

FAMILY STORY

Leslie Dening and Karen Meredith Blott have a lot in common. Both are mothers of four children, have a youngest child with Down syndrome, work over forty hours a week at demanding jobs, and have been shocked by the lack of supports for children with Down Syndrome and their families. Three years ago they were strangers. Now they are close friends working together to make a difference.

On November 30th, 2010, Leslie Dening and her husband welcomed the arrival of their daughter, Elena. As the doctors passed Elena to Leslie for the first time, her excitement turned to shock.

“They told me, we think your daughter has Down syndrome,” Leslie recalls. “I was devastated. They let me hold her for a few minutes and then they took her with my husband to the NICU to make sure she didn’t have any heart issues or other complications. I was all alone in the room and it felt like a death.”

Luckily, Elena was healthy and mother, father and baby were reunited in their hospital room. But with three sons at home, ages 8, 5, and 3, a husband battling cancer, and a full-time job she was scheduled to return to within a week, Leslie was overwhelmed by the prospect of caring for a child with special needs. She pictured her daughter struggling for acceptance in a society that values perfection and worried about her capacity to become self-sufficient.

Soon after, Leslie’s outlook began to change thanks to a visit from a NICU doctor who had a son with Down syndrome. Speaking as a mother, the doctor explained the good and the bad that lay ahead, describing a roller coaster journey of immense sadness and joy. At that moment, Elena cried for the first time, and Leslie’s mother instincts took over, “I realized my daughter needed me and all the support I could give her.”

Thirty-six hours later, Leslie and her husband took Elena home, only to return to the hospital five days later to have Elena treated for dehydration. A self-described championship breast feeder, Leslie couldn’t understand what was going wrong. No one had told her that Down syndrome children often have difficulty breastfeeding because of low muscle tone. When Elena’s bilirubin count showed that she was severely jaundiced, doctors told Leslie to take her to SickKids.

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At SickKids, clinicians helped Leslie adjust feeding tactics and provided much-needed emotional support. One occupational therapist was particularly helpful, making sure Elena was placed on a number of lists for community-based therapies. Within a week, they were back at home.

Leslie would return to SickKids two more times in the next six months. Both times Elena had to be treated for common infections that pose a greater threat to children with Down syndrome because of complicating factors like congenital heart disease and low muscle tone. Though Elena's lung collapsed on the first visit, she recovered from both infections and has since been a healthy child.

"The most challenging part," Leslie explains, "has been on the clinic side. There are so many appointments, cardiology, ear, nose and throat, developmental therapy, occupational therapy—and Elena is healthy." It can be difficult managing 10 appointments a month. But I can't complain too much. Some parents have 20 or more." Twenty or more appointments would be much more in line with Karen Meredith Blott's experience of having a child with Down syndrome. Her son, Conrad, has had a number of health challenges associated with Down syndrome.

"If it's a condition associated with Down syndrome, Conrad has got it," Karen says.

Leslie and Karen met for the first time when Elena and Conrad were a year and nine months old respectively. They had been connected by the NICU doctor who first changed Leslie's perspective about having a child with Down syndrome. The two mothers had a lot in common. Both had three other children to care for and did not know they were having a child with Down syndrome until the day their children were born. Both had busy jobs that kept them in the office for over forty hours a week. Both were shocked at the lack of a clear process for assessing and supporting children with Down syndrome and their families, and were determined to make a difference. They joined forces with a number of other parents of children with Down syndrome, creating an organization called Circle 21 to help better support families and advocate for change.

"Down syndrome is not new," explains Karen. "When a child is born with Down syndrome, there should be a checklist for parents and doctors, clear steps to follow to give your child the best possible chance of leading a healthy, full, rich life."

Leslie, Karen, Circle 21 and SickKids are now working together to realize a new vision for coordinated care for children with Down syndrome in the hopes of helping other parents and children find the support they need.

