them reach for toys or encouraging them to roll over. We watched school-aged children in the gym work on their physical coordination by riding tricycles. She took me upstairs to the classrooms, where I saw a speech therapy session and pre-schoolers learning their ABCs. When the tour was done Judy took me back down to the lounge and asked me if I had any questions. I'd carefully made out a list of points I wanted to cover but Janie had other priorities; her tummy picked that exact moment to rebel against her morning feeding. Unruffled, Judy gave me a packet of information and told me to call if I was interested in enrolling Jane in the program.

Somehow, I got my baby (and Stepping Stone's couch!) cleaned up and got myself back to my car. And not for the first (or last) time I cried for my daughter and her future. It was easy for me to live in denial as long as my little family stayed cocooned in the safety of our home. But as soon as I saw my daughter next to the other babies and children at Stepping Stones, I realized how selfish my mindset had been. My daughter *is* just like these kids; she has Down syndrome. But look at what *they* can do—she also has hope.

That night I told my husband Jim what I'd seen earlier that afternoon. We talked about our goals for Janie and agreed that we owed it to her to make sure she had every opportunity to grow up as independent as possible. We read through the program materials; we poured over the research on EI and talked to other parents whose children had benefited from Stepping Stones. Ultimately, we decided to enroll Janie. Once we'd made the decision, things moved quickly; within a week of making the call she'd been evaluated by the staff and I found myself amongst the EI moms I'd seen on my first visit.

In retrospect, being part of Stepping Stones helped me as much as it helped my daughter. I don't know if this is true for everyone but I found our family increasingly isolated by Janie's diagnosis. My friends and family didn't know what to say to me. Some were clearly uncomfortable being around us; others resorted to empty platitudes and a few completely dropped off our radar. Being able to talk to other new moms who were going through *exactly* what I was experiencing was a lifeline. I didn't have to feel their pity or explain my feelings. They knew what the reality was as they were going through it themselves. We shared practical tips on the best ways to overcome tactile defensiveness and provided each other with referrals to local specialists. We laughed and cried over our children's triumphs and setbacks, and we offered each other support as children grew and encountered new challenges.

Janie made slow but steady progress in EI despite several hospitalizations for pneumonia and a chronic case of gastric reflux. She made friends with the other children and learned critical social skills she'd need in school. She started to communicate with those around her, using sign language at first and later with halting words. That's not to say we didn't get discouraged. Sometimes it seemed for every step forward there were three we took backward. Janie could go weeks without making any progress, despite intensive work on everyone's part. There were the ongoing battles with our health insurer, who seemed to delight in inventing new and creative ways to botch our claims and drown us in paperwork. And there were those days when I just couldn't bring myself to acknowledge the progress Janie *had* made. I hate to admit it now, but for a long time I played the game 'what might have been'. I couldn't let go of the child we *might* have had and resigned myself to the fact that we would not do all those 'family things' I'd dreamed about when I found out we were expecting—camping trips at the Cape, ski outings and swim meets at the neighborhood pool.

I hit rock bottom with these thoughts when Janie was about 9 months. Exhausted from her ongoing health issues and worn out from worry, I thought that the family party hosted by Stepping Stones was just the break we all needed. The event didn't turn out at all as we'd planned. Janie fussed and cried so hard she ended up vomiting all over both Jim and I as we tried to comfort her. Sensing I'd reached my limit, my poor husband ignored his now-ruined sweater, took a shrieking child from my arms and kindly (but firmly) dispatched me to the ladies room to take a few minutes for myself.

As soon as the restroom door slammed behind me I completely lost it. To my embarrassment, I wasn't alone. There was a little girl of about 6 in there; I recognized her from Stepping Stones. Her mom was there with her, helping her fix her party dress and comb her hair. Neither seemed put off by my smeared mascara or sour-smelling clothes. The mom kindly asked me if I was OK; normally I would've kept up the pretense I was fine but something in her tone made me tell her the truth. This wonderful woman listened patiently as I poured out my fears, my frustrations and my dim view of the future. When I finally paused to catch my breath she asked me a question that stopped my whining in its tracks—"What would your life look like if your daughter didn't have Down syndrome? What would she do?"

I thought a minute before answering. What would Janie do if she didn't have DS? Why, she'd take swim classes and play sports and be an accomplished athlete like her daddy. We'd go camping as a family and take ski trips out west in the winter. I'd take Janie to the concerts and plays I'd enjoyed as a child and instill in her my love for books and music. And even though it was unlikely she'd have siblings, she'd make up for it by having a close and loving relationship with her cousins who lived in our town and by having lots of friends who would come to her birthday parties and sleepovers.

"Then do those things" the mom told me. "Make them happen."

Janie went on to finish Stepping Stone's EI program and spent three years in Barbara Ashurst's Step III class. With the encouragement and support of Barbara and her staff, Janie learned her alphabet and started to sight-read simple words; she learned the months of the year and started to grasp rudimentary math concepts. Her language skills grew slowly but surely. She's now 6 and is attending a special-needs kindergarten in our neighborhood's public elementary school. Her current teacher is pleased with Jane's solid academic skills and contagious self-confidence. From all accounts she's made it her mission to make friends with every other child in the school and know the name of every staff member from the principal on down. I'm convinced that my daughter wouldn't be doing as well as she is—academically, socially, and developmentally—if she didn't have the benefit of Stepping Stone's EI and preschool programs.

And our family? We're still in regular contact with many of the parents we met through Stepping Stones. We keep each other updated on our children's progress and on current events that matter to us as parents of special needs children. We continue to support the program's fund-raising efforts. And when asked, we don't hesitate to recommend Stepping Stones to our school district and to interested parents.

For my part I continue to pass on the best piece of advice I ever received—

*Do those things; make them happen!*

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